

Infected Kin: AIDS, Orphan Care and the Family in Lesotho

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
(Social Work and Anthropology)
in The University of Michigan
2012

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Ho bana le baholisi ba bona.

ACKNOWLEDGMENTS

I dedicate this dissertation to the babies and caregivers (*ho bana le baholisi ba bona*) of Mokhotlong who helped reveal to me the many challenges of the AIDS orphan crisis, and without whom this work would not be possible. From my earliest days in Mokhotlong, they opened their homes to me and shared with me their most personal and painful stories for reasons I cannot begin to imagine. People willingly and cheerfully gave me their time, entry into their private spaces and their friendship, and for that I am truly humbled and grateful.

The MCS staff deserves special mention. The safe home *bo'm'e* (house mothers) were always welcoming, friendly and ready to laugh at my attempts at humor in Sesotho. I am particularly indebted to the outreach workers with whom I spent countless hours driving around the Lesotho countryside chatting, sleeping, and asking obvious and countless questions. For their knowledge, time and patience I am forever in their debt.

To my trusted, wonderful and delightful research assistant, Ausi Ntsoaki, who drove hundreds of miles with me on the back of my dirt bike, who spent painstaking hours transcribing interviews with me, and who made every day in the field not only easier, but truly enjoyable. Thank you for all of that.

Finally, to 'M'e Nthabiseng: I am constantly inspired by your intelligence, strength, spirit and ingenuity. Your insight, advice and friendship have meant the world to me. *Kea leboha, haholo 'M'e!*

There are a number of other people who made me and my husband Will's time in Lesotho so much more enjoyable. First of all, to Reid and Bridget, our dear friends who lived with us at MCS for the entire duration of our stay. Although they had only been married a few months when they arrived in Mokhotlong, they cheerfully tolerated us in what I have called the longest double date ever. Thank you *uenas!* And for all our other visitors and passersby who brought some love, variety (and care packages) to our lives: my brother Dan, my mom, Sheila, who visited us twice, my sister Emily, Jamie Martin, Tasha Saunders, Jenn and Stephanie Kim, Liz Lawrence, MJ, Claire, AZ, and many others.

In particular, I am grateful for the unending support and guidance of my committee members over these past eight years: Karen Staller, Elisha Renne, Holly Peters-Golden, Gillan Feeley-Harnik and Letha Chadiha. Thank you for the countless hours you have dedicated to me, and for the wonderful advice and especially the kindness you have shown me throughout this process. I always describe you as my cheering section because even in providing much needed critical advice, you have always been so supportive. I would also like to thank the University of Michigan Department of Anthropology and the School of Social Work, whose funding and support over these years made this research possible. A special thanks to Laurie Marx for her love and good humor and to Todd Huynh and Laura Shirley for helping with the unpleasant tasks of bureaucracy. And to Mandy Terc, my study partner and dear friend who helped me get to work every day of the last two years, and who provided much needed critical assessment of my work on countless occasions. I am also indebted to the Kellogg Family Foundation

for making me a W. K. Kellogg Family Fellow in Children and Families, as this generous grant funded the majority of my fieldwork.

To my family: Mom, Dad, Jules, Jim, Emily, Dan and all the McGraths for your love, guidance, support and countless hours of babysitting that made this work possible. A special thanks to my dad, Howard, for being the most enthusiastic copyeditor and technical advisor I could ever ask for.

Finally to my husband, Will and my son, Sam: thank you for making these years not only bearable but truly enjoyable.

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LIST OF ACRONYMS

AIDS: Acquired Immunodeficiency Syndrome
ART: Antiretroviral Therapy (refers to whole course of treatment)
ARVs: Antiretroviral drugs (refers to specific medication)
CBO: Community-based organization
CD4: Cluster of differentiation 4, used to measure level of immune suppression
HIV: Human Immunodeficiency Virus
KD: Knowledge Development (from Rothman and Thomas 1994)
KU: Knowledge Utilization (from Rothman and Thomas 1994)
MCS: Mokhotlong Children's Services
NGO: Non-governmental organization
PMTCT: Prevention of mother-to-child transmission (of HIV)
UNICEF: United Nations Children's Fund
UNAIDS: The Joint United Nations Programme on HIV/AIDS
VCT: Voluntary Counseling and Testing
WHO: World Health Organization

GLOSSARY: SESOTHO WORDS AND EXPRESSIONS

- Ach: Expression signifying exasperation, like a sigh
Basotho: The people of Lesotho (sing. Mosotho)
Bukana: Health booklet
CD: abbreviation used to refer to condoms
Hlatsoa tsila: Ritual washing and shaving that follows the funeral of a close kin
Joala: Sesotho home brewed beer
Kanete: Expression meaning “I swear”
Khohlopo: rubber boots; condom
Khutsana: Orphan (pl. likhutsana)
Lehlaka: A plant hung outside a house to indicate that a newborn baby is inside
Likhomo: Literally means cows, but frequently means bridewealth
Mahae: A type of vaginal discharge
Makhooa: North American and European foreigners
Makoerekoere: African from outside Lesotho (not usually used for South Africans)
Mamello: Patience
‘M’e: Mother or Mrs.
Mokaola: A Sesotho illness, sexually transmitted; people used to call HIV mokaola
Nkhono: Grandmother
Nonyana: Disease that babies acquire characterized by rash on head
Ntate: Father or Mr.
Ntate-moholo: Grandfather
Ngaka ea Sesotho
Ngaka ea Sekhooa
Ngoaneso: Term of endearment
Pitsa: Special medicine for pregnant women
Pitso: Town meeting, usually called by chief
Rondavel: Round house made of stones and thatched roof
Sekhooa: English
Sesotho: Language of Basotho; culture of Basotho
Thapo: Band worn on arm indicating mourning of a close kin
Tlapi: a medicine used by Sesotho doctors

ABSTRACT

This interdisciplinary dissertation in anthropology and social work examines the intersections of HIV/AIDS and kinship and its impact on orphan care and the family in rural Lesotho. It presents findings from 14 months of ethnographic fieldwork between 2007 and 2009 in the rural district of Mokhotlong, Lesotho. Data collection methods included a series of 3 to 5 semi-structured interviews with 21 caregivers, interviews with other community members and health care providers, household survey data collection, archival research, participant observation and field notes.

In the context of the AIDS pandemic, I explore the physical, material, and emotional challenges of orphan care; the difficulties of treatment in a rural southern African context with a focus on the intersection of biomedical beliefs and practices with social and cultural ones; and the reorganization of families as a result of these factors. I find that HIV is fundamentally a kinship disease. My work affords a micro-level view into the everyday strategies of household caregiving practices that showcases Basotho families' experiences of AIDS and the sometimes contradictory meanings and practices that emerge in the intimate spaces of family life. I provide a framework for rethinking the ways that a biocultural approach to HIV/AIDS undergirds the negotiations people make between idealized rules of kinship and everyday practices in caring for orphans.

The findings of this study support several recommendations for the design and development of interventions. From a broad theoretical perspective, this research suggests that: 1) interventions need to recognize the deeply embedded nature of HIV and

kinship, and 2) there are malleable cultural resources, such as idealized notions about gender, that are in fact flexible and are strategically deployed to respond to the challenges of HIV/AIDS. The three empirical findings for the design and development of interventions recommend that: 1) interventions for AIDS orphans need to include caregiver support, 2) the household should be considered as a salient unit of analysis, evaluation and intervention and, 3) biomedical or biocultural interventions for HIV/AIDS need to incorporate the underlying theoretical framework of HIV as a kinship disease in order to be effective.

CHAPTER ONE

INTRODUCTION: AIDS, ORPHANS, AND A BIOCULTURAL APPROACH TO RELATEDNESS

Matseli's story

Matseli was a 2-month-old HIV-positive infant whose HIV-positive mother had moved to her parents' village in August of 2007. She moved during the late stages of her illness because her in-laws were no longer taking good care of her after her husband died. Matseli's mother died about a month later, and Matseli, who was also ill, spent almost a year being rehabilitated in the safe home of a community-based NGO¹, Mokhotlong Children's Services (MCS), in the rural district of Mokhotlong, Lesotho. At his time of entry into MCS, Matseli was severely malnourished, and in need of treatment for HIV and TB. Although his maternal grandparents were competent caregivers, he was in need of monitoring and care that was difficult to achieve in a village setting, particularly one several hours from any medical facility. At MCS, he completed his TB treatment, was successfully started on antiretroviral medication (ARVs), and received nutritious foods that helped him to thrive. He was also taken to Maseru, the capital city of Lesotho, as well as to South Africa, to receive treatment for complications related to his illness that were affecting his heart and respiratory system – treatment that he would never have

¹ NGO's are non-governmental organizations that are non-profit and are independent of government control. They can work at the local, national, or international level. A community-based organization (CBO) is also non-profit, but exists only at a local level. A CBO is essentially a local NGO. MCS could be considered either. One noticeable difference in the literature is that NGO is used more widely in the anthropological literature, whereas social work favors the term CBO (Willets 2002).

received without external support. Once his condition was stable, Matseli was reunited with his maternal grandparents and four older siblings who were eager to have him back. His grandparents took excellent care of him. In addition to being loving and affectionate grandparents, they went to the clinic whenever he was sick or needed medication, and adhered well to his complicated HIV treatment schedule.

In Easter of 2009, Matseli became sick with diarrhea and vomiting. His grandmother took him to a clinic – a two hour walk away – but it was closed for the holiday. She returned the following day carrying Matseli on her back, but the child died on the way. He likely died of dehydration – a problem that could have been easily solved by drinking oral rehydration solution or, in the worst cases, with IV fluids available at the district hospital. Despite the fact that Matseli’s maternal grandparents had cared for him and loved him dearly, he was buried at his father’s village because, according to local idealized norms of patrilineal descent, he “belonged” to them. His grandfather said, “If they didn’t want to bury him, we were going to bury him. But, if they wanted to, like they did, we just let them because that was their child.” His grandmother expressed her surprise at his death, “He wasn’t even very sick. He didn’t lose any weight. He was playing. I was getting Sesotho² clothes for him so we could take his photo...And he was so clever.” He was buried without a funeral or coffin in an unmarked grave.

Matseli’s story demonstrates the complexity of coping with HIV in a remote and impoverished rural community. Although the Lesotho government, which has local offices in Mokhotlong, provides some services, including free medical treatment for HIV-positive individuals across the country, there are numerous costs for those living with HIV/AIDS that the government simply cannot afford. This story also demonstrates

² Sesotho is used to refer to the language as well as the culture of the Basotho people.

the need for community-based organizations (CBO's) such as MCS to provide care and support to families in a resource-poor environment. Without access to available treatments, children like Matseli would have a reduced chance of survival. Matseli was able to thrive, at least temporarily, and have a happy, normal childhood because of the love and care of his grandparents. However, Matseli's situation also brings to light many of the challenges of caring for an HIV-positive child in an isolated community with high levels of poverty, and poor means of communication and transportation. These unpredictable variables mean that chance occurrences can have a significant impact on people's lives. If Matseli had not gotten sick over the holidays, he likely would have lived.

Matseli's situation also reflects the changes in care emerging from the AIDS pandemic that alter the makeup of families and challenge locally accepted norms of patrilineality. Despite the willingness of his maternal grandparents to care for him – and the failure of his paternal grandparents to do so adequately – his funeral was still technically the responsibility of his paternal family. This sense of responsibility did not seem to stem from a sense of competition between the families, but rather a submission on both sides to the idealized rules of patrilineal descent – particularly when it came to most important life events such as a funeral.

Patrilineality is an ideology that is supported and maintained through lines of power in communities. Functionally, patrilineality creates idealized descent groups. However, in reality, locally accepted norms and rules, as well as local practice, differ markedly across patrilineal groups even at the community level. Therefore, practice must be contextualized at the local level through the use of empirical evidence. Matseli's

maternal grandparents seemed glad that the paternal family buried him; they considered it the proper thing to do, and at the same time were saddened by the insignificance of his burial and the fact that he was not buried with his mother. Matseli's paternal kin did not care for him after his mother died because in practice, there are series of negotiations that take place in deciding on a caregiver, only one of which is the local idealized notions of descent and belonging³.

Both of Matseli's maternal grandparents independently expressed concern about the future, and their worries aligned with their realms of responsibility within the family. His grandfather was worried that Matseli's brothers might decide to live with the paternal grandparents when they were older, leaving no one to inherit his household and fields. His grandmother worried about who would care for the children if she and her husband died. The dissonance created by this difference in ideal versus practice has created insecurity among adults and children with regards to care, family responsibility, and the allocation of property. Challenges associated with poverty, illness, migration and care have always existed in Lesotho; however, these pre-existing problems have been exacerbated enormously by the rapid and devastating emergence of HIV/AIDS.

The fundamental contribution of this dissertation, and the theme that pulls together all the various factors that impact this vulnerable population, is to demonstrate that HIV is a kinship disease. While it may be contracted through casual sexual relationships, it spreads primarily through familial lines and other interpersonal relationships in ways that other infectious diseases do not. It is transmitted through bodily fluids such as blood, milk, and semen that are central to the ways in which kinship

³ In Chapter 6, I will discuss how these negotiations take place and demonstrate that ultimately, the well-being of the child is privileged over idealized rules of kinship and lineage.

is created and defined. AIDS infects families as much as it infects the body, which is why people's responses to prevention and treatment efforts are not straightforward, and why people employ strategies to minimize the social implications of the disease, even at the cost of their health. HIV/AIDS is deadly, requires complex treatment, and carries with it deep implications about the relationships between close kin. If AIDS had no bearing on people's relationships, their sexuality, their procreative practices, their networks of care, and their livelihoods, it would be far easier to manage. Yet, it does carry these grave implications. A biomedical understanding of the disease cannot be separated from the ways in which it implicates networks of kin and care. A nuanced understanding of the biocultural interactions of the disease with a focus on how it impacts kin relationships is of the utmost importance, and provides essential information for those interested in any aspect of HIV/AIDS, including orphan care.

The intersections between HIV and kinship impact the demographic makeup of the family and the ways in which families negotiate between idealized rules of kinship and everyday practices in deciding on caregivers for orphans. While the effects of HIV/AIDS on patterns of familial care and household composition have been well documented in both anthropological and demographic research, my work affords a micro-level view into the everyday strategies of household caregiving practices. This ethnographic approach illuminates where culture, illness and care intersect to explain how individual and community-level strategies during a health crisis have led to a demographic shift towards matrilocality. My work showcases Basotho families' experiences of AIDS and the sometimes contradictory meanings and practices that emerge in the intimate spaces of family life. I show precisely how, and why, idealized

rules of kinship affect families' decisions around care and biomedical interventions. My work provides a framework for rethinking the ways that a biocultural approach to HIV/AIDS undergirds wider demographic shifts in the wake of the pandemic.

In order to demonstrate the numerous and significant intersections between HIV and kinship, I examine the physical, economic, material, and emotional challenges of orphan care, the difficulties of treating HIV/AIDS in a rural southern African context with a focus on the intersection of biomedical beliefs and practices with cultural ones, and the reorganization of families as a result of these factors. I do so with the goal of better understanding the impact HIV/AIDS has on kinship and caregiving with an eye towards identifying potential areas of intervention and support that will help to support families caring for AIDS orphans.

AIDS and orphans in Lesotho: A demographic crisis

Lesotho is, unfortunately, an ideal place to study the impact of HIV/AIDS on families because it has been devastated by the pandemic. According to UNAIDS, Lesotho has an HIV prevalence rate of 23.6 percent among adults aged 15 to 49, the third highest rate in the world (UNAIDS 2010b). One of the greatest problems emerging from the AIDS pandemic in Lesotho is its impact on children (Tarantola and Gruskin 1998). UNICEF estimates that there are 110,000-120,000 AIDS orphans in Lesotho; of these children, 12,000 are HIV-positive (UNICEF 2009a)⁴. Lesotho has strong extended family ties, which, in the past, have worked to ensure that children were cared for in

⁴ An AIDS orphan is defined as a child who has lost one or both parents to AIDS (UNICEF 2009a; Lesotho Ministry of Health and Social Welfare and National AIDS Commission 2009). According to a report published in 2009 by the Lesotho government, there are 122,000 AIDS orphans in Lesotho (Lesotho Ministry of Health and Social Welfare and National AIDS Commission 2009). The discrepancy can be attributed to the fact that the UNAIDS data was from 2008. Also 110,000 is the UNAIDS low estimate. Their high estimate is 120,000.

times of need. Of course, care networks prior to the emergence of HIV/AIDS had flaws, but the illness has added significant new challenges for families as the number of healthy adult caregivers has decreased and the number of children in need of care has increased. In rural Africa, because extended family networks play a central role in responding to health related concerns, AIDS has placed particular strain on families. One major consequence of the AIDS pandemic is that the kinship networks that previously protected children from orphanhood have become overburdened and saturated, creating a new and growing population of AIDS orphans (Townsend and Dawes 2004; Foster et al. 1995; Guest 2003; Klaitz 2010).

Lesotho's geopolitical position as an enclave within South Africa and its economic reliance on migrant labor contributed to the swift and devastating rise of HIV/AIDS. Lesotho's economy previously depended on subsistence agriculture, but mono-cropping, over-grazing, soil exhaustion, severe erosion, land tenure disputes, and over-population forced many Basotho⁵ to seek employment elsewhere (Murray 1981:19). By the late 1970s, 70 percent of the average Basotho household income came from migrant labor, primarily in South African mines (Murray 1981).

Lesotho's "perpetual state of economic dependency" (Romero-Daza and Himmelgreen 1998:200), in existence prior to the emergence of HIV/AIDS, greatly disrupted both the jural and conjugal stability of marriage, which would later fuel the spread of HIV/AIDS (Murray 1980; Mado 2001). Apartheid laws did not allow women to join their husbands in the mining camps, and "the enforced separation of spouses generate[d] acute anxiety, insecurity and conflict" (Murray 1981:103). Even once apartheid laws were lifted in 1994, many Basotho women did not join their spouses, as

⁵ Basotho (pl.): people of Lesotho (sing. Mosotho).

the living conditions were poor (Ramphele 1993), and many had familial and agricultural responsibilities that made relocation difficult. Once HIV/AIDS began to spread in South Africa, migrant laborers were among the most marginalized populations, contracting HIV from sex workers or long-term partners in South Africa and then spreading the virus to their spouses while on home visits (Romero-Daza and Himmelgreen 1998).⁶

Although migrant labor significantly reduced between 1996 and 2005 as a result of the decrease in mining jobs and the fall of gold prices, HIV continued to spread (Lesotho Bureau of Statistics 2007b). The first cases of HIV appeared in Lesotho in the early 1990's. By 1993 the HIV rate was approximately 5 percent, after which it spread quickly, reaching 20 percent by 1997 and plateauing at just under 24 percent in 1998 where it has remained until the present (UNAIDS 2010b). In 2001, antiretroviral therapy (ART) became available in limited quantities and locations, but the lifesaving treatment only became widely available and free starting in 2004. Despite alarmingly high HIV rates as early as the mid-1990's, the government did not establish the Lesotho AIDS Programme Coordinating Authority until 2001 to deal with the national crisis, and did not have a strategic plan in place until 2004, which was undertaken by the newly formed National AIDS Commission. This late response to the pandemic took its cues from South Africa, whose history with HIV is fraught with confusion, stigma, denial and mismanagement by the government (see Chapter 2).

⁶ The high HIV rates in Sub-Saharan Africa, particularly in countries like Lesotho, Botswana, Namibia and Swaziland (ie. countries dependent on remittances from labor migration in South Africa), must be understood within the political context of South Africa, and its response to HIV/AIDS. Specifically, Mbeki's denial of the link between HIV/AIDS and the lack of access to medication were key to the rapid spread of HIV in this region. Due to space limitations, I will not explore that here, but for an excellent discussion of these issues, see Fassin 2007. Also, for an in-depth exploration of life in workers' hostels see Ramphele 1993.

By the time the Government of Lesotho rolled out its National AIDS Strategic Plan in 2000, treatment was yet to be mentioned as a necessary element of the response (Government of Lesotho 2000). ART was first available in 2002 at two urban hospitals. By 2005, 12 hospitals were offering ART treatment, and as of 2009, there were over 100 hospitals and clinics (both public and private) offering free treatment (Owusu-Ampomah et al. 2009).⁷ In 2005, only 13 percent of those in need of ART were receiving the lifesaving treatment. By 2009, this number rose to 51 percent (UNAIDS 2010b). The widespread availability of ART in Lesotho has begun to show a significant impact in reducing AIDS-related deaths. By 2013, UNAIDS estimates that the scale-up of ART will avert over 4,000 deaths (UNAIDS 2010b). For children, maternal treatment means fewer orphans and lower rates of transmission from mother-to-child (Lesotho Ministry of Health and Social Welfare and National AIDS Commission 2009). Despite these gains, Lesotho still lags behind all its neighbors in terms of access to the lifesaving treatment. As of 2009, only 25.6% of those in need of ART had access to it (Owusu-Ampomah et al. 2009).⁸ In addition, the mortality risk in Lesotho rose dramatically between 1990 and 2010 (up 67 percent among men, and 175 percent among women), during which time the HIV rate rose sharply as the population growth rate declined (Rajaratnam et al. 2010; Mwase et al. 2010).⁹

Health services for people living with HIV/AIDS in Lesotho are funded through government taxes as well as foreign governments and other external donors. There are

⁷ Free ARVs and associated medications are available at all public health facilities, including hospitals and clinics. However, if a patient chooses to go to a private clinic, the medications will be free, but they will pay for the doctor's consultation.

⁸ As compared to 83.4 percent in Botswana, 71 percent in Namibia, and 55 percent in South Africa.

⁹ The population growth rate fell from approximately 2 percent in 1996, to just over 0.5 percent in 2010 (Mwase et al. 2010).

numerous funds that are directed specifically towards the care and support of orphans.¹⁰ From 2005 to 2008, almost 60 percent of funds for HIV/AIDS services came from international sources (Mwase et al. 2010).¹¹ Services are provided by the Lesotho Ministry of Health and Social Welfare and other public sector providers, NGO's and for-profit health providers, such as private clinics. Because of the diversity of sources for both funding and health services, service delivery is inconsistent throughout the country, focused in urban centers, and susceptible to the volatile nature of international donors.¹² The Lesotho government has established a strong policy framework for HIV and TB services. Over the past few years the government developed policies and guidelines for a behavior change communication strategy, a male circumcision policy, an ante-natal care register, a delivery register, and the revision of the TB register (Mwase et al. 2010:92). However, the high demand for services strained the country's capacity for the delivery of services, and is unable to adequately provide a quality assessment of these services (Mwase et al. 2010).

Despite significant improvements over the past decade, services for those living with HIV/AIDS in Lesotho are limited. The country lacks the resources and personnel to deliver services and to implement existing policies. These limitations mean that much-needed services, such as those supporting caregivers for AIDS orphans, take a back seat to the more pressing needs such as the delivery of ART and other first line medical response needs.

¹⁰ For example, Nearly 1.5 million dollars of PEPFAR's 27 million dollar budget was used on orphans and vulnerable children in 2009. The EU directed 12 million euros to the empowerment of orphans and vulnerable children (Mwase et al. 2010).

¹¹ This study was funded primarily by USAID.

¹² For example, 38 percent of all public and private health facilities in 2006 were located in Maseru, which houses only 23 percent of the population (Mwase et al. 2010).

Theoretical concerns: Integrating levels of analysis

The ultimate goal of this dissertation is to provide a deeper understanding of HIV/AIDS and its impact on families in order to highlight the ways in which the lives of those impacted by the pandemic can be improved, with a focus on orphan care. As I have noted, the epidemiology of HIV/AIDS goes well beyond the physiological response of AIDS patients to include a host of contextual factors and relationships between kin. The theoretical framework of this dissertation exists on two levels. First, I will outline three broad socio-ecological theories that frame the dissertation as a whole. Then, I will explore the multi-dimensional, focused bodies of literature that help to illuminate specific areas of exploration.

I focus on three theories that help to explain the complexities of people in their environments and the contextually specific ways that individuals and communities respond to HIV/AIDS. Paul Farmer uses the concept of “structural violence,” which emerged from his own research on HIV/AIDS in Haiti and elsewhere, to examine how broader social, economic, and political structures can lead to health inequalities at the individual and community levels (Farmer 2003). Structural violence is driven largely by social and historical circumstances, and perpetuated by inequality. Farmer emphasizes the ways in which illness is embodied, and links this to the structural factors impacting the spread of disease. The emergence and rapid proliferation of HIV/AIDS in southern Africa, and elsewhere in the developing world, has been heavily impacted by unequal and exploitative political, economic and historical circumstances. A theory of structural violence is able to capture both the context in which illness emerges, while also illuminating the inequality inherent in these processes. It is meant to “inform the study of

the social machinery of oppression” (Farmer 2004:307). It is a deeply difficult and uncomfortable theory because it does not accept the inevitability of global processes, but instead, implicates all those who are complicit through their action and inaction. The urgently harsh nature of the term “violence” also seeks to convey Farmer’s critique of anthropological trends towards inaction and relativism.

Although Farmer’s exploration of structural violence addresses how historical and political economic factors are embodied, this perspective is fully realized in Lock and Kaufert’s (2001) theory of “local biologies,” which recognizes that both biological and social factors impact individuals’ experiences of illness. A major focus of this dissertation is to demonstrate how the epidemiology of HIV/AIDS is a fully biocultural phenomenon. Biology and culture are “in a continuous feedback relationship of ongoing exchange in which *both* are subject to variation” (Lock and Kaufert 2001:503). In accordance with this dialogical view of biocultural processes, Goodman and Leatherman note, we need to investigate “how sociocultural and political-economic processes affect human biologies, and then how compromised biologies further threaten the social fabric” (1998:5). Basotho experiences of HIV/AIDS derive from the intersection of the biological realities of HIV and available treatments, and the cultural and social factors that impact access and willingness to receive treatment. The theory of local biologies provides a framework with which to understand the claim, elaborated throughout this dissertation, that HIV is fundamentally a kinship disease.

Finally, one of the core strengths in social work research and practice, and what sets it apart from other social sciences, is the ecological approach that recognizes the need to focus on the “person-in-environment” (Hare 2004; Buchbinder et al. 2004;

Kondrat 2002). As Green and McDermott note, “Social work’s distinctive and primary contribution to the social and behavioral sciences has been its assertion of the centrality of person-in-environment to understanding the complexity of the world” (2010:2416). This ecological approach emphasizes the importance of social systems in shaping people’s experiences, and is particularly well suited to intervention research, as well as international research (Hare 2004). It is consistent with both ethnography and social work and thus works well for the ethnographic study of HIV/AIDS in rural Lesotho. These macro-level theories are integrated to form a cohesive whole that addresses the structural, the interpersonal, and the engaged concerns presented in this work.

In particular, this research contributes to the knowledge development phase of intervention research outlined by Rothman and Thomas (1994a) which will be explored later in this chapter. The theoretical perspectives put forth by Farmer (2003), Lock and Kaufert (2001), and Hare (2004) all go beyond individualistic or behavioral explanations of HIV/AIDS, to a holistic social, cultural, political, and economic understanding of the associated factors that influence responses to the illness.

The ethnographic approach of this dissertation is firmly rooted in anthropology’s methodological tradition. In addition, the empirical evidence that emerged from my fieldwork is analyzed using anthropological bodies of literature. Social work’s focus on social justice, inequality, and social change, which attempts to ameliorate the lives of the most marginalized and disadvantaged people, helped to determine the focus of this dissertation and orient it towards real-life problems and solutions. An interventionist approach is also instrumental in understanding current trends in HIV/AIDS intervention research, as well as in making recommendations that could positively impact a response

to the pandemic. In addition, social work's focus on micro (individual), mezzo (family) and macro (policy and institutions) levels of research and practice are useful in addressing the challenges of orphan care in the context of HIV/AIDS. This research necessitates close examination of all levels of practice, and a social work perspective is well equipped to handle this complexity. The person-in-environment approach recognizes the interconnections between the various levels of research and practice, and provides a bridge between the individual and their social context (Green and McDermott 2010; Weiss-Gal 2008). The first part of this dissertation, which focuses on the interpretation and analysis of ethnographic data, relies more heavily on anthropological literatures, while the solutions-oriented sections, and those that examine current responses to the pandemic, will draw more heavily from critical medical anthropology and the intervention literature.

There are three more narrowly focused bodies of literature that orient this dissertation: a) contemporary kinship literature helps to understand various forms of relatedness and to contextualize the response of families in coping with the demographic changes brought about by HIV, particularly in terms of the care of children through child fostering; b) critical medical anthropological theories help to illuminate the dynamic and complex nature of interactions between illness and culture, and shed light on how this affects individual and community responses to HIV; and c) HIV/AIDS intervention literature provides insight into potential solutions regarding prevention, testing, treatment, and stigma. Throughout this dissertation, I will draw on these three bodies of literature to explore the issues emerging from the orphan population and their families.

What binds people? Kinship, caregiving and relatedness

Although this dissertation focuses on a health crisis, at its core, it is fundamentally about how families respond to this crisis because health and kinship are intimately related in social, temporal, and spatial realms. Essential to understanding family responses to HIV is an understanding of kinship and relatedness. Basotho are patrilineal – that is, they are organized principally in agnatic groups, and their idealized rules of patrilineality govern their living arrangements, naming practices, and inheritance. Lineality is important to Basotho as an ideal and as an organizing principle, and as such, requires serious consideration. However, as Peters said of the Bedouin, “Agnation is not one thing, but many” (1990:109). Historically, anthropologists considered lineality in strictly jurial terms (Morgan 1870; Lévi-Strauss 1969; Evans-Pritchard 1951).¹³ However, patrilineality is not governed by a universal set of rules across cultures. In fact, the idealized rules of lineality are not even agreed upon by those living with them. For example, as a result of the harsh conditions of war in Sudan, the Nuer’s understanding of relatedness was in a state of flux and tension as the social meaning of a variety of unifying substances, including blood, paper, and money, was evolving (Hutchinson 2000).¹⁴ As Peters argues, and this dissertation reinforces, many complex factors contribute to the lived connections between kin as they emerge in reality, and thus need

¹³ Evans-Pritchard, in his extensive studies of the Nuer, argues for the separation of political and social life (Evans-Pritchard 1951; Evans-Pritchard 1940). However, as Schneider notes in a critique of Evans-Pritchard’s 1951 book on kinship and marriage, his data actually demonstrates considerably more flexibility of kinship practices, which Evans-Pritchard merely attributes to exceptions to the agnatic principles, when in fact they were indications of more powerful and varied kinship dynamics that spanned the social and political realms (Schneider 1953).

¹⁴ Evans-Pritchard was the first to study the Nuer. He provides extensive detail about the importance of substance through an exploration of food and food terms among the Nuer, and the centrality of food sharing in establishing kinship bonds. However, he uses this data to demonstrate the power of political relationships and structures (Evans-Pritchard 1951; Evans-Pritchard 1940). Ironically, all of his rich data has provided a platform for others to move beyond this structural approach to a more nuanced understanding of substance among the Nuer and more broadly.

contextualization. For the Bedouin of Cyrenaica, these factors include inheritance disputes, bridewealth debts, and cattle wealth (1990). For Basotho, HIV/AIDS adds a new dimension to the considerations that bind and divide kin. Factors such as migration, the willingness and ability to provide care, the health and age of potential caregivers, and the location of the mother prior to her death, all contribute to kin relations as they emerge in practice. This is not to say that the kinship rules are no longer followed because of the emerging complexities that exist in the world; these idealized rules have always been subject to various local and contextual factors. HIV/AIDS merely presents a new, significant set of factors in need of close examination.

It is, in part, the recognition of these lived realities of kin relations that brought about a major shift in anthropological studies of kinship, towards an approach that emphasizes relatedness over juristic notions of lineality and kinship. The American anthropologist David Schneider laid the primary grounds for a fundamental reformulation of kinship studies in anthropology. He argued that kinship is a “non-subject” that “exists in the minds of anthropologists but not in the cultures they study” (Schneider 1972:51). Schneider criticized Morgan and others for regarding kinship as a discrete cultural category, separate from other aspects of society such as religion or economics, when in reality they are all part of a “single cultural system” (1972:60). He argued that kinship and descent theory relied on old anthropological ideas about the primacy of the biological and were structured around genealogical relations, or what Bouquet calls the “arborification of knowledge” (1996:62). Although Franklin and McKinnon note that Schneider receives attribution for bringing about the “death of kinship” in anthropological work, he was not alone in questioning the natural basis on which

assumptions about kinship were founded (2001:4).¹⁵ It is from this blurring of the boundaries between kinship and biology that a new approach to the study of kinship emerged. Paradoxically, Schneider's work, instead of reducing kinship to an historical artifact of anthropological inquiry, helped to rejuvenate the study of kinship by troubling the natural categories of kin, thereby opening the field to previously unrecognized forms of relatedness.

Though the subject matter under the rubric of "kinship" or "relatedness" is vast and diverse, it is strikingly similar in several ways. First, it recognizes biology as culturally constructed, and "gender, power, and difference are key concerns" (Peletz 1995:346). However, as Carsten (2000a) argues, this does not mean that biology and procreation are removed from the ways that people think about relatedness. In fact, studies focusing on gay and lesbian families, as well as research on new ways of creating biological kinship through reproductive technologies, have refocused the analytical lens of kinship on alternative forms of procreation (Carsten 2000a; Ginsburg and Rapp 1991). Instead, what Carsten and others argue is that the biological facts of relatedness – and their relationship to the social – are not predestined based on North American and European ideas about consanguinity.¹⁶ New approaches to kinship are no longer seen as static, but are understood as processual, contextual, and negotiable (Carsten 2000b; Hunter 2010). Theories of kinship can adapt and shift in order to incorporate the political, economic, global, social, and environmental changes that exist in the world.

¹⁵ Early proponents of this view include Durkheim (1898) who claimed "toute parenté est sociale" (see Feeley-Harnik 1999:216), and Irving Hallowell's study of the Ojibwa of Berens River, Manitoba, which was published in 1991, but was based on fieldwork done in the 1930s and 1940s. It was written in 1960 (Hallowell and Brown 1991). Rodney Needham (1971), Gayle Rubin (1975) and others also espoused this view.

¹⁶ For a strong argument of the cultural construction of biological "facts" of reproduction see Collier and Yanagisako (1987).

Contemporary kinship studies focus on practice, examining the ways in which the everyday interactions and realities of life create – and, in some cases, destroy – bonds of relatedness. It is for these reasons that contemporary kinship theory is useful here in order to understand how the local and global, the physical and metaphysical, are impacting the organization of Basotho families as a result of the HIV pandemic, and to provide a framework for understanding the shifting definitions of kin and relatedness in Lesotho. This becomes particularly important when we consider who cares for orphans, and how the location of care and identity of the caregiver are negotiated with regards to gender, age, and lineality.

One of the primary questions that emerges from the study of kinship is: what binds people? In practice, relatedness is often established and maintained through shared substances (Hutchinson 2000; Parkes 2004; Weston 2001; Ingold 2000). In particular, shared blood, semen, milk and food provide fluid and flexible means of creating kinship. As Carsten argues, the ways that substances are related to the formation and strengthening of kin ties are highly variable and bring together “a whole range of other themes including procreation, relations between kin, bodies, personhood, gender, and feeding” (2004:132). Ingold (2000) demonstrates how standard, linear ways of thinking about substance do not adequately capture how substances move and overlap at many different crossroads. This points not only to the usefulness of substance as a way of understanding the diversity of ideas about relatedness, but also the need for anthropologists to continue to refine the relationship of substance to kinship, and to question the assumptions on which ideas about substance are based.

For Basotho, blood has very little relevance as a tie that binds kin, whereas shared (and withheld) milk and food are much more important in both creating relatedness and breaking kin ties.¹⁷ However, with the emergence of HIV, shared blood, milk and semen take on new significance. Interestingly, in the past, AIDS stigma frequently manifested itself in an unwillingness to share food with those suspected of being HIV-positive, reinforcing the importance of food sharing as a binding mechanism between kin and non-kin. This not only contributes to anthropological understandings of how illness and disease adds a new element to the study of shared substance and relatedness, but deepens the notion of HIV as a kinship disease as it implicates many of the ways that relatedness is made and broken.

The site where substance is shared, and many other important interactions and rituals occur, is the house. The house is a central location and a key actor in the process of constructing relatedness. The house was the site where most of my interviews with caregivers took place, so I could observe the dynamic nature of relationships within households on a daily basis. I observed firsthand the importance of the house for Basotho as a space where feeding, raising, sheltering, nurturing, clothing, caring, procreating, birthing, and dying take place. These are not independent events that repeat themselves in identical form, place, and time. Instead, they are influenced by the political economic and geographical context in which they occur. However, the house is not merely an inanimate structure that has no impact on its surroundings, or simply a place where events and exchanges take place. Instead, the house shapes relationships, and provides a space in which inhabitants inscribe their stories. Thus, through practice and repetition, the house generates and shapes relationships. This processual conceptualization of the

¹⁷ For detailed ethnographic examples, see Chapter 3.

house is essential to a profound understanding of the power of the house and its position as a key symbol in the lives of Basotho (Ortner 1973).

Morgan, in writing about the houses of American Aborigines, showed an early interest in the connection between houses and social life – particularly with regards to food sharing and hospitality – though he failed to fully integrate this with his broader theory of kinship (1881). Lévi-Strauss also focused on the house as a central place for reproducing and shaping kinship, but his limited analysis of the house only supported his ideas about kinship and marriage (Carsten and Hugh-Jones 1995). The architectural structure and form of the house is key to producing and reproducing social relations. Ingold advocates for a “dwelling” perspective of the house (as opposed to a “building” perspective) whereby “the forms people build...only arise within the current of their life activities” (2000:154). Carsten and Hugh-Jones also perceive the house as a place where people dwell, because it reinforces the “dynamic” and “processual” nature of the house (1995:1). Ingold views the house as an important site of socialization, and describes how physical space can shape itself onto the human body: “Human children...grow up in environments furnished by the work of previous generations, and as they do they come literally to carry the forms of their dwelling in their bodies – in specific skills, sensibilities and dispositions” (2000:186).

The house is also deeply embedded in the social and the political. Maurice Bloch (1995) describes the importance of the house for the Zafimaniry of Madagascar, giving context to the devastation of having their houses burnt to the ground by the colonial army in 1947. The Zafimaniry house is a central symbol and core of the marital unit, a connection that Lévi-Strauss also emphasized (Bloch 1995). The house of a newly

married couple is very unstable, but it becomes “hardened” over the years as the marriage progresses (Bloch 1995:78). Feeding and procreation are both important to the hardening of the house, and over time, elaborate carvings are made inside and out. This slow process of building and beautifying the house is what Bloch, in borrowing from Lévi-Strauss, describes as the “objectification and fetishization” of social relations (Bloch 1995:79). With each generation, the house becomes more important as a site for ritual activity and ancestor worship. In this context, the destruction of the Zafimaniry houses meant not only a loss of livelihood, but of personhood as well.

Carsten’s discussion of Malay houses also strongly connects dwelling to personhood and substance. The Malay house is thought of as an elderly woman, symbolized by the central pillar of the house and reinforced through ritual activity, particularly feeding. People construct personhood and kinship through feeding, and the hearth is a central part of this process (Carsten 1995). The gendered nature of the house is exemplified in Beidelman’s (1972) exploration of the Kaguru of Tanzania. From the construction of the house, to its gendered spaces, the Kaguru house “represents a joining of male and female principles” (702) and “provides a fundamental mode for expressing social (moral) values and beliefs” (705). Cooking and sex exemplify this, as two of the most valued and gendered activities among the Kaguru.

The house is also a highly politicized space that absorbs and resists the problems that exist in the outside world. For example, Lyons (1992) describes how the relocation of Zande houses by colonial authorities, in a purported effort to stem an outbreak of sleeping sickness, resulted in a drastic increase in witchcraft activities because of the increased proximity of the rebuilt houses. In describing how space affects the life of

migrant laborers in hostels in South Africa, Ramphele situates the bedhold (the only space a migrant worker controls) as a place where relationships are formed and transformed (1993). For example, after apartheid when women joined their husbands in the hostels, men became more attentive to their children. The confined space transformed their paternal interactions with their children. Ramphele sees people's adaptations to these marginal spaces as creative and resilient, but also as a way of reinforcing the status quo (1993). These varying examples bring the house to the core of kinship theory, highlighting the importance of practice, and emphasizing the house as a site where relationships are constructed through space, and human interactions with the physical, social, and political environment.

As Feeley-Harnik argues, "The house is a microcosm of the social order" (Feeley-Harnik 1980:561). This is certainly true in Lesotho where various aspects of the house, such as the floor, the walls, the roofs, and the objects within, tell the story of the inhabitants of the house over time through layering and accumulation of material objects. The house plays a central role not only in day-to-day activities such as eating, sleeping, sex, and food production, but also in major life events such as birth and death. Basotho will live in the same houses for generations, and these become places where history and sociality unfold.¹⁸ Further, one of the most important social roles that take place in the house is the care of children. This includes the care of biological and foster children.

Fostering is closely linked with houses and substance because relationships are solidified by the relocation of a child from one home to another where they share space and food, and participate in all the important events that take place in the house. Child fostering is a common practice, and has been written about extensively in parts of West

¹⁸ See Chapter 3.

and Sub-Saharan Africa, Oceania, and Latin America, and the United States (where it is typically called “kinship care”).¹⁹ It is characterized by the movement of children for a variety of purposes related to health, fertility, social responsibility, caregiving relationships, apprenticeship, and educational opportunities. Like other aspects of social life, Renne argues that child fostering necessitates, “a processual approach which incorporates changes in social organization...with changing cultural practices” (1993:333).

The form and function of fostering practices vary widely because they stem from distinct cultural beliefs about childhood and families. However, they typically find a common thread in their reciprocal nature. Child fostering may benefit children and their parents by reducing the economic burden on the family, giving the child improved educational opportunities, providing the child with vocational training or apprenticeship, helping wean a child in order to increase fertility, or simply to establish social ties that will benefit the child and family in the future (Renne 1993; Bledsoe 1989; Goody 1984). Child fostering also benefits the caregivers by providing companionship, daily assistance, and economic security (Bledsoe 1989).

Fostering practices are not, however, always beneficial or voluntary. For example, Goody (1984) describes fostering relationships in Sierra Leone that took place shortly after the abolition of slavery. According to Goody, the children of freed slaves were often taken into the household of elite Creole families in order to employ them as virtual slaves. Though not voluntary, this often benefited the child as they were fed, clothed, and schooled (Goody 1984). Leinaweaver also highlights the “constraints of

¹⁹ Kinship care in the United States has also been essential to the care of AIDS orphans, and is also dominated by grandparents. For examples, see Grant (2000) and Crumbley and Little (1997).

poverty and vulnerability” (2007:166) which caused fostering relationships in Peru to be characterized by vertical relocation, with poor families having to give up their children, usually girls who can help with domestic tasks. These examples highlight the fact that processes of creating social relationships are not always alliance-building strategies, but are often survival strategies necessitated by poverty and inequality.

Child fostering has a long history as a regular cultural practice among Basotho. Page (1989) examined the co-residence of mothers and children in Lesotho, on the assumption that, when the mother is absent, most children do not live alone with their father. Although this data is outdated, my own fieldwork confirms the rarity of single men caring for children. She found that 20.7 percent of both boys and girls in Lesotho, from birth to age fourteen, were not living with their mother. Page argues that fostering practices help to distribute social responsibility and maintain strong ties within the lineage (1989). She suggests that the absence of widespread adoption practices is replaced by alternative methods of caring for children that are adapted better to local social organization and kinship structures. Ansell and van Blerk (2004) look at children’s migration in the time of HIV/AIDS. They argue that migration is a household coping strategy that privileges care over the identity of the caregiver. My own empirical evidence (presented in Chapter 3) corroborates this evidence as well.

Conceptions of illness and caregiving practices are inextricable in rural Lesotho where the majority of care work is done in the home by extended, primarily female, kin. This pattern of care by female kin has been widely documented in sub-Saharan Africa where gendered divisions of labor are pronounced (Ntozi 1997; Ndaba-Mbata and Seloilwe 2000). Extreme poverty and limited treatment choices mean that these networks

of care are essential, not only to those who currently suffer from long term illnesses, but for maintaining social networks that provide some insurance for those who may need to be cared for in the future (Klairs 2010).

Most of the caregivers with whom I worked were currently engaged in fostering – usually grandchildren – and many had been fostered themselves as children. Again, the ideal in Lesotho is that these fostering relationships are reciprocal. However, due to political, social, and economic circumstances, this is no longer always the case. The increased prevalence of “crisis fostering”, which is not based on positive reciprocal relationships, is necessitated by emergency situations such as divorce, illness, or death (Page 1989:435). In Lesotho, HIV/AIDS has been a major factor in changing fostering patterns, as it has elsewhere in sub-Saharan Africa. According to UNICEF, in 2009, of the approximately 200,000 orphans in Lesotho, 130,000 were orphaned by HIV/AIDS (UNICEF 2012). Townsend and Dawes (2004) warn that the increase in crisis fostering may bring about a saturation of care networks so that fostering is not a feasible safety net for parents and children. Goldberg and Short (2012) found that orphans in Lesotho were widely perceived to be disadvantaged in both material and affective ways. However, as Parker and Short (2009) find, and my own research confirms, the relationship between grandchildren and maternal grandmothers provides significant advantages for orphans and needs to be protected and supported. Despite an overall concern about crisis fostering as a result of HIV, there is no research exploring the ways that these changes fundamentally alter fostering practices and kinship networks more generally. One of the primary goals of this work is to understand these changes.

A major challenge in theorizing about kinship and relatedness is that we place boundaries around what binds people together, and thus inadvertently exclude other things. The integration of this vast body of literature reinforces the importance of continuing to broaden the study of kinship and relatedness to include many diverse perspectives. In particular, studies of kinship and sexuality have been historically separated by discipline, with anthropology focusing more explicitly on relatedness, and sociology and women's and gender studies examining the sexual practices of marginal groups (Robertson 2005b; Rubin 2011; Butler 2002). Robertson (2005a) emphasizes that there is a need for the integration of the study of sexualities and kinship, and that it should not be limited to alternative sexualities. In HIV research, this segregation is evident in some studies' focus on the sexual behaviors of high risk groups such as men who have sex with men (Coates 2011; Jia et al. 2010), sex workers (Padilla et al. 2008; Alary and Lowndes 2004; Ann Burton et al. 2010), and truck drivers (Ramjee and Gouws 2002). Rarely do these studies intersect with the important new literature on kinship and relatedness emerging from anthropology. However, HIV-related stigma persists because the illness connects to deviant sexual behavior (Nyanzi et al. 2008; Bibeau and Pedersen 2002; Epstein 2007), and thus remains separate from what it means to be a spouse, a mother, a father, or a family more broadly. A view of HIV as a kinship disease pushes the intersections of kinship and sexuality to the forefront, so that it can no longer be ignored. A biocultural approach to the study of HIV/AIDS needs to consider how the physical realities of HIV transmission intertwine with notions of kin.

Medical anthropology: Biocultural approaches to HIV

Medical anthropology contributes greatly to the study of HIV/AIDS and the various biocultural and socio-economic issues that extend from it (Rugalema 2004). Early medical anthropology took a narrow functionalist view of the intersections of health and culture. However, paralleling the reformulation of kinship studies, by the late 1980s, medical anthropologists increasingly questioned “natural” categories, examined the pervasiveness of biomedical practices, and brought the Foucauldian concept of “biopolitics” to the center of its investigations (Lock 2001:480). Lock calls for the “recognition that all medical knowledge and practice is historically and culturally constructed and embedded in political economies, and further, subject to continual transformation both locally and globally” (2001:480). Paul Farmer’s work is important in highlighting the necessity of the type of approach proposed by Lock to the anthropological study of HIV/AIDS. He was the first to write a full ethnography of HIV/AIDS (1992), and as an anthropologist and physician has made important contributions in shaping appropriate treatment for those living with HIV/AIDS, focusing on the needs of the most marginalized and vulnerable patients.

The plurality of local and global transformations expressed by both Lock and Farmer led David Morris to advocate for an examination of “changed and still changing experience of human affliction” that “takes shape from specific historical convergences between biology and culture” (1998:3). He argues that a purely biomedical approach to illness does not fit with people’s actual experiences of illness – an idea that is supported by ethnographic evidence emerging in the anthropological study of the AIDS pandemic. The importance of a biocultural approach is reinforced as long-standing problems such as

malnutrition and infectious diseases are compounded by an increasingly global world that facilitates rapid population displacement, and environmental issues (Goodman and Leatherman 1998). Morris also emphasizes how AIDS has been affected and shaped by cultural practices, social attitudes, public policies, and global inequalities (1998). This framework is useful for medical anthropologists studying HIV/AIDS because it recognizes the plurality of factors that needs to be addressed, as well as the processual and dynamic nature of the problem. A postmodern approach to a biocultural investigation of HIV/AIDS also lends itself to the ethnographic method by maintaining a close connection with human experiences of illness, such as pain and suffering (Morris 1998).

Part of the biocultural approach to illness, particularly in an African context, is an exploration of the legacy of colonialism on medical beliefs and practices.

Anthropologists have made important critiques of a purely biomedical approach to illness, dominated by biomedical practices and often pursued in the interest of colonial powers. Colonization had negative repercussions for Africans' health due to economic and environmental changes that led to greater inequality, inferior living conditions and poor nutrition (Feierman and Janzen 1992). For example, Packard argues that tuberculosis did not exist in pre-colonial Africa, but was brought on by the conditions associated with migrant labor. Crowded housing, a lack of ventilation, poor conditions in mines, and changes in diet due to urban migration decreased migrant workers' nutrition, facilitating the spread of tuberculosis (Packard 1992). Comaroff notes the importance of medicalization for African colonizers, because the "unclothed heathen body" of the African was viewed as a site of infection and contamination, in need of civilized

intervention (1993:315). She argues that the public health mission promoted the economic interests of the colonizers, which relied on healthy African bodies for labor (1993). Mburu (1992) asserts that colonizers imposed biomedical systems and values on Africans in Kenya, and the legacy of these systems continues to negatively impact contemporary medical practices there. Medical anthropologists need to be aware of the ongoing legacy of colonial medical practices in Africa to understand the failures of current public health responses to HIV/AIDS.

In the post-colonial era, rapid changes in medical technology intensified biomedical approaches, and the responses from medical anthropologists are numerous (Ginsburg and Rapp 1995). Increased biomedical technology can be a source of power, agency, and resistance, but it can also be a source of marginalization and domination (Lock 1993).²⁰ The perception and dissemination of biomedical knowledge is key to people's acceptance or denial of new technologies and interventions. Dumit (1997) argues that biomedical "facts" are often perceived as authoritative and incontestable, increasing the power of biomedicalization (Dumit 1997; Lock and Kaufert 1998).

Infectious diseases, such as HIV/AIDS, are unique in their relationship to biomedical practices and knowledge because they are often lethal, necessitate state intervention, and can cause fear and mistrust in the popular imagination. Anthropological research on infectious diseases has been characterized by three approaches: biological, ecological, and socio-cultural (Inhorn and Brown 1990). Turshen (1984), in studying disease in Tanzania, criticizes a purely ecological approach that focuses only on the medical implications of a person's interaction with their environment. Instead, she

²⁰ There has been a great deal of work on biomedical technology in relation to reproduction. For a good overview of this issue, see (Ginsburg and Rapp 1991).

emphasizes the need for a “political ecology of disease”, which is grounded in power, class, and modes of production. Inhorn and Brown further what they call Turshen’s “macrosociological” perspective by arguing that it needs to be combined with a “microsociological” perspective, which examines individual behaviors and risk factors (1990:98-9). The cultural, political, and ecological conditions that lead to the spread of infectious diseases means that they are often associated with poor, marginalized populations. This has created what Farmer calls a “geography of blame” in which marginalized groups face accusations about the spread of disease that are fueled by racist media representations and inadequate responses (Farmer 1992; Briggs and Mantini-Briggs 2003).²¹ This is certainly true of HIV/AIDS, which is rampant in many of the world’s poorest countries, and is associated with stigmatized sexual practices.

HIV/AIDS treatment in Africa has a fraught relationship to a biomedical approach. Antiretroviral therapy is the only effective treatment that can extend the lives of AIDS patients by decades; however, access to treatment in Africa has been slow, expensive, inconsistent, ineffective, and wrought with political tension and resistance (Epstein 2007; Fassin 2007). Both a biomedical and cultural approach to HIV/AIDS is needed for effective prevention and treatment strategies. However, Taylor warns that although culture can be a useful concept to employ, we need to be “aware of its subordinating potential” (2007:974). She argues, “to the extent that they highlight the centrality of ‘culture’ for HIV/AIDS interventions, anthropologists, often unawares,

²¹ For example, see Briggs and Mantini-Briggs (2003). They demonstrate the racist and troublesome institutional practices that led to the spread of cholera among indigenous people in Venezuela in 1992 and 1993, bringing to light many of the complex and subtle ways that institutions, individuals, organizations and the media can not only change the popular perception of a disease, but also the social and political responses to it.

collude with and facilitate the creation of difference, and thus the hegemonic exercise of power” (Taylor 2007:974).

HIV/AIDS interventions, though often posited as apolitical, can also exert power in the ways that they engage with local and global political structures. Ferguson has criticized development projects in Africa for having the unintended effect of “expanding the exercise of a particular sort of state power while simultaneously exerting a powerful depoliticizing effect” (1990:21). It is the depoliticization of development, which is in reality a highly political undertaking, that Ferguson calls the “anti-politics machine” (1990:256). Although he is not examining a health initiative, Ferguson’s exploration of development in Lesotho reveals the potential for the unintended consequences of externally imposed programs and interventions.²² HIV/AIDS interventions run by NGO’s and humanitarian groups have also had a politicizing effect, producing “new forms of therapeutic citizenship” (Nguyen 2005:142), or what Petryna (2002) calls “biological citizenship”. Nguyen argues that the model used by NGOs and others is based on the self-help approach pioneered by the gay AIDS activist movement in the United States. He examines an AIDS self-help group in Burkina Faso to demonstrate how “access to treatment is contingent on social relations and the ability to capitalize on social networks” and “tell a good story” (Nguyen 2005:133). Robins (2006) also noted high levels of participation of people living with HIV/AIDS in activist movements in South Africa, as people often have nowhere else to turn for support. As a result, “relationships between citizens and the state are being redefined in the course of life-or-death struggles over

²² In this study, Ferguson (1990) examines a livestock and range management initiative in a rural region of highland Lesotho. The project did not succeed in improving agricultural practices, but merely facilitated government surveillance and control in the area, for example by building infrastructure such as roads and a police station.

access to health care and social welfare” (Robins 2006:320). Although NGOs claim local participation as a sign of their success, an individual’s motivation to participate in activist movements must be viewed from the perspective of unequal access to treatment, and the creation of new social subjects. This is particularly true of a local organization like MCS, which is unique in the services it offers for AIDS orphans and their caregivers. In Mokhotlong, those in need of residential treatment, home-based care or caregiver support have limited options. Regardless of MCS’s efficacy in providing these services equitably, client participation is a constrained choice.

AIDS-related stigma was initially linked with discomfort in openly addressing sexuality. Wood et al. argue that stigma is associated with “‘problematic’ and shameful sex” (2006:1925). However, several studies over the past decade linked stigma less with sexual discomfort than with death and dying (Klaitz 2005; Adebajo et al. 2003; Niehaus 2007). Niehaus argues that disclosure of other sexually transmitted diseases and the acceptance of teenage pregnancies in the South African Lowveld are common. Instead, it is the association of people with AIDS as being situated in between life and death that creates stigma. Niehaus argues that the biomedical presentation of AIDS as a terminal illness has solidified people’s fears of AIDS as certain death and created an ethos of silence. In the South African Lowveld, people with terminal illnesses are viewed as “living corpses,” considered to be “burdensome and pitiful,” and must be cared for by a select number of close relatives (Niehaus 2007:856). The physical manifestations of untreated AIDS, such as wasting, skin lesions, and mouth sores, as well as high death rates, reinforce people’s fears about AIDS, and perpetuate stigma. If antiretroviral treatment was more widely available in Africa – reducing the visible symptoms of AIDS

and greatly extending people's lives – AIDS-related stigma would likely diminish. Maluwa et al. (2002) make an explicit connection between stigma and broader structural inequalities, such as access to treatment. They argue, "HIV- and AIDS-related stigma and discrimination are closely tied to other inequalities and how they ultimately create and reinforce each other...[and] that a synergistic relationship exists between multiple forms of inequalities and that these converge in relation to HIV and AIDS" (2002:2). In this way, treatment produces not only medical, but also social benefits, and reinforces the inseparability of the biomedical and the social. Unfortunately, treatment is not available for many Africans, highlighting the structural inequality that marks Africans' experiences with HIV/AIDS.

As treatment becomes more widely available, my own fieldwork confirms a reduction in stigma marked by increased communication about HIV and Basotho's more positive and less fatalistic characterization of the illness. However, stigma is still a pervasive challenge in prevention and treatment efforts. In Lesotho, pregnancy out of wedlock is not ideal, but it is nonetheless common, and is not a cause of major social disruption within families. Accompanying this acceptance, however, is a general silence surrounding issues of sexuality and health, including HIV. People may not openly discuss their HIV-status or treatment plans with close kin, but they also do not discuss other personal topics such as the specifics of childbirth. It may be that the persistence of HIV-related stigma is not necessarily a reflection of Basotho attitudes about HIV specifically, but is, rather, a reflection this general ethos of silence and its potential to slow the reduction of stigma through a lack of communication and openness.

Trends in HIV/AIDS interventions

In southern Africa alone, there are 27 million HIV-positive people, which makes this area home to more than two thirds (67%) of the total number of infected individuals in the world (Heymann et al. 2007). As a result of the prevalence of the illness, this region has been at the forefront of programs and interventions to treat HIV and AIDS. Responses to the pandemic in Africa have been complex and numerous, and have had varying degrees of success. There have been a number of iterations in the types of approaches employed to combat HIV/AIDS in Africa. They initially focused on behavioral interventions targeted for individuals. However, they have evolved to increasingly address contextualized cultural elements and community participation (Kidman et al. 2007; Foster et al. 1996; Nyesigomwe 2005). Initially, research and interventions focused more heavily on prevention and testing efforts, but the past decade, they have belatedly responded to the need for effective treatment for people living with HIV/AIDS, as well as support for their families and caregivers, as an essential step towards meeting the needs of this growing population (Epstein 2007; Nguyen 2005).

Overall, little research has considered how current interventions as a whole are responding to the needs of this population. Instead, reviews of the HIV/AIDS literature focus on narrow aspects of this problem such as testing or treatment, but not both. As a result, there is little coherence in the overall approach to interventions, and the successes from one area of research are rarely integrated with other areas. This section will summarize the findings prevalent in the literature with regards to the three areas most targeted for intervention: prevention, testing and treatment.²³

²³ This section is based on over 150 articles that were analyzed for a thorough literature review completed for my Social Work Preliminary Examination in August 2008.

Prevention efforts in southern Africa have, until recently, focused on the ABC model: abstinence, be faithful, and use condoms. Numerous government and NGO initiated AIDS education campaigns have implemented programs in hospitals, clinics, schools, and through the media (Kelly et al. 2006; Vavrus 2006; Slonim-Nevo et al. 2001; Painter 2001). However, results regarding the efficacy of education campaigns as well as the ABC model have been mixed, given the continued high rates of new infections and low rates of testing (Kelly et al. 2006). Many have argued that the ABC model is unlikely to succeed because it does not reflect the reality of people's lives. In particular, researchers have emphasized the inability of women, especially married women, to abstain or negotiate condom use (Ndinda et al. 2007; 2005). The President's Emergency Plan for AIDS Relief (PEPFAR) also came under extreme scrutiny as it undermines prevention efforts by insisting that one third of the prevention budget be spent on abstinence education – an approach that is culturally and economically ineffective (Macklin 2005). Efforts targeted at pregnant women to facilitate the prevention of mother-to-child transmission (PMTCT) are significantly more successful because of the frequency with which pregnant women visit prenatal clinics, and the relative ease with which mother-to-child transmission is preventable (Stringer et al. 2003). However, pregnant women have extremely high HIV rates so many children are still being infected (Inciardi and Williams 2005). The most recent push in prevention efforts is an effort to increase circumcision rates in areas with high HIV-prevalence, as this greatly reduces transmission rates (Lukobo and Bailey 2007; Legeai and Auvert 2008; Brewer et al. 2007; Gray et al. 2007). One of the primary concerns emerging from widespread circumcision is the potential that it would disinhibit young men from safe

sexual practices; however, thus far this is not supported by biomedical research (Gray et al. 2007; Weiss et al. 2008).

Testing is closely linked to prevention efforts because an individual's ability to prevent transmission to others is predicated on knowledge of their HIV-status. Almost all testing initiatives follow the model of voluntary counseling and testing (VCT). Ideally, VCT is initiated by the patient, who receives pre- and post-test counseling. If the test is positive, the patient should be followed for diagnostic tests and treatment, when needed. If the test is negative, the patient should be given prevention information and re-tested every three months (Adebajo et al. 2003). Recently, studies have questioned whether the VCT model may be ineffective or may create some barriers to testing because of the low proportion of participants across southern Africa. However, the push in many southern African countries for all sexually active people to follow the popular campaign slogan, "Know Your Status", and get tested, has paid off. In Lesotho, as of 2009, 70 percent of those over 12 years of age had been tested at least once (UNAIDS 2010b).

A current debate in the testing literature considers an alternative to VCT called "opt out", or routine, testing (Wolfe et al. 2006). This type of testing approach would be initiated by health care providers during routine health examinations, and individuals would have to refuse the test in order to avoid being tested. Proponents of this approach argue that the routine testing of all southern Africans would help to prevent sexual transmission as well as mother-to-child transmission, and would also decrease stigma by treating HIV/AIDS like other non-stigmatized diseases such as tuberculosis (Cock 2005). Those opposed to routine testing argue that it violates individuals' rights, and assumes that people have all the information they need if they have not "opted out". In reality,

information may be limited and people's ability to act on that information may be constrained (Tarantola 2005). Tarantola (2005) also argues that even if testing were routine, this does not ensure a change in behavior that would lead to decreasing HIV prevalence rates. In my own experience in Lesotho, the lines between these two testing strategies are blurred, as patients, particularly pregnant women, were "asked" to test, but they often felt as though they had no choice in the matter. Nurses corroborated this feeling by arguing that it is "a must" that pregnant women get tested. There is no way to enforce or ensure that testing is actually voluntary, and patients in Lesotho are very passive in accepting biomedical interventions, a problem I will deal with more in Chapter 5. Resistance to medical interventions often occurs once the patient is at home, through non-compliance.

In the early stages of HIV/AIDS research in Africa, there was a lack of focus on treatment for people living with HIV/AIDS. In large part, this was due to the fact that effective antiretroviral treatment – a three-drug cocktail that was widely available in developed countries – was not yet available for Africans, even those with the funds to purchase them (Nguyen 2005). However, as rates of infection continued to rise, generic drugs became increasingly available, and knowledge spread about the role of drugs in reducing transmission of HIV, the need for improved treatment programs and access to antiretroviral drugs (ARVs) in southern Africa became readily apparent (Epstein 2007; Nguyen 2005). Access to ARVs has significantly improved since their introduction in southern Africa in 2002 (USAID 2011). In Lesotho, as of 2009, 65 percent of those in need were receiving treatment. Although this shows marked improvement, a large

number of infected individuals in need of treatment are not receiving it (USAID 2011).²⁴ Widespread treatment programs are of the utmost importance not only because they would improve the quality of life for those living with HIV/AIDS. Universal access to ARVs would lengthen people's lives, reducing the number of orphans, decrease mother-to-child transmission (Newell et al. 2004; De Cock et al. 2000), and reduce sexual transmission through decreased viral loads (Bunnell et al. 2005). Based on WHO recommendations, many high-prevalence nations, including Lesotho, have lowered the threshold at which patients qualify for ART, increasing the number of patients receiving treatment.²⁵ Based on the success of a recent clinical trial, many scientists advocate for a treatment as prevention strategy, whereby all HIV-positive patients receive ART, regardless of their viral load, claiming that this could bring about an AIDS-free generation (Cohen 2011).²⁶ It is important that a treatment approach is not pursued instead of prevention efforts but in conjunction with them, as community education projects and services for those living with HIV or caring for AIDS orphans remain important. Nonetheless, these findings are very encouraging, and have the potential to vastly change the global AIDS pandemic. As empirical evidence in this dissertation will demonstrate, treatment and adherence to ART are impacted by a variety of factors: structural inequalities, the complex nature of HIV treatment in this cultural context, the patient and their environment, and the healthcare system and providers. Ultimately, these

²⁴ Some countries from this study fared much better than Lesotho. In Botswana, Namibia, and Rwanda, ARV coverage rates exceeded 95% (USAID 2011).

²⁵ In 2010, the WHO recommended that countries initiate ART for patients whose CD4 count is less than 350, as compared to the 2006 recommendations that it be below 200 (USAID 2011).

²⁶ The HPTN 052 clinical trials, which reported early results in May of 2011, reported a 96% reduction in HIV-transmission as a result of universal access to ART (Cohen 2011).

factors help to shape the epidemiology of HIV/AIDS and the course of the pandemic more broadly.

Research and interventions that focus on ARV treatment provide information about the availability and accessibility of drugs in various countries and contexts (Jones 2005; Hardon et al. 2007), barriers to drug adherence (Nguyen 2005; Wolfe et al. 2006; Hardon et al. 2007), treatment-seeking behavior (Hatchett et al. 2004; Peltzer et al. 2006; Plummer et al. 2006), and the effect of ARV treatment and counseling on disclosure and stigma (Skogmar et al. 2006).

Global trends in the HIV epidemic show a marked decrease in new infections, a reduction in the transmission of HIV from mother-to-child and AIDS related deaths (UNAIDS 2010a). However, rates remain high across southern Africa, and in some countries, including Lesotho, HIV prevalence rates remain stable (UNAIDS 2010b). One prominent debate in the literature, is the extent to which multiple concurrent partnerships play in the spread of HIV infection in this region (Epstein 2007; Halperin and Epstein 2004; Tanser et al. 2011). Proponents of concurrency theory argue that it is the unique overlapping of multiple partners at any given time that fuels the spread of HIV, and that southern African patterns of relationship exemplify this model (Epstein 2007). However, others argue that concurrency has not been adequately tested in southern Africa, and that the most important factor contributing to high rates of HIV is the multiple partnerships, not their concurrent nature (Tanser et al. 2011). Other factors that are attributed to high HIV rates include poverty, a lack of consistent condom use, insufficient AIDS education, and challenges with behavior change (UNAIDS 2010b; UNAIDS 2010a).

Over the past decade, initial intervention strategies for HIV/AIDS in Africa concentrated on high-risk populations: truck drivers, prostitutes, and injecting drug users (Rugalema 2004; Schoepf 2001). In the early stages of the African epidemic, this was a viable strategy. However, the group currently most at risk of HIV infection is 30 to 50 year olds – essentially, the majority of the adult population (Uneke et al. 2007). In particular, women in southern Africa are most at-risk of HIV infection as almost 60% of people living with HIV/AIDS are women (UNAIDS 2010a; Smith 2007). Southern African women are at greater risk of contracting HIV not only because of the physical reality of their biology which puts them at greater risk than their male counterparts during heterosexual intercourse (Ndinda et al. 2007), but also because of women's lack of autonomy and power, which decreases their ability to take preventive measures to protect themselves (Vavrus 2006; Kalipeni 2000). Schoepf (2001) argues that targeting high-risk groups not only increases stigma against those groups, but also creates a sense of invulnerability among those not targeted, which does not reflect their real danger.

Although there is a movement away from a narrow focus on high-risk groups, research suggests that interventions should still be focused on sub-groups within the population in order to have an impact (Painter 2001). Demographic groups that are currently receiving significant attention are AIDS orphans, youth, and gender-specific interventions. In addition, there is increasing recognition of the need to support caregivers and partners, due to the negative impact HIV/AIDS is having on the broader community (Nyesigomwe 2005; Bachmann and Booyesen 2004). In order to meet the needs of local populations, programs increasingly rely on a community-based approach, utilizing local populations for design and implementation (Kidman et al. 2007; Foster et

al. 1996; Nyesigomwe 2005; Obasi et al. 2006; Higginbotham et al. 2001; Drew et al. 1998) In Mokhotlong, every family is impacted by HIV/AIDS in some way, and my own experience at MCS confirms the numerous benefits of a local response in effectively addressing to the specific needs of a community.

Although HIV/AIDS is a virus that can be managed through biomedical interventions, the African epidemic needs to be approached with careful consideration of the complex contextual factors that influence the medical and social epidemiology of the disease. As Madhavan et al. argue, AIDS is an “additional destabilizing mechanism in an already fragile system” (2004:1452). There is a tendency to overemphasize individual behavioral barriers to treatment over basic structural barriers such as poverty. Although non-governmental organizations (NGO), community-based organizations (CBO), government programs, and researchers have begun to recognize the role of environmental, structural, and contextual barriers to effective prevention and treatment, they have failed to systematically consider these factors and the ways in which they impact research and interventions throughout southern Africa.

In general, intervention strategies lack consideration of the contextual factors that might impact their success or failure. Interventions must consider cultural factors in their design in order to be successful. The beliefs, values, and customs that can impact HIV/AIDS interventions include social organization, socialization, gender roles and status, local understandings of illness, disease, treatment, testing, and culturally appropriate care practices (Epstein 2007; Taylor 2007; Stellway 2001). The widespread stigma associated with HIV/AIDS is another major barrier for interventions targeting testing, prevention, and treatment. Stigma creates significant emotional and material

challenges for people living with HIV/AIDS, prevents those at risk from testing and disclosing to their partners, and creates challenges for families and caregivers (Kelly et al. 2006; Daftary et al. 2007; Kebaabetswe 2007; Kalichman et al. 2006). Finally, the political economic context in which this pandemic is situated has a great impact on the spread of the disease, and on a country's ability or willingness to respond to it. Factors such as poverty, poor infrastructure, labor migration, and the availability of antiretroviral drugs – and the ways in which they intersect with the economy, development efforts, and public policy – influenced the outcomes of research and interventions in many southern African countries (Rajaraman et al. 2006; Campbell et al. 2005).

The intervention literature reveals that responses have failed to consider contextual factors such as culture, the political economy and stigma in intervention design. This dissertation attempts to fill this gap by making recommendations for intervention strategies that consider these contextual factors. These recommendations are facilitated by the deep knowledge of the community's needs provided by the ethnographic evidence presented here.

Methodology and research site²⁷

I spent June and July of 2007, and October 2008 to September 2009, conducting ethnographic fieldwork in Mokhotlong, Lesotho (see Figure 1.1). I worked closely with Mokhotlong Children's Services (MCS), a community-based NGO that provides assistance to AIDS orphans and their families through an outreach program and a safe home. MCS was initially founded by a graduated Peace Corps volunteer, Ken and his now wife Colleen, who stayed in Mokhotlong to work at another local NGO. In 2004,

²⁷ All research activities were approved by the University of Michigan's Institutional Review Board, and oral and/or written consent was obtained from all participants.

Ken was approached by a local social worker who needed assistance with a baby who had been abandoned and found by neighbors. Ken and Colleen decided to house the child, and soon they received more children in need of care, and MCS was born inadvertently. With the support of Ken's church back in New York, and some alumna from Ken's alma mater, a group of US-based volunteers established a foundation to support MCS.

Figure 1.1 – Aerial view of Mokhotlong²⁸



Over the past five years, MCS received funding through a combination of personal donations raised mostly from the US-based foundation, and institutional grants from NGO's including UNICEF, Care, Prince Harry's Lesotho-based charity, Sentebale,

²⁸ All photographs were taken by me, unless otherwise stated.

and German NGO's that support agricultural and environmental projects. MCS's annual budget is relatively small (less than \$200,000), and relies on small grants and donations to reach its annual goals. In March of 2005, MCS leadership transitioned to one of its local employees, Nthabiseng Lelimo, who is currently the managing director. MCS is the only organization providing comprehensive services to AIDS orphans and their families across the Mokhotlong district, with a population of approximately 97,000 (Lesotho Bureau of Statistics 2009). Although families receive some assistance through local clinics, hospitals, and other small NGOs, MCS is the only organization in this region that offers limited residential care, makes home visits, and provides support to caregivers; thus it is the only program to reach the most remote and isolated communities.

I began my research by accompanying MCS's outreach staff to villages, and collecting survey data from approximately 50 caregivers. This data included demographic information, basic health information, and kin relationships. While collecting this household data, I became acquainted with, and identified, 21 caregivers for follow-up. I then conducted a series of three to five in-depth, semi-structured interviews with each caregiver over the course of the year. In order to provide a comparison group, I recruited five caregivers who were not MCS clients by asking participants if there were any other caregivers of AIDS orphans living in their village who might want to participate in my research. However, because of an ethical responsibility to help those in need access services, two of these families eventually became MCS clients based on my recommendation to 'M'e Nthabiseng, and the outreach team's assessment of the families' needs.

The content of some of my interviews were of a highly sensitive nature. To address this challenge, I structured my research activities in order to increase the value of the ethnographic evidence by initially observing service delivery to AIDS orphans for several months in order to build rapport with potential interviewees as well as increase my understanding of the problem on the ground before asking questions of a sensitive nature. I visited the caregivers at least two times prior to interviewing them. I then began my series of interviews with the most general and least personal material. I also spent time during each visit chatting with caregivers and playing with the children in order to directly observe care and increase the comfort level of the caregivers. By the time we talked about sensitive issues such as HIV and the challenges of care, we had been acquainted for the better part of a year and had built a trusting relationship. Their thoughtful, honest, and personal responses reflect this effort.

I conducted interviews in both English and Sesotho.²⁹ Sesotho is a Bantu language spoken in Lesotho and South Africa (where it is called Sotho or Southern Sotho).³⁰ Sesotho is not commonly taught in American universities because of the relatively small number of speakers worldwide. Therefore, I could learn only limited Sesotho prior to my fieldwork trips. I studied the Sesotho books and guides I could find prior to fieldwork (Hoag 2005; Demuth and Indiana University Linguistics Club. 1983; Demuth and Sekhesa 1978), and hired a tutor during my pre-dissertation fieldwork. In this way, I was able to obtain a basic working knowledge of Sesotho, which improved over the course of my fieldwork. However, I employed a research assistant, Ausi (*sister*)

²⁹ Sesotho is used both to refer to the language of the Basotho, as well as to Sesotho culture.

³⁰ There are some slight differences between Sesotho and Southern Sotho, mostly orthographic. Southern Sotho is one of South Africa's eleven official languages, and is spoken by approximately 5 million South Africans as a first language.

Ntsoaki Lerotholi, who translated during interviews, and assisted in transcribing them afterwards.³¹ She also helped me gain access to people's homes, and generally made my research easier by helping accelerate my cultural learning, making sure I did not overstep my boundaries, and ensuring that I did not get lost on the many nameless dirt paths I had to travel. The interviews consisted of open-ended questions about kinship and relationships, important events in the life of Basotho men and women, and caregivers' experiences in coping with HIV/AIDS and in caring for orphans. I also conducted interviews with several other community members including HIV/AIDS counselors, hospital employees, MCS staff, traditional healers, chiefs, and religious leaders. The total number of interviews conducted was 105. Finally, I carried out ethnographic observations in hospitals and clinics, observed the delivery of community services to families, and attended community events such as HIV/AIDS awareness events, funerals, and weddings.

This dissertation is dominated by voices of women. For the most part, this is because Basotho women continue to provide the majority of carework for orphans and sick family members. Therefore, when investigating caregiving practices, female-dominated testimonies accurately represent this group. In addition, ethnographic work on caregiving such as this gives a voice to women who have been historically marginalized in the public realm. However, the male voices that are presented here indicate that much

³¹ Ausi Ntsoaki was with me every day and also developed strong relationships with the caregivers we worked with. She learned a great deal about my research and about my intentions when asking questions. I instructed her about open ended questioning and asked her to let interviewees speak for as long as they liked without interrupting. She would then paraphrase for me after they completed their answer, and learned over time which points were important to repeat at that moment. Ausi Ntsoaki would occasionally ask her own questions or clarify points on her own. Because we transcribed the interviews on a weekly basis, we were able to refine the interviewing process and the learning curve. In interviews, unless otherwise specified EB: indicates where I am speaking and NL: indicates where Ausi Ntsoaki Lerotholi is speaking.

could be gained from understanding male perspectives on care, and that men could, in fact, represent an important group of caregivers as the crisis in care increases over time. In light of this, I critically assess the role of gender ideology in narratives of care, and present the possibility of increasing attempts to recruit male caregivers to alleviate caregiver burden on elderly Basotho women.

In addition to the survey and interview data, I also gained open access to MCS's data going as far back as 2004. I assisted MCS by helping to build a database to store this data, and helped the administration input data covering the period from November 2008 onwards. MCS is committed to using the database for ongoing management of client information and clinic activities. I, therefore, have continuing access to data on all MCS clients from November 2008 until the present, and will continue to benefit from access to this growing database in the future³². I also used photography as a way of capturing visual images of people's living spaces, fields, and families³³, as well as to capture the remoteness of the countryside. Finally, I collected detailed topographical maps from the Lesotho Ministry of Agriculture on which to plot the distribution of my informants, as well as the home location all of MCS's clients. I also collected several reports on health, gender, agriculture, and migrant labor from the Lesotho Ministry of Statistics.

Because of the geographic isolation of the outlying villages, I bought a motorcycle, which allowed me to travel on rugged paths as well as paved roads. Many of the caregivers I visited required me to both drive and hike to reach their homes.

Although I attempted to visit caregivers on one day that were in the same general

³² Data from this database will appear in this dissertation where appropriate.

³³ According to my IRB specifications, oral permission was received for photos taken of any identifiable individuals.

direction, I would often have to spend several hours to reach one client, only to find them away at the clinic, working in the fields, or elsewhere. Another complicating factor is that most Basotho do not possess phones, and scheduling visits was virtually impossible. Although at first, I think people were puzzled to find two young women driving around on a small dirt bike together, the sight of our two red helmets quickly became familiar, and those expecting us would keep an eye out for our “horse,” as one grandmother jokingly told me. This painstaking and time consuming method of data collection is certainly not efficient, but I believe I was able to gain insight into the lives of rural Basotho that other more convenient methods of data collection would not allow, reinforcing the necessity of the long term ethnographic study of this community. Few Basotho living in the rural villages own vehicles, apart from taxi drivers. The challenges I experienced in accessing the villages and homes of caregivers are much greater for the caregivers themselves, and my trials provide some insight into the challenges of treating HIV in this remote rural context, which are even greater for those without money or their own means of transportation.

It is necessary here for me to say a few more words about Mokhotlong, my connection to MCS, and my position in the community. It did not occur to me until I took my first trip into South Africa how different the racial tensions and perceptions of white people were in Lesotho as compared with its powerful neighbor. The change in attitudes between whites and blacks is palpable as you drive across the border into the Free State towards Bloemfontein, where a number of Afrikaans-speaking white South Africans live. This discomfort is also accompanied by visible signs of government influence and wealth. The cracked brown-red earth of Lesotho is almost immediately

replaced by large expanses of green, and herds of fattened cattle grazing inside vast fenced-in areas. With this obvious wealth come disparities as well: shantytowns, shacks, and, in the cities, beggars and street children. Seventy-five percent of Lesotho's population lives in rural areas, and over 99 percent of the population is ethnic Basotho, which helps to explain why poverty in Lesotho is more generalized (Mwase et al. 2010; WHO 2005). Lesotho lacks the wealth of South Africa and the obvious disparity of wealth that is one pervasive remnant of the apartheid state and the ongoing racial tensions.

Compared to this, Lesotho is an extremely inviting place as an outsider. Lesotho is virtually culturally and linguistically homogeneous. Apart from a few villages dominated by Xhosa near the South African border, a small but visible Chinese population of merchants and shop owners, a small population of other Africans, mostly nurses and doctors, called *makoerekoere*, and small Indian, South African, and European and North American communities located mostly in the city, Lesotho consists predominantly of Sesotho speaking Basotho. Like most other African capital cities, the city of Maseru is the locus of many NGO headquarters, and it is common to see European's and North American's on the street and at certain local institutions, establishments, and neighborhoods. However this diversity does not extend to the mountain district of Mokhotlong.

Aside from a handful of Peace Corps volunteers, some American doctors who visit monthly, and the occasional visitor looking to experience "real Lesotho culture", the steady rotation of mostly American volunteers at MCS – primarily university students on summer internships and medical volunteers – represent the most stable foreign

community in this rural camp town. Although people in Mokhotlong approached me daily to talk to me out of curiosity, I was never once asked for money on the street. The only frequent request was by children yelling, sometimes at impossible distances, to “give me some sweets.” Rural Basotho living in the Mokhotlong district are very friendly and not aggressive when it comes to business or health. Because of its remoteness, it seems almost as though the pervasive capitalistic motivations that propel daily life elsewhere are absent here. Although the main street of the camp town is lined with shacks selling various clothes, services, and foods, sellers never call out to passersby to increase their sales, and there is no bargaining. People do not put items on sale in order to increase business, and buying four of one thing costs exactly four times as much as buying one of that same thing. In general, rural Basotho’s attitudes towards North Americans ranged from curiosity and interest to indifference, but I never experienced a sense of hostility until entering South Africa. Because there are no white Basotho, and the majority of the population is geographically isolated, the most devastating effects of apartheid on rural Lesotho appear most obviously in the political-economic realm. However, the political-economic and social realms are intimately linked. Therefore, the social implications of the structural violence caused by apartheid are nonetheless a major factor. Nowhere is this more true than with HIV/AIDS’ impact on the family.

Prevailing Basotho attitudes about North American and European foreigners certainly eased my fieldwork experience. However, this ease makes reflexivity as a result of my position as a white, educated, foreigner even more important. Among my more mortifying experiences during fieldwork was being sent by ‘M’e Nthabiseng, MCS’s managing director, on numerous occasions to collect medications for safe home

babies or MCS clients, skipping the queue for the pharmacy. It was at times like this that I was most aware of my status as a *makhooa*. MCS had good reason to do this; because they treat so many babies they would need a full-time employee just to wait in line at the hospital if they were not able to jump ahead, whereas a villager or caregiver might only have to come to the hospital once a month or less. However, it was not merely a matter of convenience that 'M'e Nthabiseng sent the foreign volunteers to do this unpleasant task. She was well aware of the authority that foreigners carry, particularly in the context of the hospital, where foreign staff and volunteers are frequently encountered. Despite my efforts to treat people with respect and kindness and to privilege local perspectives and ways of knowing, power differences are stark and unavoidable. The long term impact of structural factors such as political policies surrounding apartheid, development projects and international aid, have had an immense and lasting economic and social impact on Basotho at a national and individual level.

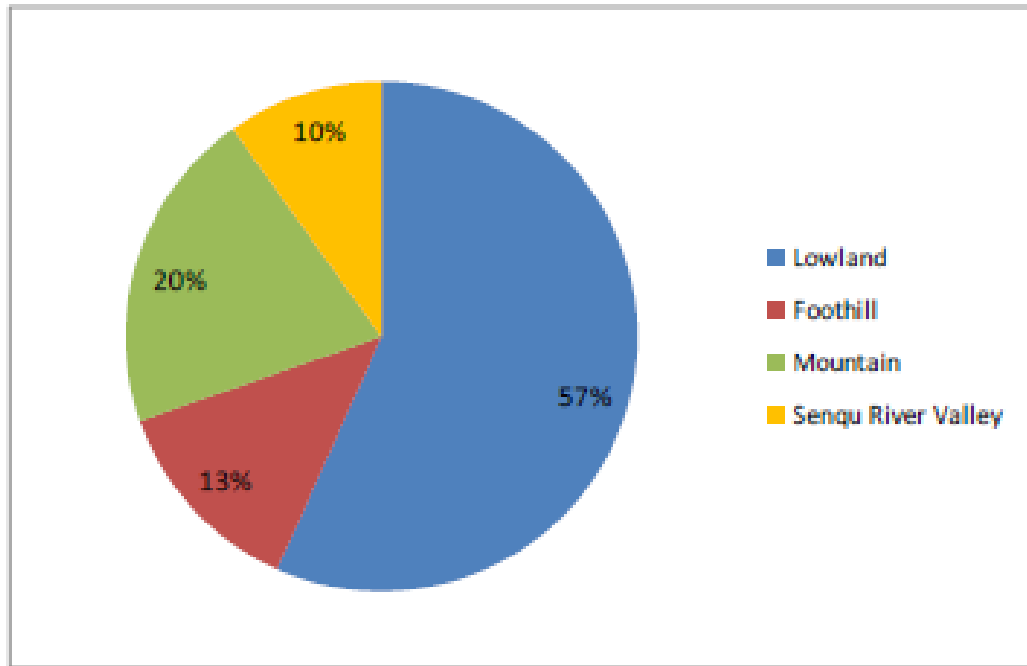
Critical international social work is particularly interested in questioning the role that social workers plays in reinforcing and reproducing colonial hierarchies, and investigating how social work education in North America adequately or inadequately prepares students for work in the developing world (Heron 2005; Razack 2009; Narda Razack 2005; Gray and Fook 2004). Razack points to the unintended consequences of work in the developing world: "Many social workers share the ideals of global justice and human rights...Some are more conscious of the limitations of their subject positions in local and global space. The power and privilege of whiteness in Southern space can interfere with their original intent to practice global justice and human rights" (2005:102). As my research makes recommendations for intervention, self-reflexivity, and awareness

of my position and the impact that my “whiteness” has on the Other, are particularly important. The ethnographic method made this type of reflexivity possible by helping to deepen my understanding of local values, needs, and perspectives, while also enabling me to build long-term relationships with caregivers so that I could work to reduce power differences in my interactions with Basotho. This reflexivity does not end with fieldwork, but is a constant consideration in my writing and my recommendations for intervention.

Lesotho’s population is primarily rural, though there has been a dramatic increase in the urban population over the last thirty years. In 1976, 10.5 percent of the population was living in urban centers as compared to 23.8 percent in 2006 (Lesotho Bureau of Statistics 2009). However, the urban population of Lesotho is living clustered in the lowlands, and the mountainous districts of Lesotho, including Mokhotlong, are still primarily rural, and consist of a small proportion of the total population³⁴. The highlands of Lesotho are further isolated because they are separated by a dramatic and abrupt mountain range called the Maloti Mountains. Lesotho, which has the highest low point of any country in the world, is high, dry, cold, and beautifully barren, and most people have very little reason to go beyond the city of Maseru. Lesotho’s isolation, climate, and soil conditions are implicated in the political formation of its boundaries, as I will address in Chapter 2. The geography of Lesotho, with limited and often impassable roads, severe soil erosion, and harsh winter weather characterized by snow and mud impact both economic choices and social patterns.

³⁴ According to the 2006 census (Lesotho Bureau of Statistics 2007a), 5.1 percent of the total population of Lesotho was living in Mokhotlong. The other mountain districts have similarly low populations: Thaba-Tseka (6.9%), Quthing (6.4%), Qacha’s Nek (3.8%).

Figure 1.2 - Population by agro-ecological zone (2006)



Source: (Lesotho Bureau of Statistics 2010)

Although I never experienced any hostility from Basotho, and was frequently welcomed into their homes, my position as a white foreigner was meaningful and greatly impacted my interactions with people. Because I was often visiting people in healthcare settings, or talking to them about their health, they assumed I had some authority as a healthcare provider. Although I did not attempt to give this impression, and explained to people repeatedly what I did, especially to the caregivers with whom I worked most closely, this was difficult to dispel. I was often asked medical questions and could sometimes help people by explaining to them what was written hastily by a doctor or nurse in their health booklet, or *bukana*, or by reading the English labels on medications.

My position with MCS was mutually beneficial and reciprocal. My husband, Will, and I had a small *rondavel*³⁵ build on the grounds of the safe home after our short visit in 2007, which now houses volunteers and medical personnel. I developed a close friendship and working relationship with the managing director of MCS, 'M'e Nthabiseng. Although I most often did my own work in the villages, and my husband taught at the local public high school, the staff considered us as long term volunteers, and frequently asked us to help with various chores, or with the babies in the safe homes at meal times or when the house was particularly full. The year we lived at MCS there was also another American couple, Reid and Bridget Rawls, living there as long term volunteers for MCS, who were responsible for assisting 'M'e Nthabiseng, writing grants, helping in the safe home, expanding the outreach program, and doing the accounts and financial reporting to donors.

Ultimately, my alliance with MCS was extremely valuable for me both socially and professionally. It was through MCS that I was connected with caregivers and orphans in the outlying villages. I was also able to observe the service delivery of aid to orphans and their families for several months by accompanying the outreach team to the villages. Living at the safe home put me in the middle of the locus of activities. As the only residential care facility for orphans in the district, I witnessed the unfolding of many cases, particularly emergencies, as caregivers brought children to MCS in the desperate hope of receiving assistance. MCS was the center of a lot of activity, with clients and potential clients constantly stopping by to ask questions, or to collect medication and

³⁵ A *rondavel* is a small, round house that is found throughout Lesotho, and is the primary structure in rural areas. The outside walls are made of stones and the walls and floors are made of hard packed mud. The room is supported by a few beams covered in dried wheat or maize stalks. Our *rondavel* was built by local contractors with cinderblocks and cement instead of rocks and mud, and had a wheat thatched roof.

supplies. The proximity, both geographically and professionally, of MCS to the district hospital, also increased my familiarity with happenings there. I was often asked to take children to the hospital, bring supplies to clients there, or check on potential clients. I got to know the African (mostly Zimbabwean and Congolese) and American doctors, and had the opportunity to observe service delivery at the hospital as well, accompanying doctors or nurses on rounds, taking children to appointments, or collecting medication.

However, my relationship with MCS was also fundamentally collaborative. In addition to the daily and weekly assistance in and around the safe home, I helped to implement an improved data collection system for MCS that involved months of work. For the first several months there, while accompanying the outreach workers, I collected data from pre-existing clients in order to bring their information up to date, and helped implement intakes and follow-ups with new and existing clients. I helped to design and test the database, trained outreach workers on data collection and data entry, and entered much of the preliminary data myself. This collaborative effort was valuable to both MCS and me, as during the data collection process I learned a great deal about the work of MCS and the clients. I have ongoing access to the database, which continues to collect information monthly from all clients. This will be an invaluable resource for me as I continue long-term study of this community. For these first few months, my work with MCS was truly profitable as there was complete overlap between my goals and the goals of the organization.

I first met most of the caregivers I worked with over the course of the year through MCS; therefore my role with them was initially confusing because they saw me as an extension of the organization. This was exacerbated by the fact that I often

delivered food or messages for MCS when I was travelling to a village to do interviews in order to save outreach workers an entire day of work, which is often what it takes to reach one or two children. Although I have no medical training, I quickly learned a great deal about HIV treatment, preventing malnutrition and dehydration, and recognizing the signs of symptoms of opportunistic infections. When visiting a family whose child was HIV-positive, I often began by looking at their health booklet and medication to ensure that they would not run out of medication before their next scheduled visit (which was often the case) and to make sure that they administered the complicated and frequently changing medication properly. I found many instances where the clinic had made errors in scheduling the next appointment, or where the caregiver was giving incorrect doses. Given the importance of adherence to ARVs, I continued this practice throughout my time there. I would also look through health booklets to make sure that a child's HIV-testing was up to date, because with young children, there is a complex system of retesting that is needed to confirm HIV-status, and this was often overlooked by the overworked and under-resourced clinic and hospital staff. Caregivers often shared with me any health problems that a child had at the time of my visit. In order to ensure that these errors were remedied, I occasionally recorded necessary information in the health booklets to alert the health care providers of the needs of the child.

These types of activities were a very small part of my visits with caregivers, and the majority of our interactions were not about MCS. Nonetheless, caregivers saw me, to a certain extent, as an extension of MCS and as a gatekeeper of services. In an effort to protect their interests as clients of MCS, caregivers were more likely to tell me what they thought I wanted to hear, especially with regards to the care they were providing for

children. Although my connections to MCS and my involvement in monitoring the health and well-being of the children in some ways complicated my role as a researcher, I felt obligated to perform these simple yet important checks that had potentially important health impacts for the children. These activities were also very informative for me in learning about the challenges of care for HIV-positive children and the failures of the health system.

Ultimately, long-term fieldwork, my ability to measure caregiver self-reporting with what I saw over the course of the year through observation, and my own reflexivity and awareness of potential biases, helped to minimize the pitfalls associated with the nature of my relationships with caregivers. It is my sincere belief that even as caregivers saw me as a potential resource, the amount of time we spent together allowed me to obtain honest and important information about HIV and care. In as many ways as my relationship with MCS created challenges, it also opened many doors for me, and gave me insight into the community that would not have been available to me without it.

Anthropology and social work: Interdisciplinarity explored

One of the most difficult intellectual tasks of this dissertation has been to integrate the diverse disciplinary perspectives of anthropology and social work. Surprisingly, it was not difficult for me to blend my goals as an anthropologist and social worker during fieldwork. I have long held that there is a place for the long-term ethnographic approach to exploring social problems and solutions. While anthropology can be inwardly-focused, it is increasingly applied – or as Fassin says, “socially useful” (2007:xxii). I agree with Fassin’s statement that “social science would not be worth a moment’s attention or labor if it had no political role,” particularly when it comes to work on

problems – like HIV/AIDS – that impacts the most marginalized and silenced people (2007:xxiii). While anthropology was far more influential in designing my research methods, my research topic was guided by a desire to investigate a pertinent social problem.

Throughout this dissertation, I analyze the cultural and social aspects of caregiving using primarily an anthropological lens. However, the findings and strategies for moving forward regarding caregiver support and addressing the challenges of HIV are directed towards social work, public health, and others interested in bringing about social change through intervention strategies. Although anthropology and social work may at first glance seem disparate disciplines, medical anthropology and social work often overlap in that they are both interested in the health disparities that exist in marginalized populations. The primary difference is that medical anthropologists are more interested in explaining social and cultural difference, while social workers are more firmly committed to working towards social change and betterment as a whole, whether through policy, advocacy, or interpersonal practice. This interdisciplinary project seeks to do both by contributing to the advancement of anthropological theory, presenting rich ethnographic data, and contributing to the knowledge development stage of intervention research (Rothman and Thomas 1994b).

Despite the paucity of ethnographic work emerging from social work, ethnography is a useful research method for qualitative social workers because, as many have noted, the skills needed for ethnographic work and social work have a great deal of overlap (Goldstein 1994; Gilgun 2010; Archer 2009). As Goldstein notes, ethnography and “humanistic” social work both “strive to appreciate the human experience as it is

lived, felt, and known by its participants” (1994:44). Gilgun speaks directly to the benefits of ethnography for intervention planning and design, arguing that the method provides “the theory and knowledge about policies, problems, and practices that are required for the development of intervention research” (2010:296). Two of the main tools used by ethnographers are semi-structured interviews and extensive ethnographic observations. Both of these techniques are useful specifically for intervention research because of the level of deep cultural knowledge and detail, and the contextualization of the human experience that they afford (Gilgun 2010).

Social workers have long recognized the value of the ethnographic approach in studying marginalized populations (McClelland and Sands 2002; Iversen and Armstrong 2006; Hall 2003; Floersch 2002)). The methodological approach of this research has been instrumental in allowing me to attain cultural competency in global social work research. However, limitations of time and resources prevent the widespread use of ethnographic methods by qualitative social workers (Gilgun 2010; Fortune 1994). Fortune (1994) recommends that social workers borrow from others’ ethnographic insights in order to gain the necessary cultural understanding for research and practice. However, it is unfortunate that social work does not place increased value on such in-depth and longitudinal fieldwork. One possible explanation is that in social work, such time-consuming research is not supported by academic rewards such as publication, funding and promotion. Whatever the reason, social work research adheres to methodological structures whereby randomized controlled trials are considered the “gold standard” and are at the top of the research chain while methods such as ethnography are “demoted to the bottom of the evidential hierarchy” (Huxley et al. 2010:424).

Rothman and Thomas' (1994a) categorization of intervention research is useful in understanding how this dissertation fits into the spectrum of intervention research in human services. This work is part of what the authors call Knowledge Development (KD), which is defined as “empirical research to extend knowledge of human behavior relating to human service intervention” (Rothman and Thomas 1994a:3). Although KD research can look much like work coming from other types of social science research, it is distinct in that it is oriented towards finding solutions to problems that arise in human service fields. My explicit goal in undertaking ethnographic fieldwork was to better understand the challenges that caregivers of AIDS orphans in this particular social, cultural, and political economic context face, in order to make recommendations for interventions that could improve the health and well-being of the children and caregivers. As Rothman and Thomas note, KD research provides an important foundation for this type of work, and is important during the initial stages of intervention research (1994a).

A long-term ethnographic approach provides a depth of cultural understanding that other forms of data collection do not allow – even other forms of qualitative data collection. Medical anthropologist Stephen Schensul is committed to converting his findings into intervention strategies. He warns that even though other fields interested in health disparities such as public health are increasingly using mixed methods, “the participant observation and in-depth interviewing for which anthropologists have used qualitative methods have frequently been short-circuited by other disciplines as a means of simply adapting Western-derived instruments or using rapid methods such as focus groups to locally modify externally-derived interventions” (Schensul et al. 2010:36). I

would argue that these modifications are useful, and worth exploring, but not to the exclusion of the findings that can be derived from long-term ethnographic fieldwork.

Schensul argues that anthropology can contribute to interventions in six specific ways: cultural perspective, holistic perspective, local perspective, emphasis on the micro-level, qualitative contribution, and culturally-based interventions (Schensul et al. 2010). As Fassin argues with regards to finding solutions to the AIDS problem, “hurried analyses and acrimonious denunciations have only made it more difficult to determine and implement effective social responses” (Fassin 2007:xiv). Anthropology is in the unique position to make contributions to a deeper understanding of health disparities by a unique sensitivity towards the intersections of health and culture, and full comprehension of the contextual factors that influence the experiences of families of communities. These insights have the potential to make important contributions to interventions in the area of HIV/AIDS if anthropologists are able to better convert their research into practice. Social work’s focus on intervention research provides both the tools and the avenue through which to make a social contribution as a result of this research.

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Chapter overview

The chapters of this dissertation that follow attempt to provide the social, cultural, historical, political economic, and biocultural context with which to understand the challenges of orphan care in a rural community that has been greatly affected by HIV/AIDS, and to illuminate the numerous connections between HIV and kinship that make this illness unique.

Chapter 2 provides an account of Lesotho's political economic history, which is inextricably linked, and often overshadowed by its powerful neighbor, South Africa. In particular, extremely high rates of migrant labor to South Africa had a vast economic impact on Lesotho. However, Lesotho's unique history at the hands of an exceptional leader, Moshoeshoe I, set the stage for a relative degree of independence for Basotho in exchange for poor land quality and the emergence of a remittance economy through migrant labor to South Africa. Migrant labor was also extremely prevalent at the time HIV began to spread, and the unknowing spread of this disease in conjunction with the separation of families inherent in migrant labor had a tremendous social and economic impact on Basotho. The political response of South Africa's government to the HIV problem, which set the stage for many of the less powerful nations in southern Africa, also had a devastating impact on the course the pandemic has taken in this region, and

these connections will be explored here in order to contextualize the situation in Lesotho today.

As kin are central to orphan care, Chapter 3 examines what it means to be a Mosotho. I explore how people live, with whom they live, and how kin ties are made and unmade. In these examples, I demonstrate that Basotho ideals about kinship are based on the principles of patrilineality, but in reality relatedness is formed, maintained, and dissolved through the practice of living. Factors such as proximity, reciprocal aid, affection, health and capacity to help are central to the formation and dissolution of kin ties. Relationships are reflected in names, houses, and shared substance more than in a set of rules, yet those rules remain important in the cultural imagination and therefore have a real impact on the structuring of social roles and ties. Cultural changes that impact the family are also explored here, in particular the changes in marriage practices and bridewealth payments, increase in divorce rates, and the role that external factors such as migrant labor and HIV have played in these changes. Interestingly, as lineality becomes deemphasized, the house has emerged as a stable place where kinship is reckoned, and as a site where demographic changes at the family level can be traced. To set the stage for a discussion of child fostering in the time of AIDS, I also explore the perception by Basotho of childhood and care for children, such as the importance of childbearing despite high rates of disease and infant and maternal death, and the strengths of intergenerational bonds as a cultural ideal.

In Chapter 4, I explore Basotho conceptions of health and illness as a way to contextualize their response to HIV/AIDS. Basotho have a wide variety of explanations for illness, which combines Sesotho medicine, witchcraft, Christianity, and biomedical

practices. Beliefs and treatment seeking behaviors vary widely based on the individual beliefs of the patient and the illness being treated, as well as availability and accessibility of treatment options for people. Although many of Basotho's choices about treatment at first glance seem to be binary opposites from which one must choose, in reality, they present Basotho with choices that give them flexibility during this difficult time. Basotho strategically navigate these binaries in ways that privilege kin and care of loved ones. Kin-based care is still prevalent in treating the chronically ill, and the beliefs of the caregiver greatly influence the treatment sought by the patient, and the level to which they can adhere to it. Even those who initially claim a fervent dislike for traditional healers will use homeopathic remedies for certain ailments – those considered “Sesotho illnesses”. Basotho will often get opinions from both Sesotho doctors and doctors at the hospital (called *ngaka ea sekhoaa*, literally, “English doctors”) when deciding on a course of treatment, or combine treatment recommendations from both branches of medicine. The majority of Basotho, regardless of their view of traditional healing practices, express great confidence in biomedical treatments available at local clinics and hospitals. The often unquestioning faith in “English” doctors (most of whom are from other African countries, though still called *ngaka ea sekhoaa*) not only reinforces the power differences that exist between different social groups, but also the social conditions that create barriers for Basotho's health. These beliefs, values, and treatment seeking behaviors set the stage for Basotho responses to HIV treatment, testing, and prevention efforts, and reinforce the importance of kin in addressing health problems.

In Chapter 5, I explore the challenges of treating HIV/AIDS with a focus on knowledge and treatment approaches. Throughout this dissertation, it is apparent that

HIV is fundamentally a kinship disease, and in this chapter, I explore the extent to which social and familial concerns dictate and shape the epidemiology of the illness. The pervasiveness of HIV in Mokhotlong permeated every aspect of life. Information about HIV is pervasive, yet inconsistent. These inconsistencies lead to differing and conflicting levels of knowledge, and thus, differing responses among Basotho to the efforts of hospitals and clinics, NGO's, and local social services. I explore Basotho's knowledge, attitudes and behaviors regarding prevention, testing, treatment, and the prevention of mother-to-child transmission (PMTCT) in the context of their approach to illness more generally. I find that there are significant barriers to adherence of treatment, and I argue that they are generated from structural factors, health care providers, and patients themselves. I also find that although there is evidence of stigma reduction as testing and treatment become more widely accepted, stigma still plays a significant role in the local course of the pandemic.

The dissertation culminates in the findings of Chapter 6, where I show how HIV/AIDS intersects with care to shape community responses to the orphan problem in Lesotho. I begin by providing examples that illustrate Basotho ideas of caregiving with reference to the widespread practice of kin-based fostering. I provide current examples as well as discuss memories of fostering, with an emphasis on the special relationship that exists between grandmothers and grandchildren. I then examine the physical, material, and emotional challenges of caring for an AIDS orphan or HIV-positive child, giving examples of both "good" and "bad" care, and how these categories are socially determined. This chapter reveals how cultural ideals about gender are not fixed, but rather are flexible cultural constructs that can be deployed to privilege orphan care. This

is first evident in the small but growing presence of excellent male caregivers. However, the malleability of gender as a cultural resource is most fully revealed in the trend towards the practice of matrilineal care in the context of an ideal of patrilineality. The ethnographic examples illustrate that while Basotho have maintained an ideal of patrilineality, in practice there has been a gradual shift towards increasing care by maternal relatives. Paradoxically, Basotho explain this shift in caregiving largely by invoking the rules of patrilineal descent. The process of negotiation and justification that occurs when families are deciding on the locality of care for orphans highlights the continued adherence to the principles of patrilineal descent and the importance of kinship in dictating the local response to HIV.

Finally, Chapter 7 summarizes the practical and theoretical contributions of this dissertation. I will explore the applicability of this work to a broader context of orphan care. I also bring together the insights provided by this empirical evidence in order to make recommendations for intervention strategies that will help to support caregivers in the difficult task of caring for AIDS orphans and HIV-positive children. Finally, I argue for the importance of a longitudinal ethnographic study of this community. This is particularly important in light of several health and demographic changes that are on the immediate horizon: the widespread need for second line antiretroviral medications, and the passing of a generation of mostly HIV-negative elderly caregivers. I expect that these two factors will add to the severity of the HIV/AIDS crisis in both health and orphan care.

CHAPTER TWO

FROM MOSHOESHOE TO MBEKI: CONNECTING THE PAST AND THE PRESENT IN LESOTHO

The Relebohile family's story

Lesotho is a sovereign nation, yet its political economic and social history is inextricably bound to that of its powerful surrounding neighbor, South Africa. As an economically and ecologically weaker nation, Lesotho's dependence on South Africa is deeply felt at the local level. The Relebohiles, like many families in Lesotho, were deeply impacted by migrant labor to South Africa. Their story is a complex one, and although the particulars are unique, it exemplifies the impact that broader social and political factors can have on a family and a child.

I originally encountered the Relebohile family on a trip to Ha Malapane, a village of approximately 400 people on the outskirts of the Mokhotlong district. I was accompanying Mokhotlong Children's Services (MCS) outreach workers, who were going there to visit four HIV-positive pregnant women in order to provide them with PMTCT (prevention-of-mother-to-child transmission) support services. One of these women was Mathabo Relebohile.

Upon arriving at 'M'e Mathabo's rondavel, my attention was drawn to a very malnourished child who was lying on blankets to one side of the smoky room. Her name was Rethabile – Sesotho for felicity. She looked like an old woman; her skin was wrinkled and desiccated as if she had once been plump but her skin now sagged on her

thin bones. Her eyes were deeply set in the bowls of her sockets. Rethabile showed signs of both HIV and TB. She was wasted and despondent. She had no appetite, and had consumed only water for the past few days. What little food she ate gave her diarrhea. Her breathing was shallow. She had an ear infection that produced a pungent smell that filled the room. This lifeless child weighed only 10.3 pounds at 21 months of age. She was in need of immediate medical care.

Rethabile had come from South Africa only days before, and was staying with her maternal grandmother and 'M'e Mathabo, her maternal uncle's wife. Her uncle, Ntate Tholang, though technically the head of the household, lived an hour away by car where he worked as a shepherd. Rethabile's mother, 'M'e Mandla, had been the third wife of Ntate Rorisang. However, they separated and she moved to KwaZulu Natal, South Africa, where she had been working for several years. She became pregnant with Rethabile while in South Africa, and continued to live there until she fell ill and died. She was buried in KwaZulu Natal because the family did not have money to transport her body back to her village in Lesotho. Rethabile was brought back to Lesotho shortly after her mother's death by a family member, barely alive.

We found 'M'e Mathabo's husband in order to obtain his permission to take the child to the hospital with us. He agreed, but his mother, Rethabile's grandmother, was concerned that if we were to take her away, she would not return. They thought her death was inevitable, and would rather she die among her family. After a lengthy negotiation process, her grandmother reluctantly agreed to let her go. We hiked to the outreach vehicle, then drove several tense bumpy hours to town while Rethabile lay quiet and limp on my lap, breathing short, shallow breaths, her nostrils flaring from the effort.

We arrived at the Mokhotlong hospital where Rethabile was tested for HIV and TB and then sent to the MCS safe home for rehabilitation. When her test results came back positive for both TB and HIV, we were sad, but not surprised. She started on TB and antiretroviral medication (ARVs) and was put on a strict feeding regimen of highly concentrated formula. The first week at MCS was exhausting. We took turns sleeping beside Rethabile on the floor of one of the MCS offices beside a heater, waking her every few hours for small amounts of formula.

Figure 2.1 - Rethabile before and after



At first she was reluctant to eat because of the effects of malnutrition on her digestive system, and a naso-gastric tube was required, which she pulled out several times.

However, after a few weeks of carefully measured feeding with a syringe, her appetite

returned. Six months later, Rethabile responded well to the ARV and TB treatments and was in the lower end of the normal weight range for her height.

Sadly, a few months after her arrival at MCS, Rethabile's grandmother passed away. Her aunt was unwilling to take her in, as she had a baby of her own to care for. Ntate Rorisang, 'M'e Mandla's estranged husband, agreed to care for Rethabile. Despite not being her biological father, he accepted her as his daughter because his social role as her father trumped any question of her actual paternity³⁶. Since 2007, Rethabile has been living with Ntate Rorisang in a village with other grandmothers (*bo'nhono*), aunts, and uncles to help care for her. Ntate Rorisang takes primary responsibility for her health, and is usually the one to accompany her to her monthly clinic visits.

I begin this chapter with this story because it is a poignant example of the local realities of the impact of migrant labor. 'M'e Mandla's marriage dissolved, and she was disconnected from her family and community for many years in South Africa. As a migrant, she was exposed to increased health risks and became infected with HIV and TB – an assumption we can make based on the status of her child. Even in her death she remained disconnected from her family. In this case, bridewealth, or *likhomo* payments protected Rethabile by securing her position in the Relebohile family. She was accepted by her mother's husband, whom she calls father, though he is now an elderly man whom I addressed with the honorific *Ntate-moholo* (grandfather).

Lesotho's history – from its beginnings as a mountain stronghold, to its current geopolitical positioning as an enclave within South Africa – has an almost fictional quality. Although the emergence of the first Paramount Chief of Lesotho in the 1820's –

³⁶ In Chapter 3, I will address the importance of the social father over the biological father.

Moshoeshoe³⁷ I – and the current AIDS orphan problem may at first glance seem disparate problems, they are connected through time, history, geography, and politics. As Setel notes, AIDS does not exist in an epidemiological vacuum, but is “enmeshed in *historically shaped* social environments” (1999:4).

The goal of this chapter is to connect Lesotho’s political economic conditions and historical processes with the emergence of the AIDS pandemic. Disease is fundamentally grounded in class, power, and modes of production (Turshen 1984; Turshen 1998). It is also grounded in political and social history (Setel 1999). These structural factors have an important and lasting effect on the course of illness. Lesotho’s relationship with South Africa was also subject to the influences of apartheid, racism, and inequality, which shaped the course of the AIDS pandemic in the region (Fassin 2007). I link the current political economic situation in Lesotho and the spread of HIV/AIDS with the past by exploring the emergence of Lesotho as an independent chiefdom, the historical and political connections between Lesotho and South Africa with a focus on migrant labor, and the social and political conditions under which HIV emerged. In doing so, I hope to show the linkages binding past and present, local and global, that provides the essential context to understanding the contemporary Basotho experience with, and response to, HIV/AIDS.

Constrained choices: King Moshoeshoe I and Lesotho’s remittance economy

Upon landing in Lesotho, you are welcomed to Moshoeshoe I International Airport, and immediately reminded of the reverence that Basotho pay to royalty, in particular to the founder of Basutoland, King Moshoeshoe I (1786 – 1870) (Thabane 2008; Rosenberg 1999; Rosenberg 1998; Sanders 1975; Hamnett 1965; Weisfelder

³⁷ Pronounced ‘Mo/sh-way/sh-way/’

1981). Despite his modest beginnings as a village boy sheltered from the vast social and political changes taking place around him in South Africa, Moshoeshoe (born Lepoqo³⁸) emerged early as a leader when he led a cattle raid with his fellow initiation age-mates on a neighboring village, earning himself the name Moshoeshoe, meaning “the shaver”, for having figuratively shaved off the beard of the neighboring village’s chief by stealing his herd (Thabane 2008; Thompson 1975). As a young aspiring chief, Moshoeshoe had a fiery temper and was impulsive, but under the guidance of a trusted local Sesotho doctor and mentor, he learned that alliances and diplomacy were preferable to war. This eventually won him the trust of his war-weary followers (Thabane 2008). Although well established as a local leader, Moshoeshoe I’s true test of leadership did not come until he was in his 30’s, when the Lifaqane wars being waged between other nearby groups such as the Zulu and Nguni clans threatened the livelihood of the Basotho. In the 1820’s, Moshoeshoe’s village was attacked, and he used a combination of diplomacy, compromise, resourcefulness, and combat to protect his people. These political tactics, which Moshoeshoe I employed throughout his life, gained him many followers as he was forced to retreat into the highlands of what is now Lesotho in order to escape starvation and death, or servitude (Thompson 1975).

As a result of continued enemy attacks, Moshoeshoe I retreated to what is now Butha-Buthe³⁹ because of its high and flat mountain top. However, the mountain had been ravaged by war, and was not easy to defend because of many routes to the top, so he eventually moved to Thaba-Bosiu, where he lived for the rest of his life. It eventually

³⁸ In Sesotho, the letter ‘q’ is pronounced as a post-alveolar click (glottalized, aspirated, or nasal depending on the letters that accompany it).

³⁹ Butha-Buthe is the name of a district and camp town in Lesotho, at the foothills that lead into the highland areas.

became the site of the country's capital, Maseru, and an important symbol of Lesotho's national identity (Rosenberg 1999; Thompson 1975). Thaba-Bosiu, a large sandstone plateau, proved to be an excellent stronghold for Moshoeshe I and his people because it was accessible by only a few routes, therefore easy to defend. It had several water sources and good nearby pasture land for grazing livestock, of which the King had many. He attracted many followers who preferred his protection, for a fee (cattle), over the insecurity of life in the lowlands. Thompson argues that Moshoeshe I "inspired a moral as well as a material regeneration among the people" (1975:53). In addition to his savvy choice of location, Moshoeshe I protected Basotho security by making difficult choices that eventually compromised Lesotho's land and wealth (Eldredge 1993). He had to defeat many other chiefs in warfare, but he also had to make sacrifices that ultimately led to Basotho dependence on remittances for survival. In 1868, in search for allies and the protection of a great power, Moshoeshe I chose to become a British protectorate (Basutoland) (Edgar and Levine 2008). Then, in 1869, this alliance worked against the Basotho's long term interests when the British and Boers signed the Aliwal Treaty whereby Basutoland's borders were defined, and much of contemporary Lesotho's arable land was effectively traded away in the interest of sovereignty (Eldredge 1993).

Moshoeshe I was certainly a charismatic and influential leader. His legendary diplomacy skills and his ability as a savvy political strategist were key to Lesotho's path to sovereignty (Sanders 1975). As Thabane states, "It is...not an exaggeration to say that the existence of an independent Lesotho in the early twenty-first century is a result of [Moshoeshe I's] statesmanship" (2008:608). The national identity of Lesotho today is built around Moshoeshe I (Rosenberg 1999; Rosenberg 1998). During the first half of

the 19th century until its independence from Britain in 1966, Lesotho was threatened with incorporation into South Africa. The emergence of numerous political parties created internal divisions, but a common element among the parties was the use of Moshoeshoe I as a powerful symbol of national identity (Rosenberg 1999). The chiefdom that exists in Lesotho today continues to legitimate its claim to power based on proximity to the descendants of Lesotho's first and most influential Paramount Chief (Hamnett 1965).⁴⁰ Symbolically, the Basotho monarchy, with Moshoeshoe I as its figurehead, acted as a source of cohesion for resistance to domination by external political forces (Weisfelder 1981). Despite Moshoeshoe I's charisma and political skill, Lesotho's history did not emerge in a vacuum. The external political pressures on Moshoeshoe I and his people were influential in shaping the conditions under which statehood emerged and the current political economic conditions in Lesotho developed (Sanders 1975).

The geopolitical boundaries of Lesotho are, at least in part, responsible for Basotho's ongoing dependence on migrant labor. Lesotho lies completely above 1,000 meters, and is surrounded by the Drakensberg and Maloti mountain ranges (Edgar and Levine 2008).⁴¹ In the 1870's, Lesotho was able to produce and export a significant portion of the region's grain supply, however, as boundaries were redrawn eliminating fertile land, and soil erosion impacted crop yields, Lesotho quickly became dependent on migrant labor to South Africa. This dependence was deepened in 1885 after South Africa's first gold mines were opened (Edgar and Levine 2008). As Eldredge notes (1993), a migrant labor economy emerges because of both opportunity and constraint.

⁴⁰ The current king of Lesotho, King Letsie III, is a direct descendent of Moshoeshoe I.

⁴¹ Lesotho's lowest point is 1,400 meters, the highest low point in the world. Eighty percent of Lesotho lies above 1,800 meters, and Lesotho is home to southern Africa's highest peak, Thabana-Ntlenyana, at 3,481 meters (Edgar and Levine 2008). Lesotho's elevated topography is a key element in the many agricultural difficulties Lesotho has had, particularly in the mountainous areas such as Mokhotlong. See figure 2.2.

Figure 2.2 – Topographical map of Lesotho



Source: (<http://mappery.com/Lesotho-Map>)

In this case, Basotho were constrained by their inability to produce adequate food supplies because of the poor quality and limited availability of arable land, and attracted by the opportunity of cash in come from labor in South Africa. However, British colonial rule also furthered the entrenchment of Lesotho as a remittance economy as the British viewed Basotho as a cheap labor reserve, and rewarded local chiefs with power and money for their compliance in mobilizing the workforce (Eldredge 1993). Eldredge states that Basotho’s “economic interests were not furthered by their colonial status beyond the fact that their territorial integrity was protected” (1993:176). Although it is easier to assess Moshoeshe I’s leadership from a historical perspective, Eldredge questions the decision to protect group unity at all costs. She argues:

“The redirection of production to meet the demands of the capitalist economy fostered the economic dependency of colonial Basutoland, and encouraged direct intervention by the British to strengthen the economic ties between the Basotho and the mines, especially with regard to labor recruitment. In the long run, then, the Basotho became trapped in the migrant labor system abroad, while at home no amount of effort could compensate for the lost land” (1993:3).

From 1893 and 1909, between 5,000 and 98,000 migrant labor passes were issued to Basotho. Patterns of migration changed over time based on various political economic factors such as agricultural yield, war, and job opportunities (Eldredge 1993). Although current migrant labor levels are much lower than they were in the 1970’s, the remittance economy is still an important economic strategy for Basotho (see Table 2.1).

Basotho have long been a part of “the struggle to achieve and sustain economic and social security in the face of environmental and human threats” (Eldredge 1993:195) and HIV/AIDS can now be added to the list of factors that threaten the livelihood of the Basotho. Structural violence against migrant laborers has been apparent since the second half of the 19th century when diamond and gold mines were emerging in South Africa (Fassin 2007). This legacy of oppression has led to inequalities that have been exacerbated by various health and social crises such as apartheid, tuberculosis, and now, HIV/AIDS. Lesotho’s historical origins have had a direct impact on its current political economy, and as a part of that, on the course that HIV/AIDS has taken in the country.

Migrant labor, apartheid, and AIDS

In 2002 Shula Marks called AIDS in Africa “an epidemic waiting to happen” (13). Although she had the benefit of hindsight in order to make this proclamation, the social and political context of a post-apartheid southern Africa was ripe for the rampant spread of disease. The following section will outline, in brief, the political economic conditions that emerged in South Africa from the 1970’s onwards in order to give the

historical context in which the AIDS pandemic emerged. This will shed light on many of the challenges associated with the social and political economic conditions in the region at that time.

As a geographical enclave within South Africa and as a result of an eroding agricultural base, poor infrastructure and reduced aid, migrant workers from Lesotho made up a large proportion of the work force in South Africa (Romero-Daza and Himmelgreen 1998). Remittances have historically comprised such a large proportion of the gross national product of Lesotho, that to examine Lesotho's economy outside of its relationship with South Africa is irrelevant (Ferguson 1990).

Table 2.1 – Number of mine workers, remittance payments and deferred payments (1996-2005)

Distribution of Mine Migrant Workers (1996-2005)			
Year	Avg. # Employed	Deferred Pay (M000)	Remittances Payments (M000)
1996	101,262	264,624	174,676
1997	95,913	169,418	127,386
1998	80,445	131,263	894,470
1999	68,604	136,911	887,172
2000	64,907	38,334	47,320
2001	61,412	152,877	102,797
2002	62,158	182,479	112,496
2003	61,416	208,450	118,333
2004	56,357	293,334	131,793
2005	52,450	169,229	167,386

Source: (Lesotho Bureau of Statistics 2005)

In the mid-1970's, at the peak of the gold mining industry in South Africa, there were more than 200,000 Basotho employed in South Africa; 130,000 of them were male mine workers (Murray 1981; Murray 1980). During this time, remittances made up 70

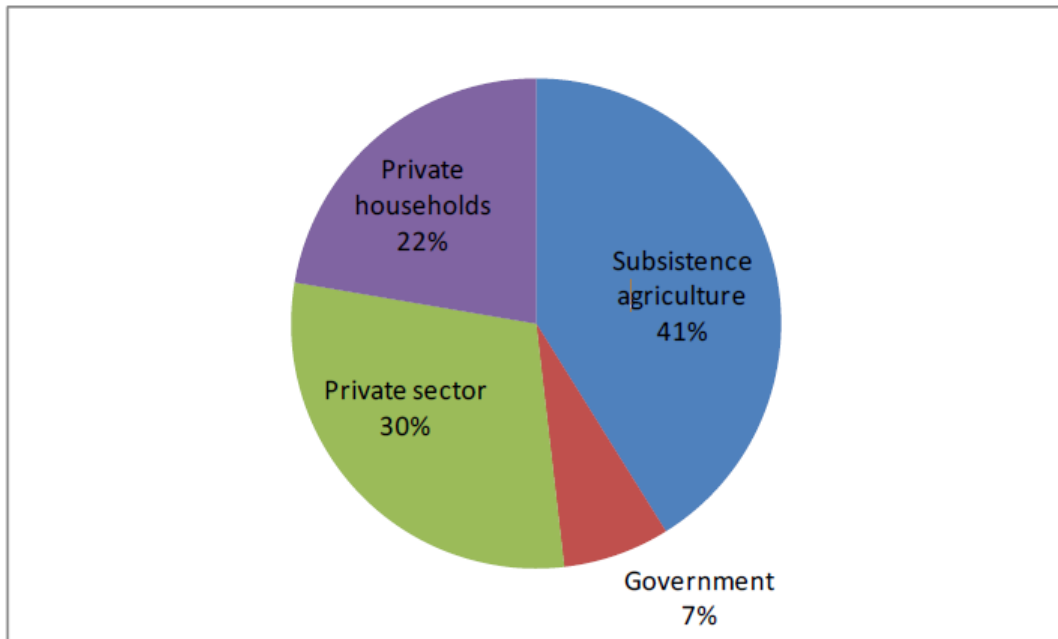
percent of rural Basotho household incomes (Spiegel 1981). From the mid-1970's onwards, the number of migrant workers steadily declined, though the average number of workers remained over 100,000 until the late 1990's. Between 1996 and 2005, the number of migrant workers from Lesotho to South Africa gradually decreased from 101,262 to 52,450 (Lesotho Bureau of Statistics 2007b). This massive retrenchment of Basotho workers from the mines was caused by fewer available mining jobs, and exacerbated by the fall of the price of gold known as the "gold crisis" (Lesotho Bureau of Statistics 2007b; Edgar and Levine 2008). The steady decline of migrant labor remittances from the early 1970's onwards created divisions within rural Basotho, exacerbating poverty for those who were not employed (Spiegel 1981). Almost all rural Basotho households were involved in subsistence farming. However, those not employed elsewhere lacked the influx of cash that their neighbors, who had a family member working in South Africa, had in addition to their crops. Although the money was partially diffused and redistributed throughout the community through local informal markets such as the selling of *joala* or home brew (Spiegel 1981), the disparity between households was significant in terms of wealth in the form of land, cash, and cattle (Spiegel 1981).

Subsistence farming is still an important strategy for the Basotho today, with a participation rate of 41 percent (Lesotho Bureau of Statistics 2010). However, crop yields have drastically declined, making some cash income a nutritional necessity. In the 1970's, cereal production⁴² peaked at around 200 kg per person. As of 2007, production due to deteriorated soil conditions and drought was as low as 40-60 kilograms per person. However, the UN's Food and Agriculture Organization estimates a minimum need of 180

⁴² Maize, sorghum and wheat are Lesotho's three most important cereal crops.

kilograms per person, so Lesotho is falling far short of its nutritional needs in terms of its staple foods (Crush 2010), and relies on food imports, and food assistance from such organizations as the World Food Program.

Figure 2.3 – Employment by sector, Lesotho (2010)



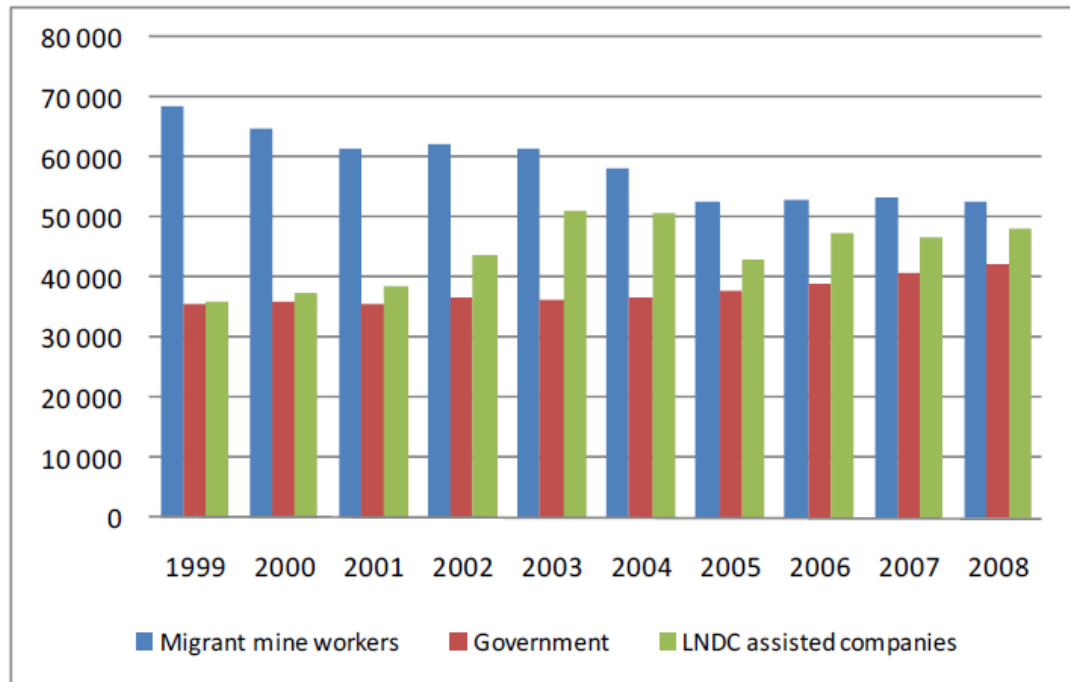
Source: (Lesotho Bureau of Statistics 2010)

Migrant work has been one of the few reliable sources of income in Lesotho for much of the last century, because wage earning jobs in Lesotho proper are scarce. Lesotho does have limited employment opportunities in three of its own diamond mines, the textile industry⁴³, and with the Highlands Water Project which is engaged in building a number of dams to alleviate South Africa’s water shortage (Edgar and Levine 2008). Government jobs also provide a limited source of employment. However, Lesotho’s

⁴³ The United States Government’s African Growth and Opportunity Act, initiated in 2000, provides economic incentives for factories in Lesotho. As a result, over a dozen Asian textile companies opened in Lesotho, but due to the strength of the South African Rand (which is tied to the Lesotho Loti) and the end of a global agreement that protected textiles, a large number of the factories withdrew from Lesotho ((Edgar and Levine 2008).

economic future does not look bright. According to the United Nations Human Development Index (UNDP 2011), Lesotho ranks 160th out of 187 nations; an indication of the endemic poverty and minimal economic opportunities that exist there.

Figure 2.4 – Major sources of formal employment, Lesotho



Source: (Lesotho Bureau of Statistics 2010)

Historically, the majority of migrant workers were male miners, but as mining jobs decreased in the 1990's, there was an increased feminization of migrant work, as well as the development of other occupational opportunities for both men and women. These shifts were caused by both the easing of migration restrictions that came about with the end of apartheid, and economic necessity for Basotho (Crush 2010). In 1999, 35.9 percent of the population of Lesotho migrated for work; 23 percent males, and 12.9 percent females. Just under half of migrant workers in 1999 were miners, and of the

remaining half, most were involved in elementary occupations such as domestic work, or skilled agricultural work (Lesotho Bureau of Statistics 2007b).

Decades of high migrant labor rates in Lesotho created dependence by Basotho families on remittances. Basotho's dependence was exacerbated by the Lesotho government's arrangement with South Africa whereby 60 percent of workers' pay was deferred (see Table 2.1). In other words, Basotho migrant workers could only receive 40 percent of their pay in Rand (the South African currency) while at work – the remaining 60 percent could be collected from the bank upon returning to Lesotho (Adepoju 2008). This strategy helped to guarantee that the majority of money was finding its way to Lesotho. Deferred pay regulations, a lack of other employment opportunities and a paucity of arable land in Lesotho only served to deepen Basotho's dependence on remittances for their livelihood.

The drastic decrease in available migrant work was keenly felt by Basotho at the local level. People can no longer rely on migrant labor as a way of increasing their household income. Ntate Kapo (KN) provides an explanation for the lack of migrant labor jobs available in Lesotho today:

EB: Do many men work in the mines now or was it something they did in the past.

KN: No, now there are not many like in the past. In the past there were many.

EB: Why is that?

KN: Why is it like that? You see that time they were striking often, and educated people see that and say that in the seventh month there was a lot of money coming in but these people who were working in the mines were not satisfied with their income and they started striking. They were just scratching their two ears and saying we have to reduce these people. That is why you see many Basotho not going to South Africa. It's because we have been reduced. Because of us - because we are striking.

EB: They want more money?

NL: Yes, they wanted more money.

EB: So who is getting those jobs now? If the mines are still going but the workers

are on strike who are they hiring to work on the mines now?

NL: There are still some Basotho but they are few.

KN: Then, after the educated people see that, [the employers] see that they have to use the machines instead of laborers. They are now making it like a factory, not joining [having people join the mines to work there]. Maybe you have seen it? (to Ausi Ntsoaki).

NL: No, I haven't. I don't know anything about mines.

KN: Maybe your eyes were seeing what was happening.

NL: No.

EB: So now that men are no longer working in the mines as much what kinds of jobs are they doing? How has it changed?

KN: Ahhh, we are just farmers only. Sometimes I can be employed by someone, say I can roof the house, or build the kraal.

EB: So would you say it's more difficult these days for families to get money?

KN: Yes, it's like that.

EB: So, is that a problem?

KN: Yes.

Ntate Kapo places the blame for reduced mine work in part on the replacement of workers with machines, and in part on the workers themselves for striking for increased wages. Although his explanation for the reduction in the migrant labor force is only partly accurate, his experience in finding work now as compared to the past is typical. People often reported doing contract work known locally as "piece jobs" where they were hired for a day or a week by the government to help fix a section of road, or by a business or individual for temporary construction work. It is common for those without their own fields to help harvest other people's crops in exchange for a small portion of the crop. However, steady and reliable employment opportunities are limited.

The pervasiveness of migrant labor practices in Lesotho is not merely interesting from a demographic or economic perspective, but has had a significant – and often negative - impact on every aspect of social life (Romero-Daza and Himmelgreen 1998). In part, this is exacerbated by the fallacy that migrancy is temporary, when in reality, it often long-term and semi-permanent. This is especially true for migrant workers from

rural districts of Lesotho, such as Mokhotlong, the majority of whom went away for a minimum of 12 consecutive months during the most active gold mining years (Lesotho Ministry of Labour and Employment 1999). During these lengthy absences from home, mine workers lived primarily in single-sex hostels. In a detailed and moving examination of hostel life, with a focus on the transformative nature of space, Ramphela (1993) explores the ways in which the bedhold – the only space controlled by the miners – changed relationships, and reinforced marginalization and poverty. In addition to the high risks of mine work in general, working and living conditions in mines are conducive to the spread of illness. Packard (1992; 1989) notes the high incidence of tuberculosis among mine workers in South Africa, citing crowded housing, mine conditions such as lack of ventilation and excess moisture, and decreased nutrition as contributing to the spread of disease.

In addition to these physical hardships, many miners were largely separated from their families for decades⁴⁴, creating tensions and divisions that harmed social relationships, and weakened marriages⁴⁵. Families in Lesotho came to rely on the money sent by their husbands; however, they also experienced hardships as a result of their husbands' absence. Gordon (1994) found that women in Lesotho experienced strain because of the oscillating nature of the remittance economy, more responsibility, and fewer resources. Migrancy also impacted the power relations between men and women, causing women to find creative coping mechanisms, such as the creation of pious women's organizations, to help deal with unstable social relations (Epprecht 1993).

⁴⁴ In 1977, the average time migrant workers spent outside Lesotho was between 13 and 16 months depending on whether they were from the lowlands or the mountainous districts (Murray 1981)

⁴⁵ For a discussion and examples of the experiences and memories of Basotho with regards to migrant labor and its impact on marriage see Chapter 3.

Murray (1981) acknowledges the inherent paradox in this dependence on migrant labor, whereby the core economic strategy of every family was also responsible for its instability. He states, “A man’s absence as a migrant laborer is a condition of his family’s survival. But his absence also undermines the conjugal stability from which his family derives its identity” (Murray 1981:102). All aspects of life were impacted by migrant labor practices – a testament to its pervasiveness as well as to the integrated nature of the social, political, and economic context in which it existed.

Although many scholars have portrayed the time of migrant labor as negative, emphasizing the hardships experienced by men in South Africa, and the difficulties of life for the “gold widows” left behind (Edkins et al. 1990), the experiences of Basotho were, in fact, much more varied. Instead of remembering the time their husbands spent in the mines with regret, elderly women that I spoke with remember those years as a time when work was easier to come by, and cash was more readily available. Although many women expressed being “sick” for their husbands while they were gone, most also remember their husbands’ working years as a time of relative prosperity. When asked if it was difficult when her husband was away, one grandmother focused on the physical, not the emotional challenges: “It wasn’t difficult. Because I had money and even if you need to plough at the fields, you would just hire someone to help you.” Another grandmother, ‘M’e Matau, whose husband worked in the mines for twelve years, said “*Ach*, I was living well. I was having everything because I had money.” She later added that she missed her husband, saying “Yes, I would just remember him as if he had taken a long time.” ‘M’e Mathapelo thinks that women were content during those days because they were not as greedy as women are nowadays. She said, “I was always satisfied

because people in the past, husbands were giving them 20 cents, and they were satisfied. If he wanted to come home, he was always coming.” However, it must be noted that these grandmothers, who are currently caring for AIDS orphans with limited resources, are romanticizing that time of affluence, and are likely to emphasize the economic advantages, while downplaying the social and health disadvantages.

One of the most significant influences on Basotho migrant workers and their families were the “repressive politics” (Fassin 2007:158) of South Africa, especially during the apartheid years (1948 to 1994). The restrictive migration rules associated with apartheid, which precluded migrant laborers being accompanied by their families, had a grave effect on social organization and family stability in Lesotho. During apartheid, the Aliens Control Act of 1963 made it an offense for black Africans to travel within South Africa without a permit. Women were granted limited entry into South Africa, primarily for domestic work, but women and children without permits were barred from travel to South Africa to join their husbands at the work sites (Murray 1981).

The social and political economic conditions were complicated and disruptive to the social fabric of the Basotho family even prior to the emergence of HIV/AIDS. Once the AIDS pandemic began to spread in the region, these challenges worsened and multiplied. The separation and destabilization of families as a result of migrant work coincided with the alarming spread of HIV (Romero-Daza and Himmelgreen 1998; Fassin 2007). Migrant workers often had other sexual partners while working in the South Africa for long periods, and on visits home, they infected their wives (Caldwell et al. 1997). Women left behind also had other sexual partners in order to procure

economic and social advantages during the periods of absence of their husbands, and the often uncertain and fluctuating remittances (Romero-Daza 1994). As Fassin argues:

“The migrant economy...favors the conditions for the AIDS epidemic to develop not only around the mines themselves but also throughout the country. In the mines, separating the working men from their families and especially from their wives, who remain in villages, induces the development of leisure places combining drink and prostitution, promoted or simply tolerated by the companies because they keep workers in the workplace” (2007:187).

However, as Ramphele (1993) notes, miners did not only seek companionship from temporary sex workers, but often established semi-permanent, stable relationships with partners in the towns surrounding the mining camps, creating the networks of concurrent relationships that are now believed by many to explain the high rates of HIV transmission in Africa (Epstein 2007).⁴⁶ The link between the mining industry and illness in South Africa is well documented (Marks and Anderssen 1992). Campbell (1997) has argued that the high level of risk that mine work entails not only created an environment where risk was part of the ethos, but made the risk of HIV-infection seem minor in comparison. As Fassin states, miners are already taking considerable risks, so “the less visible and more remote risk of being infected by AIDS is considered a mundane sort of danger” (2007:187). The image of the African body, and in particular that of the migrant laborer, as a “vector” of disease is a popular one (Setel 1999:53). In apartheid – and post-apartheid – South Africa, the high incidence of disease among blacks only served to increase the racism and xenophobia already present there (Fassin 2007).

The conditions precipitating the sudden increase in HIV/AIDS in southern Africa merely set the stage for a potentially large-scale and devastating public health crisis. It was, however, the political response by then-president of South Africa Thabo Mbeki, and

⁴⁶ For more on the concurrency debate, see Chapter 1.

his appointed ministers, that turned the negative potential conditions of poverty and migrancy into a full blown pandemic. Didier Fassin has written a comprehensive anthropological work on the “epidemic of disputes” (2007:30), which led to the proliferation and spread of HIV among black South Africans and migrants. He combines a close following of media and archival materials with ethnographic work that is invaluable in understanding how a history of colonization, apartheid, racism, and inequality shaped the course of the AIDS pandemic in the region.

Fassin and others chronicled several specific incidents that punctuated the steadily growing mistrust, doubt, and stigma surrounding HIV/AIDS by South Africans. Public scandals, followed by political backing for faulty science, and limited access to effective treatments, allowed HIV to spread among the poorest people (Epstein 2007; Fassin 2007). Even before Mbeki took office as President in 1999, the South African government’s response was mixed and fractured. Under Mandela’s tenure, in 1996, as the AIDS problem became more visible and more public, the Health Minister, Nkosazana Zuma, hired a famous playwright to write a sequel to a play, *Sarafina II*, specifically for the opening of an AIDS conference. When the media and public found out that 14 million Rand were paid for the project, there was a public scandal, as the amount was equal to one fifth of the national AIDS budget at the time (Fassin 2007; Mbali 2003). Shortly afterwards, Virodene, an experimental drug which claimed to cure AIDS, was backed by the government before it was tested in clinical trials. It turned out to be little more than an industrial solvent, resulting in increased distrust of the government and skepticism about effective treatments (Parkhurst and Lush 2004; Schneider and Stein

2001). Even after ARVs became available, the memory of the Virodene scandal was still fresh in South Africans' minds.

In 2000, the government's precarious political stance on HIV was reinforced when President Mbeki backed a group of dissident scientists on the fringe of mainstream HIV research who denied the link between HIV and AIDS, sparking controversy and division. In addition, Mbeki's Health Minister Manto Thsabalala-Msimang – nicknamed Dr. Beetroot – famously warned South Africans of the potential toxicity of AIDS medications, and instead, recommended they eat beetroot, lemon, and garlic (Kapp 2007). Local organizations, most prominently the Treatment Action Campaign (TAC), fought to curb the negative impact that the government's position on AIDS was having among the people (Friedman and Mottiar 2005). Since 1998, the TAC fought a number of legal battles for the right to obtain ARVs to prevent mother-to-child-transmission (PMTCT), to lower the cost of ARVs, and for universal access to medication for all HIV-positive South Africans (Robins 2006; Friedman and Mottiar 2005)⁴⁷. However, it was not until 2002 that the courts required that Nevirapine, a prophylactic ARV known to be effective for PMTCT, be made available to all pregnant HIV-positive women. It was not until 2004 that ARVs were available to all South Africans (Fassin 2007).

Mbeki's response to the emergence of HIV requires historical contextualization. Weary of a legacy of apartheid, and a history of racist notions of African illness by colonizers and whites, Mbeki wanted to highlight the role poverty and structural inequalities might play in the course of the epidemic (Fassin 2007; Mbali 2003). He was right to do so. HIV was disproportionately impacting the most marginalized people, who

⁴⁷ In an act of protest, one of the leaders of the TAC, a gay, HIV-positive activist named Zackie Achmat, refused to take his own ARVs until the drugs were widely available to those without the means to purchase them at high costs (Fassin 2007).

did not have access to good health care or nutritious foods. Patterson (2006) notes that public opinion has often placed a low priority on government-funded interventions for HIV precisely because other, more pressing needs borne out of poverty seem more imminent. Further, many (white) South African health authorities and biomedical researchers propelled negative stereotypes about the causes of the epidemic, which “relied heavily on racist and sexist stereotypes of a diseased African sexuality” (Mbali 2003:321). Unfortunately, Mbeki’s concern for the structural conditions under which HIV was spreading amongst the poor was emphasized at the expense of making effective biomedical treatments available, and his legitimate concerns were enacted in a way that did nothing to ameliorate the structural violence of life in post-apartheid South Africa. Rather, he merely created dissent and confusion among the most vulnerable of its citizens.

Conclusion: The political economic context of AIDS

Lesotho’s emergence as a distinct polity under the charismatic leadership of Moshoeshoe I, its geopolitical positioning as an enclave within Africa’s most powerful nation, and its political and economic dependency on South Africa has shaped its national character on every level. Moshoeshoe I, against all odds, was able to resist several invaders, forge important alliances with individuals and nations, and secure for Basotho some territory and a national identity. Whether intentional or not, he did so at the expense of the long-term economy viability of his nation due to the undesirability of the land it occupied, and the relationships he forged in order to secure political autonomy. This, in turn, placed greater importance on migrant labor opportunities in South Africa, and Lesotho came to depend on remittances for its economic well-being and survival. At

the local level, migrant labor and apartheid created significant challenges for the stability of marriage and families in Lesotho. However, the short-term benefits of migrant labor outweighed the costs to the Basotho family, and this unfortunately created the perfect conditions for the devastating rise of HIV/AIDS.

The legacy of early AIDS denialism in South Africa cannot be overstated, and the series of poor policy decisions, slow reactions, and negative public messages about the illness on the part of Mbeki and his political party had a drastic impact on the course the pandemic took in the region. Approximately one third of all adults are HIV-positive in only a handful of countries in southern Africa, including Lesotho. This rate is ten times higher than anywhere else in the world outside of Africa (Epstein 2007). Mbali (2003) uses the South African case to highlight the impact that political leaders can have on the course that illness can take due to poor leadership and policy decisions. She argues, “Decisive leadership on AIDS policy by heads of state can be crucial in turning the tide of the epidemic, especially in developing countries” (Mbali 2003:318).

It is important to reiterate here that the social conditions and practices that existed prior to widespread migrant labor, or the spread of HIV/AIDS, or even colonialism, for that matter, were never static. Social organization, marriage practices, family and sexuality, to name a few, have always been in flux even as they hover around culturally constructed, idealized notions of kinship (Franklin and McKinnon 2001). If anything, Lesotho’s relatively short and unstable history exemplifies this as Lesotho has never known a period of political or economic long-term stability. This chapter lays out the changes in Lesotho’s economic strategies and historical circumstances that are directly relevant to the emergence of the AIDS pandemic, and contributed to its dramatic eruption

among the Basotho population. Setel (1999), in his study of HIV among migrant Tanzanians, emphasizes the significance of the specific context in which HIV exists without essentializing or romanticizing the conditions that existed prior to its emergence. He states, “Hierarchies of generation and gender, and demographic and political economic processes, have operated in an era of hardship in such a way as to place women and young adults at particular risk” (Setel 1999:248). This is true for Basotho, too, whose adult population has been hit hard by HIV/AIDS.

Lesotho faces numerous current health, economic, and familial challenges, all of which need to be put in context of the political and economic history of the region. As this dissertation will demonstrate, broad structural factors are intimately felt at the level of the individual and the family. This chapter has set the stage for understanding how the AIDS pandemic played out in Lesotho and gives the social and political economic context for understanding the shifts in care that are taking place under the pressure of the emerging population of AIDS orphans.

CHAPTER THREE

KIN, CARE, AND THE HOUSE: REORIENTING BASOTHO KINSHIP AND RELATEDNESS

‘M’e Masekha’s story

‘M’e Masekha is a 60-year-old grandmother living in Mabuleng, a village two hour’s drive from Mokhotlong’s camp town – the central town located in every district that acts as the headquarters for public services and commerce. She lives with two of her orphaned grandchildren, Thapo and Keneuoe, a boy and a girl. One of her son’s, her daughter-in-law, and two young grandchildren live in the house next door. Their household is set high on a ridge just above the small dirt road carved into the hillside. These roads and paths, of varying width and durability, course throughout the rural countryside and provide access to and from villages for cars, mini-bus taxis, pedestrians, and herds of animals. There is a sweeping valley below, covered in fields of maize and wheat, and spotted with cows. The first time I went to their house, I watched as ‘M’e Masekha ran from her field when she saw the MCS truck coming across the ridge towards her village.

‘M’e Masekha had five children of her own, but both of her daughters – the mothers of Thapo and Keneuoe – have died. Two of her three sons have homes in Mabuleng, but the youngest works in South Africa the majority of the year. At the time I met her, the wife of her youngest son was visiting her husband in South Africa, so ‘M’e Masekha was responsible for checking on their two young children, both in elementary

school, who were staying for a month by themselves. As we chatted, children would move fluidly in and out of the household, so that I was often confused as to which of the little ones actually lived there, and which ones just liked to visit and eat with their grandmother. The youngest of the children living next door is one-and-a-half, and still breastfeeding. She likes to sleep with her grandmother, and will often wake up tugging on her breast in hopes of getting some milk.

I came to know 'M'e Masekha because one of her orphaned grandchildren, Thapo, a sweet and happy eight-year-old boy, is a MCS client. Thapo's mother became ill while she was still living at her marital home. She had had two other children, but both died in infancy. Thapo's parents got divorced and his mother returned to her natal home. His mother, who was HIV-positive, was already ill when she arrived at Mabuleng, and died shortly after her arrival there. Thapo's father, whose HIV status was not known, died around the same time. When Thapo arrived with his mother, he was also extremely ill. His grandmother took both her daughter and grandson to the traditional healer, or *ngaka ea Sesotho* (literally, Sesotho doctor), but their condition did not improve. Finally, in 2007, 'M'e Masekha took Thapo to get an HIV test on the recommendation of the local clinic. He was found positive and was put on ARVs shortly afterwards. He is a robust and lively boy now, always with a smile on his face. He loves school, and proudly showed us his report card during one of our early visits.

Keneuoe is the other orphan in 'M'e Masekha's care. Her parents also passed away. They had five children, four of whom are still living with their paternal grandparents. However, the paternal grandparents brought 5-year-old Keneuoe to 'M'e Masekha because they were overburdened with the other children: "They just said I

should live with the child because they wanted us to share, and they don't have enough food to feed the child,” indicating the flexibility of idealized kinship rules in everyday practice.

In order to feed her family and buy essential goods, ‘M’e Masekha works in other people’s fields. She is repaid with a bundle of whatever she has harvested that day. She also occasionally teaches at a pre-school run out of another woman’s home, but she said there were not enough students to provide consistent work. Her son also works in other people’s fields, so they are usually able to meet their nutritional needs, especially after the harvest. If there is a food shortage, she brews Sesotho home-brewed beer (called *joala*) and sells it, or borrows from neighbors. ‘M’e Masekha is happy to have her two orphaned grandchildren in her care even though it increases her labor. This is particularly true for Thapo whose HIV-status means monthly trips to the clinic and a complex daily medication regimen. Because Thapo’s mother was divorced before she died, ‘M’e Masekha is responsible for his care. Keneuoe, in contrast, is technically the responsibility of her father’s family, but the paternal family’s resources were already stretched thin, so they appealed to ‘M’e Masekha to take care of the youngest child, who was malnourished, but otherwise healthy. When I asked ‘M’e Masekha how she felt when they brought Keneuoe to her, she said, “*Ach*. I was happy because the child was not living well.”

‘M’e Masekha’s story is typical in that it represents the complex interconnections and relationships – and the associated life stories, joys, and struggles – that make up many households. Networks of extended kin in Lesotho, as elsewhere, are central to the rearing and care for children. For example, of the seventy children that have been in the

MCS Safe Home between 2005 and 2008, only three were placed in the care of non-kin, and one lives in an orphanage in the capital city, Maseru. Children are often raised by a number of different caregivers for various practical, social and material reasons. These fostering networks⁴⁸, which are common throughout Africa and elsewhere, are impacted by the nature of kinship ties and are subject to change as the needs and practices of communities change. Therefore, an understanding the context of contemporary Basotho kinship beliefs and practices is central to understanding kin-based care for orphans. This chapter will explore kin ties that bind families together, the makeup of families and households, people's attitudes towards different members of their families, the forces that disrupt family unity such as divorce, migrant labor, and illness, and the impact of all these factors on orphan care.

Family life in Lesotho has been profoundly affected by migrant labor, HIV/AIDS, and divorce. As a result, the margins that exist between people's expectations of what families should look like, and the reality of how they function and operate, has widened. The empirical evidence in this chapter is based on my interviewees' ideas about kinship ties and family responsibility, as well as ethnographic observations about everyday life. In many cases, particularly for the elderly, the past is remembered as a time when family responsibility was taken more seriously, family ties were stronger, and the income generated by migrant labor to South Africa made life easier. However, it is likely that there exists a considerable gap between memory and reality, especially when it comes to forgetting the disruption caused by migrant labor (Murray 1981). Nonetheless, Basotho ideas and experiences regarding relationships between family members, the makeup of households, and kinship and family responsibility are real. Their expectations highlight

⁴⁸ Fostering in the context of HIV/AIDS is the primary focus of Chapter 6.

the complex nature of social organization and the disconnect between the ideal family structure (patrilineality) and everyday practice.

The intersections between the HIV pandemic and kinship practices also impacts the demographic makeup of the family and the ways in which families negotiate between idealized rules of kinship and everyday practices. This chapter sets the stage for understanding these intersections, and the impact that HIV/AIDS has had on kinship and orphan care. Basotho ideologies about kinship are complex and mutable. These complexities are highlighted by a view afforded by close observation of everyday life in the changing landscape of contemporary Lesotho. While it is recognized that kinship is always in flux, certain aspects of Basotho kinship, such as lineality, are more in flux at this time than others because of the social and political economic conditions in which they exist. The following section will address the aspects of relatedness – both real and idealized – that are key to the ways that kinship ties are created and dissolved. I begin with a discussion of the household because houses are a stable and binding dwelling for Basotho, and a place where other key aspects of relatedness, such as lineality and substance, emerge and intersect. I argue that, as other aspects of relatedness are in flux, the house remains a stable fixture for Basotho. This allows for the emergence of care not only as a valued social act, but as an organizing principle of which houses are a central part.

Houses and house life

Houses and households are an important and obvious place to start when examining social relationships, based on the commonality of lived experience. Even as other changes in society are taking place (including the makeup of household members)

the role of houses and households as spaces that frame human actions, transform relationships, and reflect the social order remains paramount. Houses are important as a site where many other acts of kin-making take place, such as the exchange of substances such as milk and food (Carsten 1995). Changes due to migrant labor and increased fostering practices because of HIV/AIDS are also reflected in the house, which makes the house central to understanding the issues that are at the heart of this research. The house is not merely a built structure that people inhabit, which precedes the act of living in it. Instead, as Ingold (2000) notes, the house is a place where people “dwell” and the forms that houses take are shaped over time, and inscribe themselves on the body and worldview of those who live in them. Houses are also spaces where memory and materiality are linked and articulated (Morton 2007). Houses are, therefore, important in understanding both the social and moral geographies of Basotho society because they trace both sociality and history in a way that more transient forms and structures in society cannot. Thus, instead of starting with lineality, as many anthropological works on kinship do, I start with the house as it is the most stable, and perhaps the most important, factor in creating and reflecting Basotho kinship practices and social relations.

Basotho living in the rural district of Mokhotlong generally live in households that consist of two or more houses, a garden, and some space to hang laundry and sit outside. If the family is wealthier, they will also have a corral and fields nearby where they keep their animals and grow their crops. In some cases, families who own many cattle will have a corral with hired shepherds elsewhere in the countryside where there is more room for grazing. Familial wealth for rural families can generally be measured by the number of animals and fields, the items in their houses, and the influx of cash by

working household members. In rural villages, where there is no electricity or plumbing, houses are primarily small round houses, called *rondavels*.⁴⁹ The outer walls are made of large stones that are abundant in the surrounding landscape, and can easily be collected.

Figure 3.1 – Outside of rondavel, Mokhotlong



The inside walls and floors are made from a combination of mud and dung, and the roof is made of beams covered in carefully laid, thick, maize stalks. Rondavels also usually have one or two small windows covered with glass or wooden shutters. In the highlands, walls and roofs are regularly repaired to withstand rain and harsh winter weather, and floors are regularly recovered for both functional and ritual reasons. If a family has more than one rondavel, they will generally designate one for sleeping and the other for

⁴⁹ The word rondavel, sometimes spelled *rontabole*, comes from the Afrikaans word ‘rondawel’. The house in Lesotho is referred to using numerous terms: rondavel, *hae* (meaning house), *mokhorro* (round house), *lapeng* or *lelapa* (meaning household or family). When referring to a round house, I will use the term rondavel, as this is the term used by some Basotho, and also by the Lesotho government when discussing different house styles. When talking about a type of house other than a rondavel, I will simply use the word “house”.

cooking because of the immense amount of black smoke created by the cooking fires.

However, the number of family members living in the household often prevents this strict separation. Rural Lesotho is mountainous, so houses are usually oriented with their doors opening downhill, presumably to facilitate easy access from the road and to prevent flooding inside the house. It is often necessary to dig a palette in the earth in order to create space to build a house on flat ground. Depending on which face of the

Figure 3.2 – Rural houses and landscape, Mokhotlong



mountainside a village lays, houses will get more or less sun exposure. Thus, when it snows in the winter, certain villages will be covered in snow long after it has melted in other places (see Figure 3.3).

In the camp town, houses are mostly constructed of cinder blocks, with corrugated tin or shingled roofs. These square houses range from single to multiple rooms, and paraffin stoves are mostly used for cooking, so smoke is not a problem. Town houses are more likely to have furniture such as a bed frame and a spring mattress, a set of drawers,

Figure 3.3 – Rural village after snow, Mokhotlong



and shelving. If the family has electricity, they may also have a radio or a refrigerator, though the latter is rare. Those living in the camp town are more likely to have income-generating jobs (as opposed to food-producing jobs), and therefore have disposable income that can be used to purchase goods. The majority of town-dwellers also have houses in villages where they grew up, and where family members still live and work in their fields. Almost all Basotho live in multiple houses throughout their lives. Kin are associated with their various homes, and their current and past houses help to orient them socially. The history of one's house is an important way of creating and binding kin, and of tracing movement over space and time.

The house is a moralized space of respect and honor that is replete with symbolic and enacted social courtesies (Beidelman 1972; Feeley-Harnik 1980). The interior of rondavels in rural communities are relatively standard. They usually consist of a small hearth, or round hole, that is ten inches in diameter and is dug out approximately six

inches into the floor. Household members and visitors sit on mats, blankets, or maize meal sacks on the floor, or sometimes on wooden logs or benches. A collection of pots, storage containers, plates, and cups are usually neatly stacked along one wall, and this area is often decorated with cut-outs from newspapers, colorful flyers or posters, or calendars given away at clinics and shops. Otherwise, the walls are usually bare, though occasionally, designs are etched into the walls. Some families have bed frames, but most have small foam mattress pads

Figure 3.4 – Inside of rondavel, Mokhotlong



and blankets that they lean up against the wall each morning in order to make more room in the interior of the rondavel during the day. People's homes are almost always kept immaculately clean, a necessity in such crowded living spaces. Because my visits were often unexpected, on several occasions I was asked to wait outside so that my host could sweep, or put away dishes from the previous meal. Almost without exception, caregivers

would collect chairs or benches for me, my research assistant, Ausi Ntsoaki, and any other MCS staff to sit on – a courtesy given not only to foreigners, but to visitors from the camp town as well.

Memory is also closely linked to the materiality of houses, both in terms of their physical structures of the house and its contents (Morton 2007). As I discussed in Chapter 2, migrant labor to South Africa was common for Basotho men and women over the past several decades, but has significantly decreased in recent times. Most of the elderly caregivers' husbands worked primarily in the gold mines, and the remnants of this more affluent time are reflected within their houses. Extra household items such as bookshelves, cupboards, broken clocks, drawers, wooden trunks, tea cups and saucers, and tables point to a time when there was a greater influx of cash into the local economy. However, although these items may create an illusion of wealth, there is no correlation between them and the current income of the family, emphasizing the social importance of these items over their material importance. In many cases, elderly widows, whose homes are filled with such treasures, have very little income as they are not able to work. In the cash economy, they often struggle to meet their needs for things such as soap, oil, candles, and money for transportation to the clinic or hospital. Measurement tools used to assess household wealth in developing countries, such as the Living Standards Measurement Study developed by the World Bank as well as measures of wealth in Demographic Health Surveys, routinely use such durable goods as wealth indicators (Grosh and Glewwe 1995). In Lesotho's case, such an assessment could be misleading as to a family's current wealth and access to cash.

The importance of the house and the household is linked to a general importance of physical space. Although many Basotho move around at some point in their lives for work, they are rooted in one or two villages, and use those places as points of orientation throughout their lives. As part of his theory of practice, Bourdieu (1977), in discussing the Kabyle house, emphasizes the dialectic relationship that exists between the person and the house. He argued that the oppositions that exist within the house are also mimicked between the house and the rest of the world and are enacted by its residents through an embodiment of the physical space. The bodily orientation to the world by Basotho is evidenced by the way they describe places and things, with an emphasis on directionality, distance, and physical landmarks, and with the house as a constant point of reference⁵⁰. When I would ask about a caregiver's relationship with a neighbor or family member, they would always point out their house to me. If someone was working in the field, I would get a description of exactly where that field was located. An intimate knowledge of physical space was reflected in the ways people gave directions to things as well. For example, when I asked 'M'e Matshepo how to get to the house of a woman running a support group, she explained:

Down down down, when you get to the road. When you get to Khoarane, you go down that road until you get to Ntsike, and when you get there, there is a house and there is a water tap near it. And there are rental houses there, and you get to that house. But, if you knew that 'M'e who is working at AIDS things, you will easily get there.

This explanation was perfectly clear to my research assistant, Ausi Ntsoaki, who also knew the area well, so we had no trouble finding it.

⁵⁰ Basotho concepts of time are also vastly different from European and North American notions of time. These will be further explored regarding HIV treatment and the difficulties of adhering to strict medical regimens in Chapter 5.

Like many other ethnographic examples (Carsten 1995; Beidelman 1972; Feeley-Harnik 1980), the Basotho house is also a highly gendered space. Although there are no divisions that restrict the movement of men or women within the house, women's primary tasks, such as cooking and childcare, are centered in and around the house, whereas men's work typically takes place outside the home. After giving birth, a mother and child must stay inside their house for up to three months to allow the mother to heal, and to keep the child from ingesting harmful substances outside the home. A long reed that grows near the river, called a *lehlaka*, is placed over the entrance to the house to indicate that a baby was born, and to warn men not in the immediate family that they should not enter. During these months, male presence in the house is limited and the house is dominated by women, cementing its importance as a highly gendered space. Women are also responsible for the upkeep of the house, and any decorative elements inside the house are made by women. The maintenance of the house as a moral and courteous place is the responsibility of women.

The make-up of family members in any given household is often varied and fluid and any combination of relatives are accepted and normative. If a mother and father have many children, they will likely live by themselves. However, it is very rare for an individual to live alone. It is also common for grandmothers and elderly women without children in their household to live with some grandchildren or nieces and nephews. Girls are preferred companions by grandmothers as they are expected to help fetch water from the village tap, and help with cooking, cleaning, and laundry. Even young girls are viewed as an asset by their grandmothers. This fluidity and flexibility has turned out to be valuable in helping Basotho families cope with the increase in AIDS orphans. Both

caregivers and children are comfortable with this fluidity of movement, and its normalcy makes increased child fostering practices easily integrated into local conceptions of relatedness. It is the specific movement patterns that have emerged, particularly those that reflect changing ideas about patrilineality and the emerging realities of matrilineal care, that prove interesting in the response to HIV/AIDS.

This investigation of the Basotho house reinforces the importance of houses and households to anthropological inquiry. Houses remain central to understanding kinship for three main reasons: they reflect social changes and the social order by their structure, their contents, and by the movements of people in and between them; they are spaces where many acts of kin-making take place; and even as their membership shifts they are, by necessity, a stable feature of all societies. This dissertation contributes theoretically to the anthropological literature on the house by arguing that, above all other ways of making and unmaking kin, the house is perhaps the best measure of how people construct relatedness. It also problematizes the standard assessments of household wealth by questioning the basis on which wealth is measured. It is both by being a means of stability and a reflection of change that the house continues to illuminate culturally salient notions of relatedness in Lesotho and elsewhere.

Changing patterns of lineality in Lesotho

Patrilineality remains a pervasive cultural ideal among Basotho, who comprise over 99 percent of the population in Lesotho. It is a powerful ideology that orients Basotho to their ancestral lineages. Patrilineality is far more important as a cultural ideal than it is in the practice of living and caring in everyday life. This contrast is accentuated when compared to the house as an important space in the practice of making kin.

Lineality is one of many modes of reckoning kinship, whose importance is expressed through kin terms, names, clans, and places of origin. These terms and names reinforce the importance of lineality, and are used as a way of showing respect, honor, and positionality. As the empirical evidence will demonstrate, patrilineal ideals remain important as an anchor of moral geography and relationality, even as the social indicators of the *practice* of patrilineality, such as locality, inheritance, bridewealth and even burials seem to be more varied. This section will indicate both how patrilineality is idealized in Sesotho culture, and the ways in which it is changing. Like all idealizations of culture, lineality has never been static or strictly followed (Bohannan 1952). However, changes in the practice of patrilineality seem to be accelerated by migrant labor, changes in marriage patterns, and the demographic changes caused by HIV/AIDS.

In Sesotho culture, a woman marries into her husband's family and takes his name, though she remains part of her natal clan. The children take the father's name and clan, and are seen as belonging to the father's family, particularly if bridewealth has been paid. Even among families who adhere to these patrilineal practices, women and children continue to have an important relationship with their maternal kin, but these relationships emphasize social gains over material ones. In theory, children inherit land from their fathers, and their fathers' families are responsible for their upbringing and education. Both sons and daughters have the legal right to inherit property, but the constitution still supports the application of customary patrilineal inheritance laws, which greatly disadvantages female children (UN-HABITAT 2005). Under customary law, both unmarried and married women are considered dependent minors, and can only inherit property as a gift from their fathers. Widows are entitled to remain in their married

homes, but this is at the whim of their oldest male child (USAID 2006).⁵¹ The Lesotho Land Regulations from 2011 do not specify inheritance only by paternal relatives, however, because customary law is still widely followed in practice, matrilineal land inheritance is rare (Sekatle 2011). I asked ‘M’e Nthabiseng if women were inheriting property from either sides of the family. She said, “It’s slowly being practiced because now people decide to give their properties to their favorite kids or kids who actually provide for the family.” Here, she reinforces the importance that care has on shaping kin ties. In this case, idealized rules of patrilineality are being transplanted by the need for willing and able caregivers.

Ancestry is another important way of maintaining patrilineal kin ties, and helps to demonstrate the potency of lineality as a cultural ideal. For example, when I asked ‘M’e Mamorena, an elderly caregiver of two paternal great-daughters, where an orphan was supposed to live, she invoked the disapproval of her ancestors to affirm the importance of following Sesotho rules (meaning patrilineal rules):

Sesotho rules are difficult, ‘M’e. Because if we can follow the situation, because when we are still following the situation, somehow the ancestors will not like it. We should follow Sesotho rules. In Sesotho rules, when there are orphans, they should go to the father’s side because when the mother wakes up where she is buried, she will just come straight to my house, not to her home, and say she wants her children. And she will be asking, ‘M’e, where are my children? Have you lost them? And she will not go to her [natal] home. She will just come here.

For ‘M’e Mamorena, issues of care, ancestry, and lineality are connected, and are confirmed by her own situation as a caregiver of paternal orphans. If these grandchildren had been her maternal kin, she would likely have answered this question differently, as

⁵¹ Although customary law is upheld by the constitution, the courts are reluctant to remove a widow from her married home. Prime Minister Mosisili has recently spoken out against discriminatory laws of succession and inheritance against women, and is working to change the legal rights of the girl child because “they no longer function in modern society” (Zihlangu 2011).

empirical evidence later in this chapter demonstrate. By using the term “Sesotho rules,” ‘M’e Mamorena reveals an understanding that Sesotho culture and practice are not one and the same. Basotho’s references to “Sesotho rules” confirm the continued importance of idealized notions of patrilineality.

Patrilineality has become secondary in maintaining strong ties to family members. Instead, a sense of responsibility and obligation to kin is now being held together by such things as proximity, reciprocal aid, love, health, and the capacity to help. Patrilineality is still a salient cultural ideal, but it has become secondary to these other factors, especially when it comes to the needs of children orphaned by AIDS, and care for the sick. Instead, children and adults are cared for by the relative most willing and capable of providing them with a stable home.

The terms used to delineate kin are important because they not only reflect, but also help to reproduce social relationships (Radcliffe-Brown and Forde 1951). Kin terms used by Basotho to identify their relatives are partially unilineal – there are different terms for relatives on the paternal and maternal sides of the family – and they indicate the importance of maintaining lineal distinctions and the importance of relative age. For example, there are specific names to indicate if an aunt or uncle is on the mother’s side or the father’s side, and names to indicate a younger sibling over an older one. These are not used exclusively as people will often default to the generic forms of the word such as *ausi* (sister) or *abuti* (brother), but they will be used when distinction is deemed necessary. Not all Sesotho kin terms are unilineal. A person would use the word “sibling” (*banabeso*) to refer to one’s mother’s sisters’ children or one’s father’s brothers’ children; whereas the word “cousin” (*motsoala*) is used to refer to one’s

mother's brothers' children or ones father's sisters' children. In other words, one's parents' same sex siblings' children are called "sibling", whereas one's parents' opposite sex siblings' children are called "cousin". In practice, the closeness of the relationship between these unilineally differentiated cousins is based on other social factors such as proximity. There are also numerous terms (such as "grandmother", "grandfather", and "grandchild"), which are not differentiated based on lineage.

Sesotho honorifics are used in addressing all people, and they all translate to kin terms. The most commonly used honorifics translate into the words "mother" (*M'e*), "father" (*Ntate*), "sister" (*Ausi*), "brother" (*Abuti*), "grandmother" (*Nkhono*), and "grandfather" (*Ntate-Moholo*). Even close friends and relatives call each other 'M'e or Ntate followed by their given name. In addressing strangers, you must also choose an honorific which is most closely associated with their age – if you are not sure, you must err on the side of seniority (it is offensive to call an old woman 'M'e, whereas it is a sign of respect to call a younger woman *Nkhono*). In some cases, the term of respect used for someone does not indicate their relationship, thus elaboration is often necessary. For example, when I asked another informant about her relationship to the child in her care, she said: "Mamokete is the child of my *molamo*...It's the child of the sister of my husband." In this case, she uses the term *molamo* which means sibling-in-law, but she has to explain further in order to distinguish between a sister-in-law and a brother-in-law. When Basotho describe their kin, they often have extremely complicated and contextualized ways of describing their relationships to each other. When I asked 'M'e Maliapeng, a 47-year-old caregiver of two orphans, how she was related to someone, she replied: "When he sees the grandmother, the mother of my father-in-law, he is saying

rakhali [father's sister]". In doing so, she makes it clear that it is a relative by marriage, she indicates the generation of the relative, and uses the kin term used to describe that relative.

Age brings with it important status for Basotho, therefore using the terms for grandmother (*nkhono*) and grandfather (*ntate-moholo*) is extremely important and widely used among family and strangers. The specific relationship of people to the elderly is often unclear since all older aunts, uncles, and even siblings might be called by those terms. For example, *nkhono* is used by children to address their mother's older sisters. However, the younger sisters of the mother are called *mangoane*. A good deal of elaboration is often necessary in order to determine the exact relationship of two individuals, and these descriptions are used when distinction is deemed necessary. Those caregivers I got to know well and visited often were aware of my interest in kinship and the nature of relationships, and therefore, were specific in describing their relations to me.

Basotho kin terms help to maintain a kinship system that emphasizes the importance of a unilineal system by clearly distinguishing between the maternal and paternal sides of the family. Even though orphans are often cared for by their maternal kin, the perseverance of unilineal kin terms help to maintain the ideal of patrilineality. At the same time, the flexibility and widespread usage of more general kin terms may help to legitimate caregiver-orphans relationships that do not fit into the idealized patterns of care.

The physiology of kinship: Parenthood and substance

For Basotho, the idealized importance of patrilineality is not about biological relationships; it is a social theory of descent. The clearest evidence of the social

emphasis of lineality is the distinction that Basotho make between the *pater* (social father) and *genitor* (biological father). Perhaps the most famous example of this comes from Evans-Pritchard's ethnography of the Nuer, where, through "ghost marriage", a widow can have children with another man (either her husband's brother or a different lover) that are deemed to belong to her deceased husband (1940). The underlying purpose is to keep intact the patrilineal structure of the family, and to make sure that the ownership of cattle that were exchanged at the time of marriage remains clear. The Basotho, like the Nuer, de-emphasize biological fatherhood in favor of maintaining clarity of relationships and social positions within the family, and to allow men to establish their position as full social adults through the role of the father. Until they have a child, males are not addressed by the honorific *Ntate* (father), in instead are referred to as *abuti* (brother). Basotho understand the physiology of descent. However, the role of the *pater* is of key importance, and reflects the social reality, while the *genitor* plays a strictly peripheral role. In many cases, this social reality is reflected in care for children – either care by the father, or care by his kin.

Although it is more frequent for the *pater* and *genitor* to be the same person, in several instances during my fieldwork, it became apparent that the *genitor* of a child was different than the *pater*. The de-emphasis on paternal biology is an important strategy used by caregivers to legitimize their role in the life of an orphan. For example, 'M'e Mamorena is the great-grandmother of three orphaned sisters, the youngest of whom, Hopolang, is a client of MCS. They are the children of 'M'e Mamorena's grandson. When MCS outreach workers were filling out the intake forms for Hopolang, 'M'e Mamorena listed under "father" the name of her grandson. However, after learning more

about the family, I discovered that Hopolang was born several years after her father had left for South Africa and not returned. When I asked 'M'e Mamorena (MN) if Hopolang's father had been tested for HIV, she revealed that he had not been around for years:

EB: What about Hopolang's father?

MN: In the past! Hele! A long time ago! He left her when she had two children, when she was breastfeeding that one that I said she has visited from somewhere. And the husband left the wife for a long time and we don't know whether he is still alive or not. This wife had the child while she was not living with the husband.

EB: Does Hopolang know her father?

MN: She doesn't know him. Even this one doesn't know him [pointing to the middle child]. And they don't know whether he is still alive or not.

In my follow up question, I was trying to inquire as to whether Hopolang knew her biological father; however, this did not register with 'M'e Mamorena, as the question was not relevant for her. Although I did not ask, in such a small community, it is likely that 'M'e Mamorena knows the biological father's identity, but because she is a paternal great-grandmother and is responsible for caring for Hopolang because of her connection with Hopolang's (social) father, that question is neither relevant and would challenge her position as the caregiver of the child. In another instance, Rethabile⁵² was cared for by her pater – her mother's husband – after her mother's death. Rethabile's pater was not her biological father, and had not met her until she was almost 2-years-old and returned from South Africa critically ill after her mother's death. Nonetheless, he accepted her as his daughter and takes excellent care of her despite his advanced age and her multiple health needs.

Several other MCS clients had similar situations where the named father could not have been the biological father, either because of death or abandonment prior to the

⁵² See the Relebohile family's story in the introduction to Chapter 2.

conception of the child. However, the child's place in the family is far more important and relevant than the actual biological relationship of the father to the child, reinforcing the continued importance of the social role of the father and the emphasis on the ideal of lineality. For a child such as Hopolang, an ambiguous position in her family would create problems for her in terms of her relationship to her grandmother, and her grandmother's responsibility for her health and well-being. This is avoided by a de-emphasis on biology in favor of social security and responsibility. Kinship and lineality are fundamentally about sociality, and in the time of HIV/AIDS, this works to protect orphans from abandonment.

Just as fatherhood is the mark of manhood for Basotho men, motherhood marks a girl's transition from *ausi* (sister) to *'M'e* (mother). For men, this transition reinforces ideals about lineality, whereas for women, the importance of childbearing is focused on the mother-child bond. Motherhood marks the rite of passage into womanhood for many African women (Hutchinson 1996), and has remained important, even in those places with high HIV rates (Booth 2004; Pearce 1995). Knowing I was married, and of childbearing age, people did not ask me "Do you have children?" but rather, "Where are your children?" or "How many children do you have?" The increase in the number of orphans and the reduction in the availability of healthy caregivers have not lessened the importance of children for Basotho. This importance is reflected in the continued use of teknonyms among Basotho⁵³ – the practice of changing a woman's name after her first child to "mother-of-child's name". It is more common to name a mother after a male

⁵³ The use of teknonyms is not required, but many women still use them. Once a woman changes her name after the birth of her first child that is the name she will use throughout her life. According to Guma (2001)(2001) men also take teknonyms in Sesotho culture, but I never witnessed, nor heard of this practice, though it could be a regional variation.

child, but both male and female teknonyms are used. For example, an outreach worker at MCS was named Karabo by her parents, but after the birth of her first child, Bokang, she changed her name to 'M'e Mabokang (mother of Bokang). After the birth of my son, Sam, in 2010, 'M'e Nthabiseng, MCS's managing director, began addressing me, only half-jokingly, as 'M'e MaSam in our email exchanges. This naming practice not only reinforces the importance of motherhood in Lesotho, but also reflects the "socially embedded view of the self" that pervades Basotho identities (Gergen 1991:7; Guma 2001).

The birth of a child is a celebrated event. This is, perhaps, another reason why the adaptive strategies used by Basotho to cope with the demographic changes precipitated by HIV/AIDS emphasize the well-being of orphaned children, and ensure that care is primarily family-based. Adults who do not yet have any children are called *ausi* (sister) and *abuti* (brother) even if they are well into their thirties. It is not until they become parents that they are addressed by the adult terms of respect, 'M'e (mother) and *Ntate* (father).

Although fertility rates are declining in sub-Saharan Africa, they are still much higher than in many parts of the world. Lesotho has the lowest fertility rate⁵⁴ in the region, and Lesotho fertility rate has decreased from 5.4 in 1976 to 3.3 in 2009 (Lesotho Ministry of Health and Social Welfare 2010).⁵⁵ An overall decline in fertility in the region has been linked to changes in both behavior and health as a result of HIV. For example, studies have shown that women are delaying the age of marriage (Kamali et al. 2000), there is an increase in AIDS widows (Ntozi 1997), an increase in condom use as a

⁵⁴ Total number of births per woman in a lifetime.

⁵⁵ Fertility rates in rural areas are much higher (4.0) than the fertility rates in urban areas (2.1) (Lesotho Ministry of Health and Social Welfare 2010).

result of HIV (Glynn et al. 2000), a decrease in desired fertility among seropositive couples (Rutenberg and Biddlecom 2000), and a decrease in the pregnancy rate among HIV-positive women as compared to their uninfected counterparts (Desgrées du Loû et al. 1999).

The importance of children

'M'e Masenate is 18 years old, recently married, and caring for her husband's deceased sister's one-year-old son, Tebello. When I asked her how many children of her own she would like, she said she would like to have two children, but she is not sure how many her husband will want (implying that he will want more). When I asked Ntate Kalasi, the father of five children, how many children was a good number to have, he said "Heh! I can't tell you. People in the past they were having the children up to 9, but nowadays, when they are this [holding up 5 fingers] we have to stop because of this life nowadays." Although a few older caregivers said women should not have children if they are not married, more said that women should not get married because they will just end up divorced, but if they want children, they should have them at their natal home.

For example, 'M'e Maliapeng (MP) said:

MP: Ach, I just think it's better for the girl to stay at her home because marriage has changed. It's no longer the same as in the past.

EB: Why do you think it's so different?

MP: It's because I just see, if I was not married maybe I was going to live in a good way at my home maybe with my parents.

EB: So, do you wish that you had not gotten married?

MP: Very much.

EB: Why?

MP: It's so difficult in marriage, and life is not easy.

EB: So you were not very happy with your husband?

MP: It's true we were happy but it's difficult.

EB: So, if you think girls should stay with their parents, then should they just have babies at home?

MP: Yes, even if she can have children it's ok, but she should stay with the parents.

'M'e Maliapeng is a 47-year-old widow. She was married for many years but she and her husband were unable to conceive. Ultimately, she was left at her husband's village widowed, childless, and HIV-positive, so it is clear why she might wish she had never gotten married, even though she seemed to have affection for her husband (here and in other interviews). I asked her if their infertility caused problems for her:

EB: I know you have said that you wanted to have a child, but you weren't able to. Did your husband want children?

MP: Very much.

EB: Did he get angry with you? Did he think it was his fault?

MP: I don't know what to say, because he was taking me to the doctors.

EB: Did he treat you badly because of that?

MP: Ach, *kanete*, no, he wasn't treating me badly.

EB: And did you notice, do other people treat you poorly because you do not have children?

MP: Ach, yes, his family was encouraging him to marry again.

EB: Did he want to marry again?

MP: No.

EB: So when you saw them were they cruel to you?

MP: Ach, it's other people, but I was living well with him.

'M'e Maliapeng's infertility caused tension with her in-laws. She was fortunate to have a supportive husband who did not want to remarry. However, fertility is clearly a crucial consideration in the marriageability of a partner. My husband, Will, was teaching at the local high school during our time in Mokhotlong. One of his school friends, a teacher, said he wanted to sleep with his wife before they got married to make sure she was fertile, but she would not let him. By protecting her virginity, she was protecting her marriageability as well.

Childbearing is considered a fundamental function of marriage (Pearce 1995), and Basotho were repeatedly confused as to why I had no children of my own. When asked, I

usually explained that I had only been married a few years and that I would have children when I completed my schooling. 'M'e Mamorena (MN) equated childbearing with happiness:

MN: How many children do you have?
NL (Research Assistant): She doesn't have any children.
MN: Why don't you have children, yet you are always happy like this?
EB: I will have them when I go back home.
MN: Heee, ha! Ok, ha! *Kanete* [I swear].
EB: I wanted to do my work first.
MN: Oh, *ngoaneso* [term of endearment].
EB: First I have to finish school.
MN: Ooooooh *ngoaneso*. Ah! My friend. Hahahahaha.

Another grandmother told me that when I return, I should bring my children so that she can babysit for me. My husband, Will, was also asked occasionally by his colleagues if he had any children, particularly once they knew he was married. However, it is common for Basotho men to marry younger women, so a childless man in his late twenties is not as unusual as a childless woman of the same age.⁵⁶

Naming practices for Basotho children also demonstrate the importance of children, while reflecting lineality, history, and social norms and values (Guma 2001). Basotho names, taken from the Sesotho lexicon, are seldom chosen at random (Ashton 1967).⁵⁷ Children are often named after grandparents or great-grandparents, linking them to their ancestry. It is common to name children after something positive because Basotho believe that names will influence the character of a person (Guma 2001). For example, children are often given names that reflect the gratitude of the parents such as Mpho (gift), Realeboha (we are thankful), and Rethabile (we are happy). Names that

⁵⁶ Once, when a male outreach worker found out that I was a year older than Will, he replied embarrassedly "Oh, in Lesotho, that is not ideal!"

⁵⁷ The importance of personal names in Africa is a widely observed phenomenon (Suzman 1994; Tonkin 1980; Alford 1988; 1988, [c1987]; Mobolade 1973; Renne 2002).

indicate positive traits are also common such as Keneuoe (patience), Tlotliso (honor), and Keletso (advice) which was my Sesotho name.⁵⁸ If an infant is born preceding the death of a previous child, the child will often be given a negative name such as Ntja (dog), or some form of the name Tseliso (condolences) to ensure that the child stays alive by indicating that he or she is not overly loved.⁵⁹

The continued importance of children is a double-edged sword in rural Basotho communities. On one hand, the high value placed on children ensures that children are well cared for within the extended family network even in times of crisis, such as orphanhood. On the other hand, the high value placed on childbearing as a prerequisite to adulthood is true even for HIV-positive women and men, which means that more children are born to HIV-positive mothers; therefore, there are more children living with HIV, and more children at risk of orphanhood. The same values that protect orphaned children from abandonment put them at risk of contracting HIV.

As I have demonstrated, parenthood, for both Basotho men and women, marks an important transition into adulthood. However, relatedness is not established with the birth of a child. Instead, the lived experiences of realizing and nurturing relationships occur over time with a variety of kin. The process of creating relatedness is often connected to the mutable, fluid and flexible creation of personhood through shared substance (Carsten 1995).

⁵⁸ Even visitors to Lesotho acquire a Sesotho name. Shortly after arriving in Lesotho, foreigners are offered a name by their friends or acquaintances. My Sesotho name was given to me by 'M'e Nthabiseng, the managing director of MCS.

⁵⁹ Many of these naming practices exist in other African cultures. For example, naming among the Yoruba of Nigeria for *abiku* children (children who die and are reborn several times) can serve to express the sorrows of the deaths of earlier children in order to convince the child to stay (Mobolade 1973). Zulu names often express the circumstances surrounding a child's birth, or the emotions the parent is feeling upon the birth of the child (Suzman 1994).

Shared substance

Surprisingly, among Basotho, blood was deemphasized as an important shared substance. Blood was never brought up independently as an important factor in a relationship by the caregivers I spoke with. However, when prompted by me, some would say that it was important, and several shared with me the Sesotho expression “*mali a llelana*” (blood cries for blood). For older caregivers in particular, blood symbolized a close kin. When asked to list those who they shared blood with, elderly caregivers often included their husbands and in-laws. When I asked with whom people shared blood, they listed their closest relatives, and many focused on their *ngoaneso hantle* (real siblings). However, there was no uniform answer or overarching narrative about the exact role blood played in people’s relationships, and when I asked one young mother who she shared blood with, she replied “Ach, I don’t think it can happen.”

Among the Malay, Carsten (1995) noted the belief that one would not be able to receive blood from a sibling because the blood is too similar. In contrast, ‘M’e Maliapeng, who was living in her husband’s village, told me that if she needed blood, she would have to go to her natal home to receive it. She said, “If someone needs blood from someone, I won’t be given blood from one of these people, but they would prefer to go to my home. They would prefer to go to take my sibling at my home. I will be given the blood from the one who has breastfed from the same mother.” In this case, even though she expresses a theory about shared blood, it is in the context of shared milk, which, as we will see, is much more important as a unifying substance for Basotho. Others noted that blood was important because it indicated someone who would pity you, or who would help you if you asked them for help. Thus, in the case of both older and younger

caregivers, the substantiality of blood was not important, but rather blood was alluded to as a symbolic representation of relatedness that indicated closeness and reciprocal responsibility. There was no universally accepted understanding of blood relations, but this varied based on the closeness of individual's to their various kin. Again, the lived reality of kin relations surpassed any biologically determined markers of kinship. Like lineality, Basotho theories of blood were reflections of the social reality, and like other forms of relatedness, Basotho ideas about blood are not fixed, but are mutable and can change over the course of their lives.

Establishing and creating relatedness for Basotho is about the give and take of key substances – exchanges not possible with blood. In comparison to blood, shared food, and as a subset of that, shared milk, were much more prominent in both their symbolic and transformative powers. Sharing milk and food for Basotho are key binding elements of social life as they are both nourishing and kin forming. Shared milk is particularly important as an indication of the closeness of siblings, and unlike blood, Basotho brought up the concept of shared milk regularly. Caregivers repeatedly noted that shared milk was the key factor in creating a sympathetic relationship with their siblings. However, like Basotho notions of blood, shared milk was referenced most frequently as a marker for the closeness of a relationship. Basotho firmly believe in the transformative bonding power of shared milk, while maintaining a grounded understanding of the lived reality of sibling relationships.

Basotho women do not routinely breastfeed any child but their own⁶⁰, including those of their relatives, so only biological siblings share milk. Many women noted that

⁶⁰ Although it is possible that breast milk is occasionally shared, I encountered no examples of it, and when I asked about it, caregivers seemed confused by the question. 'M'e Maliapeng said: "They don't

they had breastfed from the same mother as a way of explaining how their relationship to their siblings was different than their relationship to their husband's siblings. 'M'e Maphonolo (MM) mentioned breastfeeding as an indication of siblingship, but recognized that this does not necessarily indicate the strength of a relationship in practice:

NL: And what does it mean to say you are related?

MM: It means we are siblings [*ngoaneso*] but we have not breastfed from one mother.

EB: Ok, so if you breastfed from the same woman, what does that mean about your relationship?

MM: We are siblings [*ngoaneso*]. We are the children of the same stomach.

EB: So the thing that makes you closest with your siblings is that you came from the same woman? Or that you shared the same milk?

MM: Ach, I don't know, really. It can happen that we are the children of the same mother, but hate each other. And we don't go together at all. And someone who doesn't know us would not agree that we are children of the same mother.

Because she used the same term (*ngoaneso*) to describe both sets of siblings, she explained the difference between these in terms of the physical ways the relationships were different. Other caregivers who brought up breastfeeding as a way of explaining relationships, upon further questioning revealed that they thought it was more significant that they grew up together, not that they shared milk. Ntate Kanelo (KN) and 'M'e Maliehi (MN), the elderly grandparents of Matseli, had different opinions on this matter:

EB: How important is breastfeeding?

MN: Breastfeeding is important because if the child has not breastfed they will have some diseases. At least they should breastfeed for 6 months, even if they can stop [after that].⁶¹

NL: And what about in terms of making a relationship with the mother or with the siblings? Like, the children will be crying for the mother. Is it because of the milk? Does the milk do something for the good relationships?

KN: Ach.

MN: Ach, it's like it's difficult. Can you answer it *ntate-moholo* [grandfather]?

breastfeed; they just buy food for them." When I asked why she said: "I don't know. I don't know. [laugh] Because, this mother...I don't know."

⁶¹ Here, she is likely referring to what she learnt at the mandatory HIV adherence sessions where they emphasize exclusive breastfeeding for 6 months then rapid weaning for PMTCT patients. She attended these sessions because she is the primary caregiver for her HIV-positive grandson, Matseli.

KN: I think it's the same because the child can love the sister more than the mother.

EB: Because they shared milk?

KN: Because they are used to each other.

EB: So, is it important for siblings to share milk?

KN: Ah ah [No].

EB: So, your siblings that you shared milk with, you don't think of differently than the siblings that you didn't?

MN: Ach, I have more love for the ones that I have breastfed with than the others. Ach, I still love those ones that I have not shared milk with. But, I love the ones that I have shared milk with most.

EB: Because you shared milk? Or because you grew up with them?

KN: Because you have grown up together.

MN: Ach, it's because we have shared milk. And I don't know if milk makes love between people.

EB: Ntate-moholo do you feel closer with the ones you shared milk with?

KN: yes.

EB: But, you think it's because you grew up together?

KN: Yes, it's like that.

'M'e Maliehi thinks the closeness of siblings is perhaps related to breastfeeding, but she only reveals this after my prompting. In contrast, Ntate Kanelo thinks his close relationship with his siblings stems from their shared upbringing.

Breastfeeding is also perceived as an important practice by mothers in cementing the mother-child relationship. In the following passage, 'M'e Malefu (ML) indicates the importance of breastfeeding in bonding a mother and child together. I asked her how important breastfeeding was, and she replied:

ML: It is important because it makes children to love their mothers. And the mothers, when they see their children, they feel pity for them. And also the children, when they see their mother, they have more love.

NL: Let's say there are two children and the mother, what makes these children to love each other?

ML: It's the love from the mother.

I asked several caregivers about the scenario where a mother was unable to breastfeed one of her children, and in all cases, the caregivers responded that this did not change the relationship between siblings. In contrast, 'M'e Maliehi said it would cause her to feel

“more pity” for that sibling because she had lost her mother. This view emphasizes both the symbolic importance of breastfeeding and the flexibility of conceptions of shared substance as a means of physical transformation. In the context of HIV, where approximately one third of mother-to-child transmission occurs through breastfeeding, the prevailing view of breast milk as wholly nutritive and unitive becomes even more complex, as I will address in Chapter 5.

Food, like milk, is both nourishing and kin forming, but it is also about hospitality, courtesy, and the morality of the domestic space. The potential for food to transform and shape relationships is even more powerful than that of milk because it is not limited to the mother-child and sibling bonds, but extends to include extended kin, neighbors, friends, and ancestors. Food-sharing has long been recognized in anthropology as a way of maintaining social connections, with more recent explorations demonstrating that food sharing is a way of expressing care and of making kin (Hutchinson 2000; Carsten 1995; Peluso 1996; Leinaweaver 2005). Holtzman (2002) has noted among both the Nuer and Samburu that women’s power and dominance in the domestic domain, particularly regarding food preparation, extends beyond of the realm of the household and is transformed into political power as well. The preparation and distribution of food is also a highly gendered domain in Lesotho. Although men slaughter animals for special feasts, women prepare all the food, including the meat. It is customary for Basotho women to serve men, who rarely, if ever, dish out their own food. Even at MCS staff parties, where all of the leadership positions are held by women, some of the female employees would form a line, dancing in and out of the kitchen where food was being prepared, and serve it to the rest of the (male and female) staff. In these ways,

women are responsible for the nourishment of kin and the execution of hospitality that is important in both everyday life and ritual occasions.

Food was a central and necessary component of ritual occasions. Events such as weddings and funerals centered around a shared feast, which usually included a slaughtered animal (the type of animal would depend on the wealth of the family). In addition, *papa* (maize meal), *moroho* (chopped, cooked greens), rice, other vegetables, and *joala* (home brew) were served. Because of the increase in AIDS-related deaths, it is common for a Mosotho to attend a funeral every weekend, thus increasing opportunities for making social connections. Although funeral costs were burdensome for most families, they saw food-sharing as an essential element in the occasion, and a source of pride. In the following example, 'M'e Masello (MP) described the funeral she had for her otherwise healthy 12-year-old grandson who died unexpectedly of a brain aneurism. In this interview, she proudly focuses on the food she provided her guests:

EB: Were there many people at the funeral?

MP: Hele! There were many, it was as if he was an old person,⁶² and all those sheep were cooked, but they ran out while other people did not get it, because there were many people. There were many people, as if he was an old person. The meat ran out, yet they were only giving them one piece, one piece. It got finished.

EB: Two whole sheep ran out!

MP: Yes, two. But, they did not finish the *joala* because there was much. They drank it until they were tired, and they came back on Sunday again, and they got tired again, and they came again on Monday, and they got tired, and they came on Tuesday, and they did not finish it. And on Monday when they were going to the fields, they were taking it in their buckets, some in 5 liters, some in 10 liters, and then they went to the fields. They went to the fields. And we had too much of sorghum porridge...Yes, they went to the fields. Even when they came back, they were taking it with their buckets, and they drank it when they got to their homes. Having the fire at their homes. Yes, yes, 'M'e. It was good, very much. There were only white things. [The sheep] was fat. Mmm, hae, hae, hae!

EB: So, the boy came on Friday, and the funeral was on Saturday, and you made lots of food and ate two sheep. What else happened at the funeral?

⁶² Because the elderly are highly respected in Sesotho culture, their funerals are widely attended.

MP: I have forgotten that even beans were there. There were some people from my home who came with beans, ach, and there were many because we still have them here at home. And they finished that pot of beans...

NL: Yes, and what else happened at the funeral other than eating food.

MP: I said pumpkin...and we slept.

NL: Besides food, what else happened besides food?

MP: Bread, and drinks. And Ntate Ntsele came with a big box, and drinks and soup - the big one, which is mixed with other foods.

Despite my attempts to foolishly steer the conversation several times away from food,

‘M’e Masello persisted until she was certain she had listed everything that was served.

The ability to hold such a bountiful feast for her grandson’s funeral is not only a point of personal pride, but an indication of her social connections, and her strength as a hospitable head-of-household.

When I asked about the burden of funeral-costs, most people responded that, although they were expensive, food was necessary in order to “accompany the person to the grave” – a common phrase used to describe the purpose of a funeral. The family needs help to carry the coffin and dig the grave, and the people assisting them need to be fed. In this same interview, ‘M’e Masello, who was lamenting the financial burden this funeral had been on her family, explained this need:

EB: And do you think people should still have funerals even though they are a great burden on families? Do you think people should still have all those things?

MP: How will we bury that person? How will we bury that person because we are not the ones who have made the funeral? Because, we have to go and dig the grave and there is no other way that we can bury the person...

EB: Is it important to cook or to just bury the person?

MP: Ach, what about those people working hard digging the grave? How will they feel? We should still cook. We can still bury the person by cooking beans, and some use only *papa* [maize meal], and they bury the person only with *papa* and beans. With no *meroho* [vegetables]. But, people have harvested beans.

As ‘M’e Masello indicated, even if you are too poor to provide meat, you should provide something minimal. Yet many, like ‘M’e Masello, whose own health was poor and was

caring for seven orphaned grandchildren in one small rondavel, made immense sacrifices to provide a feast, despite her poverty.

At one of the funerals I attended for a 4-year-old MCS client, Tahlelo, Ausi Ntsoaki and I ate a large breakfast beforehand because it is common to arrive for a funeral in the morning and not eat until late afternoon. However, we were considered guests of honor because we had cared for Tahlelo during his final weeks, because we were from town, and, of course, because I am a *makhooa* (white person), which is unusual in these rural parts of Lesotho⁶³. Upon our arrival, we were given a large plate of rice, noodles, vegetables, potatoes, and mutton at 10am, and then were required to eat another large plate in the afternoon after the burial had taken place. The family was proud to have us at the funeral and was proud of the feast they were able to offer, and they demonstrated this by giving us an abundance of food. It would have been rude of us to refuse.

While food sharing has the power to draw friends and relatives closer, it can also be used to create distance between kin. The absence of food sharing or the refusal to share food is highly destructive to relationships.⁶⁴ In the following passage, 'M'e Matshepo, a young woman who is having problems with her husband, described a major conflict where he refused to eat food that she had served him.

My brother by that time when I said there was a funeral for the child of my sister, no, she's not my real sister, she's the sister-in-law, and when I was going to give

⁶³ Although, undoubtedly, my status as *makhooa* was an important element in my special treatment, whenever I went anywhere with my research assistant or other outreach workers, we were always all treated equally as special guests. Basotho make a distinction between people working and living in the town and those living and working in the villages as farmers or shepherds. In order to distinguish themselves, MCS outreach workers prided themselves on their fancy, modern clothes. On outreach visits, chairs or benches were always fetched for all of us. At a wedding I attended for one of Will's teacher friends, all the other teachers (including us) were separated by the village people as we sat in chairs under a tent, and everyone else sat around on blankets and maize sacks.

⁶⁴ In Chapter 5, this will be discussed with respect to HIV and stigma.

[my husband] food, because the food was finished, he refused to take it. And I went back crying because I was very angry. And I told my brother because he was there at the funeral. And his brother, who is working at the mines, was there and my mother-in-law was very angry. And I told them that he has not eaten it, like I always do [tell them]. And his mother said she doesn't know what to do because he's old and she can't beat him. And I'm always telling her that the life I'm living is so difficult. And sometimes he doesn't buy me some shoes, and sometimes I go where he is working and report all the things that he is doing, and there are many things that make me angry. I can talk for a long time.

'M'e Matshepo's husband refusing food is seen, even by his own mother, as an extremely rude and disrespectful action to take against his wife. 'M'e Matshepo also told me on numerous occasions that her husband had failed to bring money for food for her and her two children, and she was required to ask his family for help. Through these actions, 'M'e Matshepo is severing important ties that are made and maintained by shared food. His refusal to eat what she has served him is equated with his not providing basic necessities for his family. Men rarely serve themselves food, as long as there is a woman around to dish it up. Because of the importance of food sharing, and the wife's role as cook and server of food, this refusal goes beyond a mere marital dispute, but rather, goes to the core of the relationship between 'M'e Matshepo and her husband, as well as the relationship between the two families. It indicates significant strife between the couple.

The transformative power of food is not limited to relations between living persons, but is carried into people's relationships with ancestors. Food is the primary substance used to connect the living with the dead. Honoring ancestors through food offerings, like the importance of accompanying the deceased to the grave, is not only about respect and honor, but about maintaining ideals of lineality. Basotho remember their ancestors, especially during the harvest season when food is in abundance, by cooking for them and brewing *joala* (which, when brewed for the purpose of honoring

ancestors is called *mohlaba*).⁶⁵ ‘M’e Marefiloe (MS), the grandmother of Nkhabu, described this:

EB: Is there anything you ever do to honor your loved ones or ancestors who have died?

MS: yes.

EB: What do you do?

MS: I make *joala*, and cook food, and call other people to eat.

EB: And do you say something about that person before you eat or drink?

MS: Yes. When I’m brewing *joala*, when I pour the water in the drum, I will talk and say, I will call them by their clans, I will start with my family, and the family where I’m married, my husband, and his children who have died, and here are the foods, I’m making them for you.

Many of the caregivers, particularly the younger ones, said they no longer believed in ancestors, but instead believed in God. However, self-identified Christian elderly caregivers saw these two beliefs as compatible. ‘M’e Maliehi (MN), the grandmother of Matseli, who went to the Catholic Church regularly and was part of a women’s group and choir there, still cooked for her ancestors, combining her beliefs in God and what many call “Sesotho Culture⁶⁶” in a creative way:

MN: Sometimes, when I have cooked the food, and I call my friends and neighbors, and I will say, “I have called you here to all be happy. And I have cooked also for the grandfathers and grandmothers, and we should also be happy with them. And those who are not there.” And sometimes I know that they have already died. Yes...After we have cooked the food, we take one plate, and we put everything, everything, everything that we have cooked on it, and we put them there outside. And we pray for them. And we say, “We have cooked for the dead people and the living people.” And they will be eaten by old people. Not [just] anyone.⁶⁷

NL: These ones that we put on the plate?

MN: Yes, they are eaten by old people only.

EB: And so do you pray out loud? Or in your head?

MN: We pray so that everyone can hear...I pray to them mostly when I have

⁶⁵ *Joala* is brewed by women, and is used for mundane, social, and ritual purposes. It is also a primary source of income for women who are not otherwise employed. The economic and ritual importance of home brew has been noted across Africa (Spiegel 1981; McAllister 1993; Saul 1981; Karp 1980).

⁶⁶ People use the phrase “Sesotho culture” to discuss traditional things such as Sesotho medicine or customs performed around birth or death. They use it as a noun, as in “doing Sesotho culture”.

⁶⁷ Only the elderly are allowed to eat the food that is on the plate for the ancestors. Everyone else eats from the food that remains in the pots.

problems. And I say, “Grandmothers and Mothers, do you see me how I am? And I’m working hard.” And I pray to them and to God to make those things go away.

EB: And do you ever think that they help you?

MN: Yes, I will say they help me. Even if I was helped by God. But, the fact that I have mentioned their names, I will say they have also helped me.

EB: And, so once you have your harvest are you going to cook for them?

MN: Yes, in Sesotho we do that.

When ‘M’e Maliehi referred to “Grandmothers and Mothers,” the kinship networks that are invoked by this terminology include ancestors. Despite the disapproval of her Catholic faith, the syncretism displayed here by ‘M’e Maliehi reinforces the role that ancestors play, not only in memory, but as active kin that can have both positive and negative impact on the living. I asked Ntate Kanelo how often he cooks for his ancestors and he replied, “Many times. Yes. So that they can remember us.” For Ntate Kanelo, recognizing his ancestors not only helps him to honor and remember them, but ensures that they do not forget him and that they intercede on his behalf. This confirms the active nature of ancestral kin, especially for older Basotho, and the important role food plays in fostering and maintaining these connections.

Food-sharing among Basotho is an important way of connecting people, both living and deceased. Outside of special events and feasts, food was shared regularly among family members and neighbors. I was sometimes given food during my home visits, but because I was going during odd times of the day when the fire was not lit for cooking, caregivers often apologized for their inability to share food with me. Reciprocity is viewed as very important in food sharing, so that one might share food only with those who had shared with them during times of need. Food could either be given or lent. Most people said that if someone asked to have food, they would give it to them without any expectation of reciprocation. However, if someone asked to borrow

food, they were expected to return whatever they had borrowed at some point in the future. A liter of maize would be paid back with a liter of maize, and so forth. Whether you asked to have or borrow food would depend on your reciprocal relationship with that person. Basotho keep a mental list of what they owe and to whom. For the elderly, this is usually paid back at the end of the month when they receive their pension money. This network of borrowing also helps to maintain connections with family and neighbors, resulting in a fluctuating balance of power within the community. The failure of a family member to share food was sometimes given as evidence of tension within the family. In comparison with breastfeeding and blood, food is a transformative substance for Basotho that links people and communities together on a daily basis, and has important implications for indicating which family members one could turn to in times of need, including providing care for orphans.

Shaping relatedness through raising and caring

The act of raising and caring for children is not merely about the physical exchange of substances, the shared space of the house, or the change in social position that comes with parenthood; instead, these are the key social exchanges that help to foster and shape emotional ties between people. These practices are invoked in the process of raising someone you care for and love. Emotional attachments to natal kin, for young women in particular, do not end with marriage or relocation, but rather, continue into adulthood as young people get married, have children, and form new ties with extended networks of kin. Basotho maintain the relationships and social obligations with those who have raised and cared for them. In the literature on the cultural construction of emotion in Botswana, several scholars have noted that love is not merely a feeling, but an

act of doing (Klaits 2010; Durham and Klaits 2002; Alverson 1978). As Klaits (2010) demonstrates, activities that occur in an around the space of the house impact love and affection, and thus have the power to transform relationships. In Lesotho today, spousal and affinal relationships are under a great deal of stress, in large part because of the social and political economic consequences of HIV/AIDS. As a result, the social geography of relationships between people is gradually shifting, with a de-emphasis on affinal ties, an emphasis on caring, and the emergence of the house as a crossroads where raising and caring present the most stable form of social and emotional investment.

Cultural attitudes about love and emotion cannot be taken as natural, but rather, emotions are socially constructed narratives that reflect, in part, caring relationships. Basotho are affectionate with their children, talk about love between married partners, and emphasize the strong love that exists between grandparents and grandchildren. However real these feelings, affection and love are also culturally constructed and caregivers justify their material attachments to children through emotion and love. In general, Basotho women discuss their relationships to their natal kin in terms of love, affection, and pity, whereas their relationships with their affinal kin are much less frequently described in terms of emotional attachment, but rather in terms of reciprocal responsibility and duty.

Women's attitudes and feelings towards their natal kin, as compared to their affinal kin, may shed some light as to why, in times of need, they turn towards their natal kin to support them and to care for their children. When I initially would ask women about the difference between their natal family and their in-laws, most of them said there was no difference. However, once we started discussing the matter in depth, Basotho

women revealed attitudes about their in-laws characterized by a sense of reciprocal responsibility, which was amplified if bridewealth had been paid. This relationship is also closely linked to households because women live and work in their husbands' villages, houses, and fields. Because of proximity and mutual responsibility, in-laws are the people to whom they turn when they are in need. In contrast, people expressed feelings of "love" and "pity" towards their natal kin. In general, the relationship between a woman and her parents, siblings, and grandparents was described as loving and supportive. Therefore, when marriages fall apart, or a husband dies, young women often turn to their parents or grandparents for assistance because they feel that they are more sympathetic. This is especially true in the context of the weakened marriage bonds, and the shortened lifespan of young adults in Lesotho. Older married women were more firmly established at their married homes, and therefore developed deeper emotional and material attachments to their affinal kin over time. Even in situations where the husband was deceased, or the husband and wife were estranged, an older woman was more likely to remain at her married home.

'M'e Matau (MM) is a woman in her 60's for whom these sentiments towards kin are evident.⁶⁸ In this interview, she touched on the importance of bridewealth, and the impact that locality had in dictating responsibility. Although she did not bring up breastfeeding herself as a mechanism for creating closeness between natal kin, she saw it as an indicator of a relationship characterized by love and pity.

EB: What's the difference in the family where you're married and your family where you're born?

MM: Ach, there is no difference, but they have the difference of cows [bridewealth].

⁶⁸ Her exact age is unclear as she was confused about which year she was born. She said she was born either in 1940 or 1954, but she is less than 70 because she is not yet receiving her old age pension.

EB: So, is your relationship with your family where you're from and your family where you're married the same?
MM: Yes, 'M'e.
EB: So, what's the difference between your siblings and your husband's siblings?
MM: Yes, but, my siblings are on top of those ones.
EB: Why?
MM: It's because they are the children that I have grown up with.
EB: Is breastfeeding important in that relationship?
MM: Yes.
EB: How?
MM: They feel pity for each other because one will say "this is my sibling".
EB: So, do you feel pity for your husband's brothers and sisters?
MM: Yes, 'M'e.
EB: But, less?
MM: Yes, but not the same as my siblings.
EB: If you need help would you go to your family where you're from or where you're married?
MM: I ask for them where I am married.
EB: Why?
MM: Because, it's where I live.

Thapo's grandmother, 'M'e Masekha, did not express a difference in her feelings towards her natal and affinal kin, but regarded her married home as the one where she has many responsibilities. When I asked her about this difference, she said, "I do everything here alone". I then asked her if she ever went to her own brothers and sisters for help, she said: "Yes, if I need something, I go and they help me. I don't like to go often [to ask for help]. I want them to be happy when I go." In this response, 'M'e Masekha indicated that she prefers not to ask for assistance from her natal kin so that her visits remain primarily social. She has been married for a long time and is well established at her married home. This is not the case for some of the younger caregivers who have been married only a few years.

'M'e Maphonolo is a young woman who is separated from her husband. She lives with her three children, and also cares for two young brothers who were orphaned when her parents died several years ago. Her youngest daughter, Lintle, a MCS client,

was conceived after 'M'e Maphonolo and her husband were separated, although he is listed as the father on MCS's intake form. She lives near her sister and brother, though her brother and his wife work in South Africa and only come home on holidays. I asked 'M'e Maphonolo (MM), when she was still living with her husband, how she would explain the difference between her siblings where she was born and those where she was married. She responded:

MM: I can say these ones are the ones where I'm married, and these ones, where I'm born. I can say that if I don't love them.

EB: If you were living there, would you have different responsibilities towards the two sets of relatives?

MM: On the marriage side, I have to do more things than where I'm born because I have gone there by cow [meaning bridewealth was paid]. Yes, I have to do more things where I'm married.

Interestingly, she suggested that you would only make the distinction between your own siblings and your husband's siblings if you disliked them. In her case, the estrangement and separation from her husband would inevitably have created tension with the rest of her in-laws.

As 'M'e Nthabiseng told me, it is common for there to be tension with affinal kin, particularly between a woman and her mother-in-law. This tension, combined with the decline in customs such as bridewealth payment that helped to maintain alliances between families, has resulted in a shift towards matrilineal patterns of orphan care. 'M'e Nthabiseng's perspective is informed by the many examples she has witnessed as the Managing Director of MCS. This provides reliable evidence that these trends are occurring across the local population in Mokhotlong. I asked 'M'e Nthabiseng who in the family provided the best caregiver for an orphan, and she replied:

You know what? I think also that's hard to answer. Because I think what my own judgment or conclusion would be if I had a good relationship with either my

in-laws, or my own siblings, or my parents, my child is going to be better off with those people. Whoever I was in good terms with. So if you say mother-in-law and daughter-in-law, in most cases they really don't go along that much. So, if you really didn't like the mother of this kid, it's really hard to adjust in caring for this kid. That's what I've seen. So, I think it's hard to say. It depends on which side the baby...the mom was really better cared for. So, what happens is, if the kid stays with paternal parents because the father, the mother passed away, and they stay with paternal, so they like this kid because it's their son's kid. But, if this kid...kind of...the father is still alive but the mom passes away, they see it as her kid. So, it doesn't really get the best care, as, she should go to their mother's side. Especially when they are still young, they should go to their mother's side. So, it's kind of like how the other relationship situation is. I think the better the situation, the better the care that the kid will get no matter how many other kids are in the family.

Several caregivers cited tension with a mother-in-law as a primary reason why a woman might look to her natal family for support for her and her children. When I asked 'M'e Masenate (MM) and 'M'e Matsiu (ML) about this, they indicated a general disposition for dislike between women and their mother-in-laws:

EB: Why do you get angry with your mother-in-law?

MM: I don't know. Sometimes we might see that the mother-in-law is silly to the daughter-in-law, or the daughter-in-law is silly to the mother-in-law.

ML: I have seen that when the daughter-in-law is being silly to the mother-in-law, they will always fight. And if there is a girl in that family, the girl will be silly, and the mothers always listen to their daughters. If the daughter-in-law is good, they don't care.

Even though both these women attributed the daughter-in-law's behavior as at least partly contributing to the tension, they indicated that the mother-in-law may unjustly dislike her daughter-in-law even if she is not causing any problems. These tensions recede over time as women establish themselves more firmly in their married homes and as the older generation of in-laws age and pass away.

In contrast to her friend, 'M'e Matsiu has a strong relationship with her affinal kin. Like these other caregivers, 'M'e Matsiu's opinions are characterized by her own experiences. She was orphaned as a teenager, and indicated that she felt more supported

by her in-laws than her own network of extended kin.

EB: Now can you tell me the difference between how you think about your family where you're married and your family where you're born. How are those relationships different?

ML: At my home, where I'm born?

NL: Yes.

ML: I have seen them not caring for me. I am cared here.

NL: Where you are married?

ML: Yes.

EB: Why does your family where you're born not do things for you or care about you?

ML: I have heard them saying they don't have anything when we ask for help. Yet, there are some animals. They just pretend as if they don't have anything. They will always say, *ngoanaka* [term of endearment] we don't have anything, you see that we are not working, 'pretending like they are feeling pity for you. I'm always asking why, and I know that my grandfather has a problem, and is not able to see. He always tells me that he wants to help me. The problem is my uncle [*rangoane*] doesn't want to give me money. He says there is nothing he can do because he is not able to see. I have seen that he would like to help me, but my uncle doesn't want to.

EB: So, where you are married, they are good to you?

ML: Yes, they are good. Because I have seen them helping me if I need help. Even when I don't want anything, I have seen them bringing something.

EB: And what about the relationship between your siblings and your husband's siblings. How are they different?

ML: My siblings are troublesome [laugh], but I love them more than my husband's siblings. I love them more than those ones. Maybe it's because we have grown up together.

Despite being helped by her in-laws, she still admits stronger feelings of love for her own siblings. These strong feelings of love, in contrast with the tensions inherent in relationships with affinal kin, help to explain the shift towards matrilineal care during difficult times. Because HIV/AIDS has had the greatest impact on young married people, who are more likely to have young children, women often turn towards their natal kin to help care for them during their illness, and to look after their children after they have passed away.

As the literature on marriage and the family has ascertained, political economic

circumstances such as high rates of migrant labor, apartheid, and the AIDS pandemic have contributed to the changing landscape of marriage and affinal kin ties (Murray 1981; Romero-Daza and Himmelgreen 1998; Modo 2001). These factors have fundamentally changed both Basotho's approach to marriage, and the role of marriage in creating and maintaining social ties. However, as African ethnographies have well established, and as these new circumstances reinforce, marriage has always been a process (Bloch 1995; Radcliffe-Brown and Forde 1951; Parkin et al. 1987). For Basotho, this entails the process of coming into adulthood, and the broadening web of social relations that, as Bloch (1995) says, "hardens" with the birth of children. Widening relations in Sesotho culture through the process of becoming an adult is a sensitive process, and changes to this process are an accurate assessment of the changing social geography in Lesotho. Social developments such as marriage, the birth of children and the exchange of bridewealth used to be good markers along the processual road to adulthood. Although the emerging instability of these social markers has created increased vulnerability, it has also revealed both flexibility and adaptability in finding new ways to establish and maintain important relationships.

There is general agreement among Basotho that marriage is no longer taken as seriously as it was in the past. For example, 'M'e Maphonolo's brief marriage to her husband demonstrates some of the complex ways the bonds of marriage have been weakened as a result of the changing economic and cultural landscape. In her mid-20's, 'M'e Maphonolo is now living in her natal village with her three children and her two orphaned brothers. Unlike most young couples in Lesotho today, who marry for love, 'M'e Maphonolo was stolen by her husband – a practice whereby a man essentially seizes

a woman who he wants to marry, brings her back to his village, and consummates the marriage. This form of marriage used to be much more common, and was not seen as rape or abduction, but as a legitimate way of obtaining a partner. She described the day she was stolen:

“He stole me, you know! There was somewhere where I was staying and he stole me and I did not know him. It happened like, there were two other women who arrived during the day and they told me that there is a boy who loves me and he wants to marry me. And I said, ‘How will I stay with someone that I don’t know? And what will we talk about?’ And then another old woman came and she said, ‘Go and get vegetables down in the garden’. And the gardens were a little bit far, and we went and were delayed in coming back. And these people were just sitting beside the road. And they caught me there.”

‘M’e Maphonolo said she could have left her marriage right away if she wanted to, but she initially decided to stay. However, after a short time, her husband left for work in South Africa, and she returned to her natal village. She said: “What is the use of being there when there is no one taking care of me? And there were no cows [meaning bridewealth]. And I came back.”

Despite this ominous beginning, ‘M’e Maphonolo remained married to her husband, and had two children, although she was not living in his village. However, his absence for work in South Africa put a strain on their marriage as it was not strongly established. I asked ‘M’e Maphonolo (MM) how long they were married before he went away:

MM: Ach. He marries me on Monday, Tuesday, Wednesday, Thursday, he spent two weeks at his home, then he went to Natal.⁶⁹ And he came back. And he spent about three weeks at home, then he left again. Then he came back again. And when he was there he was not staying for a long time. About a month.

EB: And you were happy then, or you were not happy?

MM: Yes, *kanete*, we were happy.

EB: And did things start to go badly before he left?

MM: It happened like this. My parents needed cows from his father. And his

⁶⁹ KwaZulu Natal is a province in South Africa where many Basotho work. Many also work in the province of Gauteng, where the majority of the gold mines are located in the area surrounding Johannesburg.

father said he would bring his son to come back home. And his son told him that he will not come back home at all. He's going to stay in Natal. And his father told me that: 'He has another wife, your husband'. And I told myself that I'm going back home.

EB: So do you think he will ever come back here?

MM: Ach, I don't think so at all.

In 'M'e Maphonolo's case, a hasty non-consensual marriage, separation due to migrant labor, the absence of bridewealth, and her husband's infidelity created insurmountable obstacles to the success of the union. When I asked her if she wanted to get married again, she replied "I have had it, and it's enough". She views the institution of marriage as fundamentally different from when her parents and grandparents were young.

Ach. We [young people] are just playing. Or it's because I was married while still young. Or I was married without a good mind. Without a good mind. I don't know, or, I was still young. I don't know. I don't know what happened because I didn't like it. To be married, I didn't like it...Old people really had a good marriage, *kanete*. Because they are still saying that, even when looking at them, you can see that. They were living very well. But, no, ah ah, *kanete*, we are not...Love, *ngoaneso*, is gone now. It is not there at all, at all, at all, love. It is gone. Gone, gone, gone, gone.

'M'e Maphonolo's sentiments about marriage were echoed by many other women, both young and old. A common sentiment stated by both generations is that "there is no more love", and that in the past people were more "patient" (*keneuoe*) in their marriages.

Although many of the younger caregivers remember their parents and grandparents as being happier in their marriages, the older women admitted to conflict. Seventy-eight year old 'M'e Marefiloe's opinion reflects the general sentiment of elderly women today:

Old people were always happy at their marriage. And even when it was difficult, they were patient. But these ones are not patient...*Ach, ngoanaka*, nowadays, there is no marriage. The child stays for two days at the marriage, on the third day you'll hear that she has gone. She's at Natal. Or Butha Buthe⁷⁰. They don't stay at their marriages, they get divorced, *kanete*."

⁷⁰ Natal is the province of KwaZulu Natal in South Africa, and Butha Buthe is a town in the lowlands of Lesotho. Many people go to both places to find work.

'M'e Matau (MM), the grandmother of Tsepi, however, gave a more realistic picture of marital conflict when she was younger.

EB: And were you happy in your marriage?

MM: I was happy.

EB: Were there ever difficulties for you in your marriage?

MM: Yes, we sometimes fought. He was fighting with me.

EB: But, in general you were happy?

MM: Yes, we were always happy.

EB: Did you ever think about leaving your husband?

MM: Yes, sometimes I left him and went to my home. I would go back to my home and he would come to collect me. I came back happy and I could see that he was also happy, too. We stopped fighting, and we lived together.

EB: So, if you were extremely unhappy do you think you would ever leave your husband?

MM: Yes, *ach*, I was going to leave him. I was going to leave him.

EB: Why did you change your mind?

MM: We stopped fighting. And we had children, and we stopped fighting.

Many of the older women also pointed to their own families as contributing to their marital stability. When fighting with their husbands, many women said they would return to their natal family until the conflict subsided. The couple's parents would then work to bring the couple back together. For example, 'M'e Maliehi, Matseli's grandmother, explains why marriages were more successful in the past. She said of the elderly, "They were patient. Even if it wasn't good, even if they told their parents that their partners are not doing good things, like this, and this, and this, the mother or the grandmother will just say, you should be patient my daughter, or my granddaughter. And they said you must do good things for your husband to be happy. You must be patient."

Of course, not all old people had successful marriages. Kotsi's grandfather was deserted by his wife when his children were still very young. He raised them by himself, and is now raising the two sons of his deceased daughter, including Kotsi, who is HIV-positive. Although they never divorced, his wife has a new family in the lowlands of

Lesotho, and he has not seen her for over twenty years. 'M'e Malefu, an elderly village health worker and caregiver for two teenaged orphans, is also separated from her husband. She lives in his family's village, where she has been for many years, and he occasionally comes to visit, but he stays elsewhere and they no longer share resources. When I asked 'M'e Malefu (ML) if she wanted him to come back, she indicated that the current situation suited her better:

ML: My husband is living somewhere else. He just comes here like someone who is visiting. And in the evening, he goes somewhere else. And if he has money, he doesn't give me any. And even me, I don't give him, if I have any. I have been praying for him, but it seems like he doesn't understand. And what I have, that I get from this job as a village health worker, I don't give him. I'm using it with these children.

EB: Would you be happier if he were living here, or is it better for you that he's not living here?

ML: It's better if he is living there because the chief said I should take him to court and I said, *ach*, ah ah. I didn't want to take him to court. He will see if he will come back. And I don't want him to come back because he will bring some diseases to me.

Because she is a village health worker, she sees his absence as beneficial not only to her financial situation, but also to her health.

Of the nine younger caregivers with whom I conducted extended interviews, four of the women were divorced, separated, or never married. In contrast, only two of the twelve elderly caregivers were separated (the two I previously mentioned), although many were widowed. These trends are influenced by the increased potential for women to earn money for their households, and the increased educational opportunities for women in Lesotho. However, the empirical evidence was not conclusive in this area. Most acknowledged the changing role of women in general, however, some caregivers viewed increased education as a stabilizing factor in marriages, whereas others saw it as a destabilizing factor. Those who saw education as a positive factor for couples viewed it

as a general good, and therefore extrapolated that it would be beneficial to marriage. 'M'e Mahlompho viewed education as taking strain off a marriage by giving couples some independence from each other: "If one is a nurse and one is a teacher, and we all go for work, I just think it's better. We cannot easily be fighting because we are not always together. You would just be together for a short time." Those who saw it as a drawback pointed to the temptation of having other partners outside of marriage, especially when spouses were differently educated. In reality, education likely has little impact on the quality of a marriage, but, as 'M'e Maliehi alluded, it decreases the dependence of women on men for their livelihood.

Education is also causing people to get divorced...Like, if the husband is doing things the wife doesn't want, the wife will just say, I don't care. I'm going because I'm educated. And I don't care. And that's the end...I just think it's because they are educated. And one will be saying, I will work for myself, and no one is caring for each other. And the girls are not patient with their husbands because they know that they can work for themselves. And the husbands are like that too.

The ability for women – educated or not – to participate in the cash economy makes divorce a possibility when it previously had not been an option.

Bridewealth revisited

Caregivers were also of mixed opinion when it came to the role that bridewealth played in strengthening marriage bonds. Of course, like other cultural ideals, bridewealth payments have never been uniform or consistent, and there have always been complexities. However, it is clear that bridewealth is declining in practice, and in its potency as a cultural ideal. The decline in bridewealth in some ways causes instability, but it also creates opportunities for new patterns of relatedness in a way that privileges care over lineality.

Traditionally, bridewealth (usually called *likhomo* by Basotho – Sesotho for “cows”) was ideally paid, at least in part, from the man’s family to the woman’s family at the time of the marriage. In fact, a couple may move in together without a ceremony, but the exchange of cows signals the beginning of the marriage. The form of the marriage ceremony also varies. Couples may have a Sesotho ceremony in their village, a church ceremony (often called a “white wedding”), or some combination of the two. Although many marriages are registered with the government, they are socially recognized even when they are not. Usually, *likhomo* payment is established with reference to a certain number of cows, but cash or a goods equivalent can act as a substitute. Even in cases where the payment is made in cash or goods, it is counted in cows, and it is called by the Sesotho name *likhomo*. For many older women, the number of cows their in-laws provided, and the speed with which they were delivered, is a point of pride.

Among young and old Basotho alike, there exists the shared opinion that the practice of *likhomo* has changed. In general, people pay fewer cows, if any, and these are often promised, but not paid in full. Kotsi’s elderly and blind great-grandmother, ‘M’e Matlotliso, sits outside of her rondavel all day, enjoying the sun and talking to passersby. My research assistant, Ausi Ntsoaki, and I approached her one day looking for Ntate Kapo, her son, and Kotsi, who had gone to work in the fields. She said she would like to talk to us, so we waited while she followed a wire that Ntate Kapo has put between her rondavel and the outhouse. ‘M’e Matlotliso is in her 70’s, and she is confused by the changes that have taken place in Lesotho during her lifetime. When I asked her about HIV, she knew very little, even though she lives next door to her grandson, who is on ARVs. However, when I asked ‘M’e Matlotliso (MM) about changes in marriage and

likhomo, she had a clear and strong opinion:

MM: Ach, nowadays, they don't pay *likhomo*. They just take the girls. If they pay one, kanete, they have paid *likhomo*. Or if they have paid two or three, you must know that they have paid a lot, oh ho! [laugh] They have paid the *likhomo*. And sometimes they take the girl for some years, not paying anything... And the girls nowadays are just married without paying *likhomo*. The marriage is if they can take care of my children and be good to my children, and my children will also be good to the boy who was attracted to her, ah ah, no problem. I have seen it happening like that.

EB: how do you think marriage has changed between now and when you were married?

MM: There is a difference because they don't pay anything for the children. At least in our age, there was something paid. And they gave it to our parents, because they were the ones caring for us.

'M'e Matlotliso makes a direct connection between *likhomo* payment and care. It not only solidifies the responsibility of families in terms of property, but in terms of providing care and support.

Some of the caregivers made a direct connection between the decrease in *likhomo* payments and increased divorce. 'M'e Mahlompho is a young woman who still lives in her husband's village with her three children, even though he is deceased, and even though she does not get along with her mother-in-law, because she likes the independence of running her own household. However, she sees the lack of bridewealth exchange as a factor contributing to her independence. I asked 'M'e Mahlompho (MR) if she thought old people were happier in their marriage:

MR: Even if they were not happy, the fact that *likhomo* was paid...it's not like now. I can now go at my home because there was nothing paid. I could just take my children and go, but the fact that I have my own house, I won't go anywhere. And it's easy for me because no one will say, 'where are you going with these children?'

EB: Why do you think young people are getting divorced more than old people do?

MR: Nowadays, because there is no *likhomo*. If *likhomo* is paid, the parents can stand between to make those people stay together. And they will say, my cows have gone out so go back to your marriage. But nowadays, they just get divorced,

and no one stands between them. Because there is no *likhomo*.

However, other caregivers rejected 'M'e Mahlompho's hypothesis by giving examples of those who stayed in their marriage even when *likhomo* was not paid, or those who left when it had been paid. When I asked 'M'e Mapoloko, 77, if she thought a decreased in *likhomo* payment was a factor in the increased frequency of divorce she said: "Is it so? I don't know. I don't know because I have seen some that *likhomo* are not paid still living with their husbands and the husbands still living with their wives. But some, they just marry one today and tomorrow they marry another one, just like that. Because they are lazy, they did not work for *likhomo*." 'M'e Masenate is 18 and having conflict with her new husband. There was no *likhomo* paid for her at the time of her marriage because her husband had no cows, and his job does not provide him with enough money to pay their monthly expenses and *likhomo*. She had recently informed me that she was considering leaving her husband. Her opinion on the impact of *likhomo* on divorce perhaps reflects her unhappy situation. I asked if she thought a woman would be less likely to leave if *likhomo* had been paid. She said, "Ah ah, *kanete*. If you feel like going, you must go."

Despite these differences of opinion, *likhomo* payments have both historical and contemporary importance in creating bonds between families. In reality, it is unlikely that 'M'e Masenate would be as free to leave her husband if *likhomo* had been paid because of cultural pressures and the intervention of her family. As Ntate Kapo told me, if *likhomo* has been paid, and you want to bring your daughter back to care for her, you must return the cows.⁷¹ Extended families are more invested in the success of marriages

⁷¹ Customary law dictates that, upon divorce, a woman's family is required to return the *likhomo*, and must return to her natal home with only her personal possessions. If there are children, they must remain with their father's family (Gill 1994). In practice, this is much more flexible. If a woman returns to her natal home for care, she may not be considered divorced, and in some cases, as these ethnographic examples

where *likhomo* has been paid, because the process of untangling the marriage is more complicated. 'M'e Maliehi argues for the positive aspects of this entanglement when she says, "*Likhomo* brings two clans together. When you are married there, they are your siblings. Yes, they are your siblings." As some of the previous examples have shown, parents were more frequently involved in bringing a quarrelling couple back together in the past, when *likhomo* was paid. In some ways, the changes in marriage have made families unstable by creating less support within the immediate family. But in other ways, the breakdown of marriage customs, in particular, *likhomo* has made it possible for parents and family members to seek the best possible situation for an orphaned child without violating the idealized rules of patrilineality. It has also given young women (and men) more autonomy in deciding the fate of their marriages. In this way, one of the factors causing instability and insecurity within families is also helping to create flexible responses in determining who cares for an orphaned child.

Conclusion: The social geography of care

In the midst of increasing levels of marital instability, strained relations between women and their affinal kin, the changing role of lineality and a de-emphasis in the practice of bridewealth exchange, the house has emerged as the most stable element connecting Basotho. The house is a key crossroads, and a nest where Basotho intersect in different configurations, and with different family members throughout their lives. It is a space where substance is shared, most importantly milk and food, and it is the central locus of caregiving practices for a broad network of kin ties. As such, it is also the site where physical connections and emotional bonds and feelings of love and affection are

show, the paternal family may not want to or be able to care for the children. However, the potential for a woman to lose rights to her children creates complications and gender imbalances when deciding on the location of care for a sick mother.

nurtured. With this new focus on the house comes a focus on care. While investigating caregiving practices for AIDS patients in Botswana, Klaitz finds that activities taking place in the house “shape people’s sense of the possibilities that they will receive love and care from others” (2010:126). Care has always been an important element in Basotho relationships, and the house has always been a space where caregiving has been enacted. Care thus forms a central part of the courteousness and respect that takes place in the house. Of course, not all household members are equally caring. However, as was the case with ‘M’e Matshepo whose husband refused food, a lack of care results in the dissolution of kin ties. The social expectation of care within the house helps to maintain the house as a space where care is enacted. Whereas the act of caring has always been emphasized as a valued characteristic of Basotho social life, as evidenced by fostering practices and respect and care for the elderly, the reconceptualization of patrilineality has made care one of the primary organizing principles of the house, and thus of Basotho social life. Care is no longer merely a valued social act, but a primary action that has changed, and continues to transform, the social geography of rural Lesotho.

This refocus on the house, which is newly organized around care, has important implications for the care of AIDS orphans. The house is a space where people can go to seek help and care from kin, and this is increasingly important as the numbers of sick and orphaned Basotho rises. Rural communities in Lesotho are reorganizing themselves in ways that privilege care. This is possible because of the flexibility and fluidity of kinship, and the disconnect that exists between idealized notions of kinship, patrilineality, and everyday practice. It is common for Basotho to live in households composed of various members from both sides of the family. Likewise, children are accustomed to

movement between households for both material and emotional reasons. A flexible understanding of relatedness allows Basotho to cement bonds between more distant kin in order to expand networks of care when families are in need.

The testaments of many of the caregivers I interviewed indicate that some of the things that are threatening the unity of the family are also helping to ensure that children are not left without care. First, there is the strong – almost self-evident – belief that orphaned children should remain within the extended family. The rural and close-knit nature of the villages surrounding the camp town of Mokhotlong, as well as the virtual absence of institutional facilities, means that families rarely consider options for care outside of the family unit. Unifying practices such as bridewealth payments are happening with much less frequency and consistency. This appears to be weakening the connections between affinal kin, and reducing the incentive for parents of a married couple to intervene, in order to maintain ties between clans. However, the decline in bridewealth practices also creates a space where the idealized rules of Sesotho kinship can be negotiated in order to provide the best possible situation for children. Similarly, childbearing remains important among Basotho as a rite of passage into adulthood, even as many young parents are getting divorced and dying. Further, more children are being born to HIV-positive mothers, and thus are contracting the illness themselves. These factors create insecurity for children. Yet, the importance of, and general affection for, children has helped to maintain a strong commitment to the well-being and care for children within the extended family network, ensuring their protection and care even after their parents have died. The resulting negotiations for the care of AIDS orphans are then centered on the house as the central space where Basotho kinship is enacted. The house

is useful as an analytical tool because it reflects changes in social geography, and provides a stable measure of kinship practices and relatedness even as other aspects of Basotho kinship ebb and flow.

CHAPTER FOUR

PRIVILEGING CARE: CONCEPTIONS OF ILLNESS, THE BODY, AND TREATMENT-SEEKING BEHAVIORS IN RURAL LESOTHO

'M'e Malelang's story

'M'e Malelang is a Sesotho doctor (*ngaka ea Sesotho*) in her late 30's who runs a booth along the main strip of Mokhotlong's camp town. 'M'e Malelang's booth, which consists of a flimsy blue tarp roof and a table strewn with roots and different sized jars filled with powders, liquids, and herbs, looks almost haphazard. I asked 'M'e Malelang about her decision to become a Sesotho doctor. She said, "I have become a Sesotho doctor by dreaming about it." When I asked her to elaborate she told me that she dreamt that she saw a woman wearing a Sesotho doctor's beads – the same beads which she wears in her own hair – so she sought out a Sesotho doctor whom she believed to be the woman from her dreams, and was trained by her. Although her formal training only lasted a week, she said she had also been shown some things by her ancestors who visited her in dreams.

'M'e Malelang told me about the kinds of ailments she most frequently treated. She began by naming a few symptoms such as sharp pain and headaches. She then mentioned *nonyana*, a cluster of symptoms common among Basotho children, for which most Basotho seek help from a traditional healer. She described what she does for a child with this Sesotho illness as follows: "When the child has *nonyana*, they have a white thing in the mouth, and have a rash at the back of the neck. And I dig a medicine called

tlapi, I fry it, then use it to clean the baby. And I dig another one which is cooked with milk.” When I asked her to point out that particular medicine on her table of supplies, she told me, “Ah ah, now it’s gone.” Every so often, when her supplies run low, she or one of her colleagues must make a trip to KwaZulu Natal, a nearby province in South Africa, where most of the medicines can be found in the soil.

I asked ‘M’e Malelang what she would do if she suspected one of her patients was HIV-positive. She told me, “I can cure it... Yes, but I don’t believe the infection is there.” She revealed that she does not believe in the existence of HIV because she said, “I have seen when people are suffering from headache or anything, people say they are infected.” When I asked her to elaborate, she revealed that she, too, was diagnosed as HIV-positive: “The first time when I was sick having *moea* [wind or spirit⁷²], I went to the doctor⁷³, and they checked on my blood, and they said I had AIDS. But, until now, I haven’t used their pills, and I was cured after I have been a doctor.”

Like many Basotho, ‘M’e Malelang relies on readily apparent symptoms to manage her own health problems, and those of her patients. Sesotho doctors do not have the tools or knowledge to run blood tests, x-rays, or other diagnostic tests that may indicate the underlying cause of illness. Instead, they must rely solely on symptoms – both physical and social – to detect illness. Once those symptoms disappear, it is assumed that the illness is gone and wellbeing has been restored. It is likely that ‘M’e Malelang’s viral load is still low; therefore, she has not yet experienced symptoms

⁷² *Moea* means wind or spirit, and is used to talk about people who dream about being a Sesotho doctor. When you dream about this you become sick and then the Sesotho doctor tells you what you have to do to get better. This is often how people are called to become a Sesotho doctor, according to ‘M’e Malelang.

⁷³ People almost always say “*ngaka ea Sesotho*” when talking about a Sesotho doctor. Although they often say “*ngaka ea sekhoaa*,” (English doctor) when talking about the doctors in the clinics and hospitals, they also use the word “*ngaka*” (doctor) by itself to mean an “English doctor”. Where “doctor” is used without clarification, it is primarily in reference to an English doctor.

signaling her HIV infection. She assumed that because she was asymptomatic, she was not infected, confirming her disbelief in the existence of AIDS. I asked her if she had ever sought treatment at the hospital since becoming a Sesotho doctor. Although she told me she would never encourage one of her patients to seek treatment through modern medicine, she admitted that she would go herself, but only for something like a burn or a broken leg. Otherwise, she would treat herself.

Sesotho medicine is still practiced widely in Lesotho, and *lingaka ea Sesotho* like 'M'e Malelang are legitimized by the continued use of their services. Every district camp town and the markets and taxi stands in the capital of Maseru are lined with booths carrying a wide range of herbs, extracts, and roots. Many booths have small private enclosures made of sheets or a tarp, where Sesotho doctors can perform consultations and procedures, though they also make house calls. Their continued existence is evidence of the economic viability of the profession and the continued need that many Africans have to treat problems that cannot be solved through biomedicine (Langwick 2011). However, many Basotho have mixed feelings about Sesotho medicine. While some view Sesotho doctors as useful for certain things, others dismiss them as dishonest and ineffectual. Those who seek treatment for HIV from Sesotho doctors such as 'M'e Malelang are in the minority, as increased availability of free ART and the visible improvement it has made in many patients' lives has encouraged a biomedical approach for this disease. Many Basotho have adapted to the availability of new pharmaceutical drugs by combining traditional and biomedical approaches in a way that balances their desire to improve their physical wellbeing while working within the constraints of their social networks of kin and care.

Most Basotho seem to view illness and select their treatment approach based on a culturally mediated understanding of a series of apparently rigid binaries: biomedical versus supernatural causality, symptoms versus disease management, and “English” versus Sesotho medicine. However, instead of presenting rigid, mutually exclusive dichotomies for patients and caregivers to choose from, Basotho negotiate between these binaries as a way of employing multiple strategies in response to health problems. Patients and caregivers are able to draw on these malleable resources in order to make choices that consider both the physical and social implications of their beliefs and actions. This flexibility allows them to navigate difficult and complex situations while privileging networks of kinship and care.

Basotho’s choices about treatments and the underlying explanatory models of health and illness implicate issues of kin and care. People choose treatments that are most likely to improve their health or the health of a child in their care in such a way as to protect caregiving relationships. Here, as elsewhere, social relationships are emphasized over biomedical knowledge about disease transmission and etiology. Yet, even in situations where biomedical knowledge is denied, biomedical treatments are favored precisely because they help to protect the health of loved ones. Ultimately, the ethnographic data regarding treatment seeking and conceptions of illness presented in this chapter serve to elucidate Basotho’s responses to HIV and reinforce the notion that HIV is a kinship disease. Just as Basotho forego strict adherence to idealized notions of lineality, so do they respond to illness in ways that privilege kin and care.

Lesotho's health care system: Structure and funding

Before exploring in-depth the ways people negotiate the medical landscape in Lesotho, it is contextually important to establish the choices that are available to them. Basotho's navigation of the seemingly rigid binaries between choices in medical treatment regimens and disease etiologies do not exist in a vacuum. Rather, structural and social inequalities constrain treatment choices, thus Basotho's decisions and their understanding of illness and treatment must be viewed within this context. Rural Basotho face limited access to health care facilities, debilitating poverty, weather conditions that frequently constrain travel, and overworked medical personnel who are unable to provide quality care. This section will examine the broad structure of Lesotho's health system, and describe the health care options available for Basotho living in the Mokhotlong district.

The Ministry of Health and Social Welfare is the government branch that coordinates medical services in all ten districts of Lesotho. In addition, there are numerous private organizations, most notably, The Christian Health Association of Lesotho,⁷⁴ Baylor University, Médecins Sans Frontières, and Partners in Health, which fund and run numerous hospitals and clinics throughout the country. According to the Ministry's website, there are 22 public and private hospitals in Lesotho (Lesotho Ministry of Health and Social Welfare 2011). The district of Maseru, where the capital city is located, has the highest number of hospitals (7), and all other districts have either one or two hospitals (see Table 4.1). Maseru has the country's highest population concentration and also receives patients from across Lesotho who need specialized care or complex

⁷⁴ CHAL is part of the larger US-based NGO, Global Ministries which is run by the Christian Church (Disciples of Christ) and the United Church of Christ. They are funded by numerous local and global donors, and also receive money from the Lesotho government.

surgery. There are also 184 public clinics and numerous private clinics throughout the country.

Table 4.1 Distribution of hospitals and clinics in Lesotho

DISTRICT	Population	Hospitals	Clinics - public	Clinics-private
Maseru	477,599	7 (incl. 2 specialty)	49	70% of country's private practitioners
Berea	300,557	2	12	4
Leribe	362,339	2	31	5
Buthe Buthe	126,948	2	10	3
Mokhotlong	89,705	1	10	1
Qacha's Nek	80,323	2	12	1
Thaba Tseka	133,680	2	20	3
Quthing	140,641	2	9	1
Mohale's Hoek	206,842	1	12	3
Mafeteng	238,946	1	19	3

Source: (Lesotho Ministry of Health and Social Welfare 2011)

Despite a seemingly large number of health facilities in Lesotho, there is an acute human resource shortage in the health care sector. According to the WHO (2006), Lesotho has a density of health care providers (including doctors, nurses, and midwives) of only 1.15 per 1000. The WHO recommended threshold for density of health care providers is 2.3 per 1000. At the time of this report, there were only 89 doctors working in Lesotho, and 1123 nurses and midwives. Lesotho also has a young workforce in comparison to other countries, which is problematic for training and mentorship among health care workers (WHO 2006). A country report from Médecins Sans Frontières (MSF) noted that the majority of doctors working in Lesotho are from other African countries, and see their posts in Lesotho as temporary until they can find higher paying jobs in other parts of southern Africa. MSF supports 14 clinics, and as of December 2007

when this report was generated, half of the nurse's posts at these clinics were vacant, as were over 30 percent of nursing posts at the district hospital in the region in which they were working (Medecins Sans Frontieres 2007). The US government, through PEPFAR (President's Emergency Plan for AIDS Relief), has been funding HIV prevention and treatment programs in Lesotho since 2007. In 2009, they extended their commitment to funding programs impacting all levels of HIV treatment, prevention, care, and support. One of the main goals in this contract extension is to support and retain human resources in Lesotho so that the other goals of the partnership can be accomplished (PEPFAR 2009).

When seeking medical care in Lesotho, there are multiple courses of action a patient can take that are decided by a complex combination of factors including cost, proximity, and available treatment. At the district hospital, patients have to pay a nominal fee for treatment and medications. Treatment at the government clinics and CHAL clinics are free, but some medications are not. Private clinics are the most expensive, and are used by wealthier Basotho. Most people visit their closest clinic or hospital, depending on the type of care needed. Clinics can provide most basic outpatient services and medications, subject to availability, including antibiotics, immunizations, HIV-testing, ART, prenatal care, and well-baby care. However, patients need to go to a hospital for inpatient care, IV-fluids, minor surgeries, and certain tests that require specialized machinery such as x-rays and liver function tests. Samples for TB and CD4 counts are collected at the clinics and brought to the district hospitals, however TB patients in need of chest x-rays need to make the trip into the camp town hospitals.

The majority of people in the Mokhotlong District use the government run hospitals and clinics, or CHAL clinics, though they will occasionally pay to go to the private clinic for anonymity, speed and quality of service, or for a second opinion. At the district hospital, one is likely to wait half a day to see the doctor plus another half a day to receive medications from the pharmacy. Since 2004, ARVs have been free in Lesotho, and the government has been expanding access to treatment, clinic by clinic, across the country. ARVs were first available at select clinics and hospitals, and spread first to the government clinics located closest to the camp towns and then to the more distal clinics – an important step in improving access to care for those living in the most remote villages. At the Mokhotlong District Hospital, ART patients skip the main outpatient building, and walk up the hill to the very back of the hospital property where the Lerato Center is located (*lerato* is Sesotho for *love*). There they will have their monthly ART appointment where their adherence is monitored by counting left over pills, their medications are refilled, and any other problems are addressed. In the rural clinics, one day per week is dedicated to treating only ART patients. Patients are able to receive all necessary medications, but certain diagnostic tests require them to travel to the hospital for care. On the whole, patients in Mokhotlong utilize a variety of available treatment venues depending on their ailments, desired treatments, cost, and convenience. Basotho draw on these – and other – available sources of treatment and information in strategic ways in order to balance their desire to protect their social relationships as well as their physical health.

Disease etiologies: Biomedical and supernatural causality

When discussing health and illness with Basotho, the tension between biomedical and supernatural etiologies of disease seems rigid at first glance. However, after several conversations with people in multiple contexts over time, this rigidity is revealed as a careful selection of the causality of disease that best protects networks of kin and care. Conceptions about the origins of illness are at once scientific and speculative, and can come from both natural and supernatural causes. A single person might provide a range of explanations for illness that includes God, witches, and airborne causation. Although, in the abstract, Basotho may mention an illness spreading from person-to-person, they rarely expound on the details of this when discussing specific cases. Yet, as the examples below demonstrate, patients are comfortable with the contradictions that arise from these beliefs and treatment seeking behaviors, and do not see multiple etiological explanations as being mutually exclusive. Basotho are comfortable with a lack of clarity about the causes of illness. This flexibility is not borne out of ignorance, but rather is used as a resource to protect both health and social networks. One of the primary ways that Basotho avert placing blame on loved ones is to focus on divine causes of illness, even as the biological ones are well known.

The majority of Basotho are affiliated with some branch of Christianity. According to Lesotho's 2004 Demographic Health Survey (Lesotho Ministry of Health and Social Welfare 2005), less than one percent of women, and only 5.6 percent of men did not associate with a Christian religion. Christian churches have a long history in southern Africa, and are appealing because of their healing powers (Klaitis 2010;

Comaroff 1985; Janzen 1992).⁷⁵ These healing-focused “churches of the spirit” have an appeal “based on bringing participants’ sentiments to bear on one another’s bodies in ways that enhance well-being” (Klaits 2010:8). Mokhotlong has Christian churches of all denominations and varying levels of permanency, including churches focused on healing. While some are housed in large permanent stone structures, others meet weekly in tents set up in a large field. The enticement of religious healing in Mokhotlong is strengthened by the devastation of HIV. People draw on their Christian faith to help explain the origins of their illness, yet they do not merely rely on prayer or faith-healing, but continue to seek biomedical treatments for certain illnesses, while using Sesotho medicine for others.

Many people, such as the elderly couple, the Ntho’s, represent this range of beliefs and responses. When I asked them where illness comes from, they both expressed uncertainty and awe. Ntate Kanelo said “It’s something which is there, but we don’t know why, because...” and his wife interrupted, “We are so surprised, *kanete*. We don’t know why so many people are getting sick. Old and young people in the same way.” Then, Ntate Kanelo ventured a guess: “I don’t know if I’m correct to say we breathe it from the air.” ‘M’e Maliehi, who is an observant Catholic (*Roma*), wonders about the possible connections between illness and God, connecting it to her own theology: “*Ntate-Molimo?* (God the Father) [laugh] *Ach*, I don’t know. Maybe He is the one because everything is provided by Him.” Although the Ntho family rarely seeks treatment from Sesotho doctors, they claim it is because they are too expensive. They also frequently

⁷⁵ Christianity in Africa has been widely critiqued, specifically with regards to its impact on HIV through abstinence-only education, discouraging condom use, and AIDS denialism (Campbell et al. 2011; Ruth Prince 2009; Parsitau 2009). This critique is outside the scope of this project. Here, I am merely focusing on the comfort that religion provided to many of the caregivers with whom I worked.

make medicines out of roots and leaves in order to cure common illnesses such as a cough or the common cold (*sefuba*).

In the face of a devastating illness such as HIV, many of the caregivers I spoke with turned to God to explain the inexplicable. When asked about the cause of her granddaughter's albinism, one woman claimed there was no explanation: "No one knows how one becomes albino...I don't know, it is God who makes that." Despite discouragement from their Christian religious leaders, many Basotho maintain beliefs in certain aspects of "Sesotho culture" such as witchcraft. For the most part, the churches ignore this kind of ideological indiscretion, though in some cases, certain behaviors are punished. For example, if a young person chooses to participate in the three-month-long initiation school that is a rite of passage into adulthood, they may have to do community service hours for their church as punishment. These mild repercussions do not dissuade Basotho from following certain aspects of what they call "Sesotho culture", particularly when it comes to seeking treatment for illness. Basotho are comfortable with the inherent tensions in their syncretic beliefs, and may combine Sesotho and "English" medicines while simultaneously attributing an illness to God without a second thought. Even Ntate Leseko, another Sesotho doctor whose booth was set up across from 'M'e Malelang's, told me that he believed in God and thought He was instrumental in helping him with his work. However, his work as a Sesotho doctor did limit his ability to practice his Christian faith. When I asked him if he attended church, he replied, "No, now I don't. The problem is the church that I was attending doesn't go with the medicines. And I am meant to use the medicines. And I'm not able to go to church because of that. My children are attending that church. And their mother has passed away, and she was still

attending that church.” He viewed his profession as a calling, one which even faith in God could not alter.

For many Basotho, natural causality does not preclude divine causality. Thus, they are able to understand and explain illness by invoking God, even though they realize that the immediate cause might be something more earthly. In the following conversation with ‘M’e Masello, she insisted that God was the only cause of HIV and therefore the only cure, but at the end of the conversation, she acknowledged the importance of taking ARVs. When I asked her where sickness came from, she said, “It’s how God has provided it” and then went on to explain original sin by summarizing the story of Adam and Eve. Ausi Ntsoaki, my research assistant, tried to get to a more proximal cause by asking, “Are we infected by other people, or do we take it from the air, or we eat in from food, or witches, or spirits?” ‘M’e Masello (MP) refused to answer. Instead, she offered the following insight:

MP: Ha ha, God has provided illness. We will not find only the good things from Him. We should know that we are the visitors in the world...It’s only God. Not people. We can run to the doctors, but if God doesn’t want us to be cured, we won’t be cured. But, if God raises up His hand, we will be cured. Not because we are cured by the doctors but by Him.

EB: So, do you think God can cure HIV? Or does he provide the medicines? How does that work for AIDS?

MP: They are still doing them [ARVs], those who are doing them. And they are cured and they become fat. AIDS patients, they go there when they are not able to walk, being taken by wheelchairs. And, they are given only those pills, and a lot of food.

‘M’e Masello believes fully in God’s omnipotence. Yet, she is also aware of the transformative powers of ARVs, which she has witnessed working on her own grandson, Lebo. However, dwelling on the supernatural cause of illness in this situation is socially powerful, and does not negatively impact her grandson’s health or treatment in any way.

Basotho know much more about HIV/AIDS than they did a decade ago. In the context of the high AIDS death rate in Lesotho, and limited treatment options, an acceptance of the unknowable and de-emphasis on actual modes of transmission allows family members to ignore the implications of sexual- and mother-to-child-transmission. Near the beginning of my fieldwork, I am embarrassed to recall how I asked the caregivers of HIV-positive children if they knew how the child had become infected. My goal was to gain information about knowledge of HIV, and I was dismayed by what seemed like a lack of knowledge in this area. However, I later realized that giving voice to this answer would mean acknowledging the responsibility of a loved one in infecting another loved one with HIV. When I asked 'M'e Mamorena if she knew how Hopolang was infected, she quickly answered no. I asked if she had any guesses, and again she replied no. However, when I asked if she thought she got it from her mother, she said, "Yes, I think so, because I said the child was very young and she was in the stomach [of her mother]. How has she gotten this? I was asking [myself], has she gotten this from her mother? And other people who were coming to see her said she has gotten it from her mother. *Ach*, Hopolang...she was so sick." It became evident that, when pressed, people could talk in more detail about biomedical disease etiologies – they just preferred not to in certain circumstances. I soon realized that this line of questioning was forcing caregivers to voice knowledge that compromised both the memory of their deceased loved ones and their caregiving relationships [Klairs 2010].

Although Basotho generally understand how HIV is transmitted, dwelling on the modes of transmission would place blame on husbands for infecting wives, and mothers for infecting children. Yet, it is these husbands, wives, and mothers who will likely be

called on to care for – or be cared for by – these family members. A focus on the inevitable facts of transmission creates challenges for the caregiver and those receiving care by placing blame, and creating tension between family members. This tension would not alleviate the caregiver’s burden, but would merely add to their stress by challenging the legitimacy of the caregiving relationship.

By ultimately leaving life and death up to God, people avoid focusing on the implications of their actions on their partners and children. As ‘M’e Masekha said, “If He wants to take you, even if you have gone to the doctors, He will take you.” In the context of high AIDS death-rates and orphanhood, faith in God helps people to understand why even innocent and helpless infants become ill, and why loved ones could infect each other. ‘M’e Masenate said, “I think He has brought the illness in general, because I haven’t heard someone who has said they haven’t gotten sick.” In other words, illness impacts everyone, even innocent people; therefore, it must be God’s doing. A supernatural etiology of HIV also helps to explain why ARVs help some people on the brink of death while others perish, or why some mothers infect their children through breast milk, while others do not. In some cases, biomedical explanations do not have the capacity to elucidate differential patient outcomes and resiliencies, leaving many questions unanswered.

Reluctance to acknowledge biomedical facts of HIV transmission could feed ignorance about prevention by closing lines of communication. However, many Basotho have at least a basic understanding of the biomedical etiology of HIV, but it coexists comfortably with a supernatural understanding of illness. Basotho make choices about knowledge and action at different moments to balance their physical and social needs.

They rely on both biomedical and supernatural resources when they need to, and these malleable resources allow them to navigate both the medical and social worlds in which they move. In this way, Basotho use a variety of resources to navigate difficult situations, and can focus on the physical tasks of caregiving, without threatening their social relationships.

Symptom versus disease management

Concepts of illness, health and treatment are central to issues of care. The AIDS pandemic has amplified the need for kin-based caregivers, even as the number of healthy caregivers is in decline (Townsend and Dawes 2004; Heymann and Kidman 2009). Yet, as the work of caregivers increases, the threads that hold together networks of kin weakens through illness, death, divorce, and the increasing instability of marriage (Romero-Daza and Himmelgreen 1998; Modo 2001). Additionally, the increase in crisis fostering is putting strain on the resources of caregivers, and decreasing the quality of care (Heymann and Kidman 2009). Basotho protect care networks by drawing attention away from methods of disease transmission, and instead focus on supernatural causes of illness and on symptoms and symptom management.

Another binary negotiated by Basotho is between managing the outward symptoms of a disease and its underlying impact on the body. Like the emphasis placed on supernatural causes of disease (God), the emphasis on the surface effects of illness (symptoms), is a strategy that draws attention away from modes of contraction and blame, helps to maintain networks of kin, and protects the relationship between caregiver and care receiver. Basotho responses to HIV/AIDS focus on mediating the social and relational consequences of the illness in creative ways, while also addressing the physical

illness. It may, at first, seem as though Basotho only acknowledge the outward manifestations of illness, which could create significant challenges in the treatment of chronic illnesses that required lifelong treatments, such as HIV. Particularly in the absence of diagnoses, Basotho patients and caregivers tend to focus on locally salient symptoms of AIDS, as has been found elsewhere in Africa (Chimwaza and Watkins 2004; Liddell et al. 2005). However, if the focus on symptoms were to play out to its logical conclusion, we would expect to find poor rates of adherence to ARVs once a patient's viral load had recovered. However, studies have shown that adherence to ART is possible in an African context (Mills et al. 2006a; Nachega et al. 2004), and the focus on symptom management has not been found to be a significant factor in impacting adherence to treatment (Bhengu et al. 2011).

I spoke with caregivers who emphasized symptoms rather than underlying indicators of HIV such as CD4 counts, but who successfully adhered to treatment regimens well after they experienced a drastic improvement in their health or the health of the child in their care. Thus, the focus on symptoms and symptom management was not at the expense of the management of the underlying disease, but was a contextually selective strategy used by Basotho caregivers to balance both physical and social needs. On one hand, a symptom-centered approach is often the only feasible approach in this remote rural context. The observable and lived reality of illness, in a context where multiple diagnostic tests and careful explanation of the inner workings of illness are neither possible nor expected, necessitates reliance on the physical experience of illness. However, a symptom-centered approach also has the benefit of drawing attention away from the underlying illness, its causes, and its potential long-term outcomes. In the

context of HIV, this helps to remove blame, and focus on the caregiving relationship (Chimwaza and Watkins 2004). It is neither medically nor socially advantageous to focus on the underlying long-term implications of the disease, as long as the emphasis on the symptomatic embodiment of illness does not come at the expense of adherence to lifesaving treatment protocols. The focus on symptoms and symptom management helps to privilege kinship networks, and reinforce the important role of the caregiver.

Symptoms of disease intersect and overlap with both biological and social realities. This is evident in the way that certain symptoms recur frequently among Basotho when discussing their experiences with illness. Symptoms do not exist solely in the realm of the physical, but rather, they are socially constructed and mutable. For example, some common symptoms that recurred frequently were complaints of swollen body, swollen feet, chest pain, and foot pain in addition to more common symptoms such as cough and headache. One potential consequence of Basotho's focus on symptom management is a tendency to stop treatment once the symptom has disappeared, if the treatment is seen as no longer useful. For example, 'M'e Malefu, a Village Health Worker, who presumably knows the importance of taking medication, particularly for those with HIV and TB, chose to take her prescribed medication only for a limited time until she was able to get her symptoms under control (though she was not being treated for HIV or TB). She described her reluctance in taking medicines for long periods of time:

ML: Because I have taken them not happy, I take them for a short time then I stop taking them. I just take the medicine and it doesn't go where I want it to go.

EB: So, sometimes you don't finish them?

ML: I don't finish them. I just take them for two or three days. I stop them and the second day I go to the CHAL (Christian Health Association

of Lesotho) clinic.

Despite this reluctance, she still took the medication for a period of time and continues to go to the clinic, so she must see them as a valuable form of symptom management. She also distinguishes between different illnesses, as she later told me that a patient must not stop taking their medications for HIV or TB: “If they stop them I have seen them getting sicker. I have seen from the patients that I’m looking after. Especially TB patients. If they stop them, I have seen them getting very sick...No, they cannot stop them.”

Although some HIV and TB patients do default on their medication, most Basotho clearly see treatments for these illnesses as useful even after symptoms have ceased. The adherence sessions that all HIV-patients and caregivers are required to attend emphasize that ART is for life. Yet, structural barriers such as poverty, poor infrastructure, and distance create greater barriers for adherence to ART (Hardon et al. 2007; Ncama et al. 2008; Crane et al. 2006).

The focus on symptom reduction by patients is also reinforced by the treatment choices made by biomedical health care providers in Lesotho. Doctors and nurses are accustomed to testing for and diagnosing a number of high profile illnesses such as TB and HIV (as well as malaria, which does not exist in Lesotho). However, if the health care provider does not suspect one of these illnesses, it is not uncommon for them to treat the symptoms without inquiring into the cause of illness. In many cases, health care professionals are overworked and do not have time to make a proper diagnosis. For example, ‘M’e Mathabelang, an outreach worker, and I took 6-month-old Reitumetse to the private clinic because he had been vomiting. When we told the doctor about Reitumetse’s symptoms, he prescribed antibiotics, anti-diarrheal, oral rehydration

solution, and multi-vitamin – an array of medications to address all these various symptoms. He did not ask us any more questions about the child’s medical history or make any attempt to further diagnose the underlying medical condition. Given Reitumetse’s health, it is likely that his vomiting was caused by a viral infection and therefore did not need treatment with antibiotics. This interaction, which was viewed as a normal and effective response to Reitumetse’s symptoms by both the doctor and the ‘M’e Mathabelang, is indicative of a systemic emphasis on symptom management that needs to be addressed in the context of HIV treatment.⁷⁶

People living with HIV who are not experiencing any symptoms – either because their viral load remains low, or because they are managing their disease effectively with ART – avoid thinking and talking about the underlying implications and the long-term ramifications of their illness. A poignant example of this was a discussion I had with ‘M’e Nthabiseng Lelimo, MCS’s managing director, who has several HIV-infected members in her immediate family, including her adopted daughter, Lerato. ‘M’e Nthabiseng’s knowledge of HIV transmission, treatment, and prevention is extensive. She makes decisions for the health and care of the hundreds of babies served by MCS, is kept up-to-date on current research and care standards by visiting doctors, and is a certified HIV counselor and tester. She is also well aware that Lesotho has limited treatments available, and that the eventual need for second line ARVs is inevitable, even for those – like Lerato – who have near perfect adherence. Whenever I asked her how Lerato was doing, she always assured me that she was doing well. In trying to dig a little deeper, I asked her if she had any fears for Lerato’s future, and she told me, “No, I don’t

⁷⁶ The focus on symptoms will be explored further in chapter 5 regarding Basotho’s understanding of HIV’s impact on the body, and barriers to good adherence.

have fears about her future as long as by the time she decides to leave, she's old enough to take care of herself." I then asked her if Lerato's HIV status is a cause of concern. She replied: "I don't even think about it. It's normal. I see it as normal life. It's not anything to worry about, because I could die before Lerato does, so for her to have HIV it's not changing anything. It's a normal life. What happens happens..." Lerato is an astonishingly normal 8-year-old, given her rocky start in life. HIV has become normalized because of its prevalence. However, 'M'e Nthabiseng avoids discussing the potential long-term hardships that Lerato might face, and the likelihood that her life will be shortened by her disease, in the interest of protecting her current happiness and place in the Lelimo family. Yet, for the Lelimo's, and other caregivers, this avoidance does not come at the expense of the health of the children, but is a strategy that reinforces the importance of kinship and care. One of the primary indicators of the strategic choices caregivers are making in the interest of children's health is that, despite an emphasis on symptom management, there is a shift towards a biomedical approach when treating HIV.

Treatment seeking: Combining Sesotho and "English" medicine

Basotho negotiate illness in a range of ways, including pluralistic treatment seeking strategies. Approaches to health and illness by "English" and Sesotho doctors are drastically different, and are based on fundamentally different explanatory models and assumptions. However, these approaches are not at odds. Since biomedical treatments have become available and affordable, Africans have combined both biomedical and traditional healing practices in selective ways based on their efficacy and their compatibility within a local understanding of disease etiology (Janzen 1981; Cocks and Dold 2000; Kleinman 1980). As Janzen (1981) noted of the Kongo of Western

Zaire, traditional healers were quick to recognize where biomedical approaches were more effective than traditional medicines, and they adjusted their treatment practices accordingly. However, these same healers were also aware of the limitations of biomedical approaches, in particular their inability to address local causes and symptoms of illness such as witchcraft, pollution, anger, and vulnerability (Janzen 1981). Similarly, Langwick demonstrates how healers in Tanzania blur the boundaries between “science and nonscience” (2011:7). She puts the current treatment seeking behaviors of Tanzanian people and the practices of local healers in historical and political economic context by examining the ways “colonization, missionization, postcolonial state building, international development, and transnational capitalism have shaped the practices known as healing”(Langwick 2011:7). Following a similar approach, most Basotho combine self-made herbal remedies, traditional healing, and biomedicine when seeking treatment for a health problem. As with the seemingly contradictory explanations for illness, and the management of symptoms, they view the availability of seemingly contradictory treatment options as an opportunity to draw on multiple resources in different contexts. Basotho’s treatment-seeking decisions are based on the underlying desire to provide the best possible care for themselves and the children in their care.⁷⁷

In the context of AIDS, treatment decisions take on critical importance as more caregivers are required to make decisions for the children in their care. They are responsible for administering complex drug regimens and for treating the multiple opportunistic infections that are common among AIDS patients. Basotho do not make treatment decisions haphazardly. They are based on the perceived difference between

⁷⁷ This section examines the tensions between Sesotho and “English” treatments, and explores the underlying causes of treatment-seeking behaviors. In Chapter 5, I will look, in-depth, into treatment seeking choices specifically with regards to HIV/AIDS.

modern illnesses and Sesotho illnesses. The distinction between these two types of illnesses manifests itself symptomatically on the body. Sesotho illnesses are identified by clusters of specific symptoms. “English” illnesses, such as HIV and TB, are often more difficult to pinpoint symptomatically, and necessitate listening or looking inside the body – a skill only believed to be possessed by “English” doctors (*ngaka ea sekhooa*).

Fortunately, Basotho generally seek biomedical treatments when treating HIV; however, with this treatment comes problematic power relationships between healthcare providers and patients. There also seems to be a shift away from traditional healing to biomedical approaches, as non-Sesotho chronic illnesses such as HIV and TB become more prevalent. This shift away from Sesotho medicines for the treatment of these chronic illnesses is indicative of how Basotho strategically make treatment decisions based, ultimately, on the best interests of their health of the health the child in their care.

In Lesotho, doctors at the hospitals and clinics are called *ngaka ea Sekhooa*, which translates literally into “English doctors,” despite that few of them speak English as a first language. The majority of them are African (mostly from Zimbabwe, Kenya, and the Democratic Republic of the Congo). Outside of a medical context, non-Basotho Africans are called *makoerekoere*. However, all doctors at the hospitals are called *ngaka ea Sekhooa* regardless of ethnicity or language or origin. In this case, the word *sekhooa*, does not refer to the English language, but rather to a set of ideas about the pathology of illness and the body and treatments that are associated with the biomedical approach. In contrast, traditional healers in Lesotho are called *ngaka ea Sesotho* (literally, Sesotho doctors). In this case, the word Sesotho refers to cultural norms of which the Sesotho language is a part. As the following section illuminates, Basotho seek treatment from

both “English” and Sesotho doctors, but their treatment seeking behaviors point to clearly demarcated differences in the types of illnesses that necessitate different approaches to care. These differences are based on both symptom clusters and disease etiologies. Even as there is a shift in favor of biomedical treatments over Sesotho remedies, Basotho deemphasize biomedical knowledge. As I discovered, people are interested in receiving effective treatments, but are slow to acknowledge the underlying implications about the transmission and etiology of disease if it threatens their social relationships.

In general, I witnessed treatment seeking behavior that favored biomedical intervention, but strategically used Sesotho doctors and home remedies for certain types of ailments, mostly those that Basotho view as being distinctly Sesotho illnesses. In contrast, most Basotho seek treatment from the “English” doctors when treating illnesses perceived as modern, such as TB and HIV. Tensions do exist between the two approaches. Patients are often told specifically not to mix “English” and Sesotho medicines as there can be contraindications. However, patients are able to reconcile the approaches by viewing them as serving distinctly different functions. One young HIV-positive mother, ‘M’e Mahlompho (MR), used multiple treatment options to obtain a second opinion. I asked her which kind of doctor she went to when she was sick:

MR: If you are sick, because you will not know what you are suffering from, it is better if you can go to both doctors, so that they can see your illness. But, sometimes if you go to one doctor, it’s true that they will give you pills, and you will say you are ok. And when it comes back again, it comes worse than before.

EB: So, do you go to both kinds of doctors?

MR: Yes, I go to the two of them.

'M'e Mahlompho implies that the two different types of doctors might arrive at different diagnoses. Knowledge about both possible ailments allows her to make a more informed decision about her treatment options.

'M'e Marefiloe would go to the Sesotho doctor when she had pain in her body for *qobola* (sucking), a technique used by Sesotho doctors to remove impurities. Afterwards, she said she would go to the "English" doctor as well. She clearly saw the value of both approaches: "These doctors are important in general. Sekhooa doctors are important, and also, Sesotho doctors are also important for other things." Another young mother on ART, 'M'e Maphonolo, described her treatment seeking strategy, which also combined the expertise of both approaches:

EB: And for what kinds of things do you go to the ["English"] doctor? When do you think, ok I can't do this by myself or with Sesotho medicines?

MM: Like, sharp pain. And diarrhea and vomiting. And nowadays, there are now diseases that you can say you can sit down and you drink Sesotho medicines. It's true that you can drink them because you don't have money. But, they are diseases that when you have taken Sesotho medicines and when they get better, you should go to the doctor. Even if you are better 100%, but you should go to the doctor.

EB: Are there some things you go to see a Sesotho doctor for?

MM: Yes.

NL: What?

MM: Like when I have a toothache and eyes. Like now you see I'm able to see. And the next day I'm not able to see at all. Like the diseases that are brought by the witches, they are made by people.

EB: And how do you know it's something by the witches?

MM: I will be told by the doctor.

EB: Oh, but what makes you decide to go to the doctor?

MM: Ach, sometimes I might think that I was still living well yesterday, but today I have knee pain, and let me go to the Sesotho doctor first. I will go to the English doctor later.

Although many Sesotho and "English" doctors see each other's treatments as contradictory, 'M'e Maphonolo views them as a network of resources from which to

draw.

Other illnesses frequently treated by Sesotho doctors are considered "Sesotho illnesses" and do not have English translations. They are local illnesses characterized by distinct and culturally recognized clusters of symptoms. For example, *letsoejane* is a sickness common in children that is characterized by a fever, heavy breathing, fatigue, and sharp pain. *Nonyana* (which means bird) is found in babies and looks like a diaper rash, but can appear on the back of the head and body. Basotho attribute *nonyana* to mothers who did not drink *pitsa* (a medicine made out of the roots of the *qobo* plant) during childbirth. *Kokoana* is an illness that causes redness in the nose, mouth, and other openings in the body, and is thought to be caused by insects. A similar characterization of local illnesses is seen elsewhere, such as in Botswana where a "complex disease category" incorporates the symptoms of many common illness such as polio, meningitis and malnutrition (Klairs 2010). Basotho used to attribute the symptoms of AIDS to a local illness category called *mokaola*, until it became more widely diagnosable and treatable.⁷⁸ When Basotho present with symptoms of "Sesotho illnesses", they are more likely to seek a home remedy or help from a Sesotho doctor. 'M'e Malefu, who took her daughter to both types of doctors during her illness (which she says was not HIV), said the Sesotho doctor told her that the symptoms of abdomen pain, chest pain, and vomiting were "things for Basotho". Unfortunately, neither type of doctors was able to treat her daughter's illness, and she died undiagnosed.

However, a pluralistic approach to treatment is not universal. There appears to be a general move away from Sesotho medicine, particularly among younger Basotho. Some of the caregivers I spoke with never sought treatment from Sesotho doctors for

⁷⁸ I will discuss Basotho perceptions and use of *mokaola* more in Chapter 5.

themselves or the children in their care, while others were outwardly scornful. For example, 18-year-old 'M'e Masenate said, "I'm afraid of Sesotho doctors. I go to the Sekhooa doctors." Others, such as elderly 'M'e Masekha, were harsher in their opinions. She said she never visited Sesotho doctors because "Sesotho doctors are liars. And some of the things I don't believe. That's why I don't go to Sesotho doctors." 'M'e Maliapeng, a woman in her mid-40's, agreed: "Hae! The Sesotho doctors are lying. People are just paying them and they are always saying they are going to cure them, yet they are not." Significantly, 'M'e Maliapeng's health had recently markedly improved after starting ART, so her faith in a biomedical approach was strong. 'M'e Matsepiso, who saw her young son Tsepiso recover from near death after receiving TB and HIV treatment, explained that there is a shift toward the biomedical approach because the illnesses that are now killing Basotho are not Sesotho illnesses. She said, "I don't think there is a cure from the Sesotho doctors. There is only a cure from the Sekhooa doctors. It's better if you take them to the clinic. Sesotho is not helpful now." The unspoken implication here is that Sesotho medicine may have been useful in the past, but it has become irrelevant as more "modern" illnesses are affecting Basotho.

In tandem with a declining faith in Sesotho doctors, particularly for treating illnesses perceived as "modern," is an almost blind confidence in "English" doctors. I once visited an HIV-positive child whose caregiver had been giving her a new medication, but when I asked what it was, she did not know. It turned out that Bactrim, a prophylactic taken by most ART patients, had merely come in a different bottle, so she was in fact taking the same medication as before. However, her caregiver had not asked, and was giving the medication out of a deep faith in the veracity of the treatments

prescribed by the “English” doctor. Interactions between patients and health care providers at the clinics and hospitals often involved very little conversation, and patients rarely asked questions. Patients, who waited hours to see the doctor, were often not told their diagnosis. The doctor merely wrote their prescriptions in their health booklet (*bukana*), and then they silently joined another long line for the pharmacy. Despite these shortcomings, the majority of patients expressed great faith in the recommendations of the doctors. This combination of faith and deference was reinforced when ‘M’e Matau told me that people’s reaction to the complete recovery of her near-dead grandson was to say “We are afraid of *Makhooa* if this child is old. They are saying that, and they said they know big things. They didn’t think this child would survive.” The power of a “*Makhooa*” (in this case referring to the “English doctors”) to cure such a sick child so that he could grow “old” reinforces the perceived infallibility of “English” doctors and their treatments.

For patients like ‘M’e Masello and ‘M’e Mapoloko, this confidence in biomedicine and its practitioners emerged from past positive experiences with doctors and medications. ‘M’e Mapoloko, who took her grandson Joki every month for his ART appointment, had faith in the medical system, as she said, “Yes, *kanete*, they are working for me. From when I was suffering from TB.” When I asked ‘M’e Masello, whose chronic asthma had been correctly diagnosed and treated by several doctors, if they ever made a mistake, she responded:

They are always right. Let me tell you from the beginning, beginning, beginning. This thing that I’m suffering from [asthma], they said, every winter I should go to the place where it’s warm. This thing doesn’t like the cold at all. And I once went to the lowlands, and when I was there, ah ah, [the asthma] wasn’t there.

Even though she was presenting with symptoms of TB, her chest x-rays always came back negative, and she expressed approval at the “English” doctors' ability to make a correct diagnosis, even when she and others suspected that she was suffering from TB based on familiar symptoms.

Confidence also stemmed from the tools of the “English” doctors’ trade, which people perceived as being authoritative and infallible. Several people expressed a preference for “English” doctors because, unlike the Sesotho doctors, they listened to your body using a stethoscope. ‘M’e Malefu echoed the sentiments of others who use Sesotho medicines only for externally identifiable illnesses: “Every illness in the body needs the Sekhooa doctor because Basotho don’t know the illnesses of the body. And, Makhooa know because they put metal and listen.” The “English” doctors’ ability to understand illnesses whose symptoms were hidden or internal made them better suited to treat modern illnesses like HIV. Many patients, like ‘M’e Mapoloko, also saw the pen as an authoritative tool: “I think they are correct because they are writing them in the book.”

I was struck by the lack of communication between “English” doctors and their patients, and by how little this seemed to bother the patients. ‘M’e Mamorena expressed a desire for the doctors to explain what they found, but did not seem to be overly disturbed by their silence:

EB: And did the doctors explain to you what they were giving you or what was wrong with you?

MN: Mm mm, he doesn't tell, the doctor.

EB: Do you think the doctor should explain to you what’s going on?

MN: Yes, I wanted to know but he did not tell me.

EB: Why didn’t you ask?

MN: I asked but he ignored me. I was asking him why don’t you tell me what is going wrong with my stomach. And he was laughing at me.

EB: So were you angry with the doctor?

MN: Ah ah, I wasn’t angry. We were laughing.

EB: Why not?

MN: It's because I have seen that the Sekhooa doctor does not explain. And they will not tell you like Sesotho doctors.

EB: So you think Sekhooa doctors aren't supposed to tell you what's going on? Or they don't have time? Or what?

MN: They don't tell people. I have seen that. They just cure people.

EB: Are you ever worried that they don't know what's wrong with you? Or they make mistakes?

MN: I was seeing that they are doing their work and they don't want to tell other people.

EB: Do you think Sekhooa doctors can make mistakes or be wrong?

MN: Ah ah. They can't be wrong.

EB: So, they always know what to do?

MN: Yes.

EB: When you go to the hospital or the doctor, do you like to go?

MN: Yes, a lot.

EB: What do you like about it?

MN: I want them to listen to me, to use the metal [stethoscope]. Even if they won't tell me, but I want them to put it there [pointing to chest]. To listen that here's like this, here's like this. Even if they don't tell me.

'M'e Mamorena felt relieved that someone was listening to her body, even if they did not communicate their findings to her.

Many patients also noted being rushed while receiving medical care at the hospitals and clinics. 'M'e Maliapeng told me that she had not yet encountered anyone who communicated well with her while at the doctor. I asked her if she had ever inquired about it and she said, "*Kanete*, I haven't asked them because sometimes after you tell them your problem they just say you should leave quickly. After they have written all the things that you need, they say go out go go go." Although she seemed slightly more annoyed than 'M'e Mamorena, she said it did not alter her treatment seeking behaviors because the doctors listened to your problem and could "solve it." Eighteen-year-old 'M'e Masenate also believed that Sekhooa doctors never made mistakes – in fact, she claimed that if there was an error, it was likely the fault of the pharmacist who provided the wrong medications. However, unlike 'M'e Maliapeng, she did not think the doctors

even listened to patients. I asked her why she did not ask the doctor more questions, and she described the following rushed scene:

They are always in a hurry. The doctor will be touching you, and saying, "What are you suffering from? Where is it painful?" while he is writing. And then he will ring the bell for the other patient to come in. [laugh] Fast. They will say, go out, 'M'e, go out. And the other patient will be coming in. And you are supposed to go out.

'M'e Malefu, a village health worker and caregiver for two orphans, had a similar experience as 'M'e Maliapeng, but, in a rare expression of dissatisfaction, she was not as forgiving of the poor treatment she received at the hospital:

EB: Do you think they should be telling you more without you having to ask the questions?
ML: Yes, because I am expecting them to tell because I have gone there to tell me what is going on so that I can care for myself.
EB: So, is that the only problem? Or are there other problems when you go?
ML: That's the only problem.
EB: Do you think the doctors ever make mistakes?
ML: Yes, they make mistakes.
EB: Have you had them make mistakes with you?
ML: Yes, when I enter the door, before I explain, you will see them writing in the book, writing in the book, and when I explain to tell them that I have problems here and here, they will say, 'Yes, I have already written that,' and I'm always complaining that they have not worked for me.
EB: So you think the doctor is just guessing about what you have without actually asking you?
ML: Yes, I just think when looking at people's faces they just guess. They just think this person is suffering from this and this and this.
EB: So, sometimes they get it right and sometimes they write the wrong thing down?
ML: Yes, I just think they write the wrong things because I have not explained what I'm suffering from.

'M'e Malefu is the same woman who said she did not always finish her medications. Perhaps her faith in the authority of biomedicine has been weakened by her increased exposure to biomedical practices and information through her experiences as a village

health worker. However, she also mentioned that information could help her to better care for herself – a role to which she is accustomed because of her village health worker post. Those without the benefit of knowledge and training may not see any advantage to increased knowledge. Although they are aware of these pitfalls of the current medical system, they are not bothered by them.

Many of these patterns of doctor patient-interactions are the result of overworked health professionals and limited diagnostic tools and medical supplies. These structural impediments to optimal health care make Basotho's acceptance of biomedical authority worrisome, as doctors are prone to errors and misdiagnoses as a result of severe human resources shortages. While I lived in Mokhotlong, there was a steady and changing stream of doctors at the hospital, mostly foreign African (*Makoerekoere*) doctors from the Democratic Republic of the Congo and Zimbabwe, as well as some Cuban doctors. Lesotho does not have a medical school, but it does train nurses, though there are also many Kenyan nurses working in the country. Maintaining sufficient doctors at the hospital was a challenge. At one point, shortly after I left Lesotho in 2009, several Cuban doctors completed their contracts, two doctors, including the District Medical Officer, left to take positions elsewhere in the country, and two others left to take better paying positions in Botswana, leaving only one Congolese doctor – Dr. Mike – at the hospital. Dr. Mike was the sole doctor on call 24 hours a day servicing a district with a population of 130,000 people.⁷⁹ Even though the country-wide ratio of doctors to patients is 1.15:1000, this ratio is much worse, and far more variable, in the rural mountainous districts. I witnessed a number of failings on the part of medical staff during my time in Lesotho, some of which directly resulted in loss of life. However, these errors need to be

⁷⁹ A few other doctors in the district worked at the private clinics.

contextualized in the face of extreme personnel shortages and other issues of structural violence. I will address some of these tensions more in Chapter 7.

HIV necessitates biomedical intervention. Therefore, from a public health perspective, it is important that Basotho continue to undergo HIV testing, and adhere to antiretroviral treatments. I spent much time at the Lerato Center, where HIV-positive patients are treated at the Mokhotlong Hospital. Despite ongoing stigma surrounding HIV, I was impressed by people's willingness to sit and wait in the open, thereby acknowledging their HIV status or the status of the child in their care. As one caregiver told me, "Ah ah, *kanete* [I swear], I wasn't afraid. To that door, I went straight to it!" Many Basotho noted that, even though they were likely to run into someone they knew, all the other patients are also positive, so there is reduced fear of being stigmatized. Their willingness to seek treatment at Lerato is not only a sign of stigma reduction – it also points to Basotho's strategic use of treatment options to manage care. Caregivers have learned that they can provide better care for an HIV-positive child by denying knowledge about disease transmission while adhering to a biomedical treatment regimen. At the Lerato Center, the potential for social stigmatization was secondary to the importance of receiving ART.

However, Basotho seeking biomedical treatment for HIV do not do so to the exclusion of traditional approaches. Several South African studies have noted the selective and continued use of traditional medicines among HIV-patients, including those on ART (Peltzer et al. 2008; Babb et al. 2007). However, as Peltzer et al. (2010) found, after six months of taking ARVs, there was a sharp decline in the use of traditional medicines by South African patients. It is important to note that choices are constrained,

and the use of traditional medicines for certain ailments is sometimes the product of a lack of availability and affordability of biomedical therapies (Romero-Daza 2002). For example, Farmer (2004) notes that Haitians' explanations of the cause of TB shifted from witchcraft to airborne infection once treatments became widely available, indicating that in the absence of effective treatments, Haitians sought other explanations for the cause of the disease.

Lock and Kaufert draw attention to the "taken-for-granted knowledge" in biomedicine (1998:6). In Mokhotlong, silent acceptance of this biomedical knowledge gives power to the medical authorities over the bodies of Basotho in problematic ways. Lock and Kaufert argue, "The claims of medical knowledge to a privileged status depend on the belief, shared by medical professionals and the public alike, that scientific knowledge, being factual, cannot be subjected to epistemological scrutiny" (Lock and Kaufert 1998:6). In a community with low rates of education and literacy, this shared acceptance of authority is pronounced, and represents a more problematic imbalance of power. Health care providers and policy makers need to be particularly careful of the power dynamics and the ways in which they play out in marginalized communities. To successfully treat HIV, a biomedical response is essential. However, as Lock (2001) has warned, it is precisely this need for medicalization that increases the likelihood that imbalances of power and political coercion will be obfuscated in the interest of stopping the progress of illness. As Lock (1993) points out elsewhere, biomedical practices are also places for agency and defiance. Although Basotho may not exercise this agency in their interactions with medical authority, they may do so in the privacy of their homes, as they make choices about their own treatment and care. For example, 'M'e Malefu visited

the hospitals and clinics, and did not openly challenge the doctors. Yet, in the privacy of her home, she chose how and when to administer her medication.

Despite a trend away from indigenous healers, the continued use of Sesotho doctors among Basotho indicates the importance of this approach, and the inadequacy of biomedical approaches for responding to all of people's physical, emotional, cultural and spiritual needs. Instead of being binary opposites, many Basotho take a pluralistic approach to treatment. This allows them to selectively choose from a range of choices in order to expand and improve their health outcomes and protect their networks of care.

Conclusion: Contradictions or adaptations?

When confronted with illness, Basotho are faced with a series of seemingly contradictory, and often incompatible, binaries. Yet, they have demonstrated a tendency to strategically employ various explanations for illness and treatment-seeking behaviors based on complex motivational and temporal factors. There is a tendency to draw from multiple resources and explanatory models in ways that emphasize the importance of kin relationships and care. Basotho emphasize supernatural causality, which helps to remove blame regarding modes of transmission and stigma that could potentially threaten networks of care and the memory of loved ones. Yet, they demonstrate at least limited knowledge about the biomedical causes of illness when it is necessary for access to therapeutic resources. Likewise, although Basotho focus on the outward symptoms of illness, and tend to manage illness by focusing on symptom resolution, they continue to take medications when they view it as beneficial to their health – such as when treating HIV and TB. Finally, they employ pluralistic treatment strategies, drawing on both biomedical and non-biomedical approaches, and they select from among these based on

their assessment of the type of treatment that would best respond to their needs at that moment. The negotiation of these binaries, then, should be viewed as strategies that expand the resources of a people with many structural disadvantages in ways that address both the social and physical needs of children and adults.

Basotho's fundamental understanding of illness guides their treatment seeking behaviors. Typically, Basotho treat symptoms that are clustered to form Sesotho illnesses by seeking care from Sesotho doctors. In contrast, illnesses that are viewed as being "modern," foreign, or internal are treated with "English" medicine, located in the hospitals and clinics. However, increased biomedicalization is necessitated by sharp increases in HIV/AIDS and TB rates, so Basotho have become more familiar and comfortable with a biomedical approach. Many people continue to seek services from both kinds of doctors, but for different types of illnesses. However, there also seems to be a tendency, particularly for young Basotho, and for those dependent on biomedical treatments such as ARVs, to turn away from Sesotho medicine altogether. This may be linked to free and widely available treatments for HIV-positive patients in Lesotho, including any costs associated with opportunistic infections. In contrast, Sesotho doctors' fees and medicines may have become prohibitive for some patients whose resources are already being stretched. Even though Basotho are no longer seeking the treatment of Sesotho doctors as frequently, a continued reliance on symptoms management poses problems for the treatment of HIV, which often does not present itself symptomatically until a patient's viral load is already very low.

The power dynamic that has emerged between health care workers and patients is one of unquestioned authority, especially at the time of the doctor's visit. The use of

biomedical treatments for HIV/AIDS is a key component to stopping the further spread of the pandemic. Antiretroviral treatment reduces a patient's viral load, which in turn, reduces the likelihood of transmission to sexual partners or from mother to child. However, the uncontested interactions between health care providers and patients creates challenges for patients and caregivers as they struggle to understand the fundamental nature of the illness and treatment, and therefore are often unable to respond accordingly when challenges of poverty, geography, or political economy arise. Even as Basotho turn towards biomedical solutions, they turn away from biomedical knowledge that might threaten their social relationships and their networks of care. In an effort to disseminate biomedical knowledge to patients – of HIV or any other disease – there is a need to recognize this tension, and to present biomedical knowledge in a way that enhances care without challenging the role of the caregiver. Ultimately, the unquestioned acceptance of biomedical knowledge is problematic because it does impair the ability for caregivers to make decisions for children and for themselves. As the following chapter will illuminate, the fundamental issues related to illness and treatment presented here shape the ways Basotho view HIV prevention, testing, and treatment. Ultimately, an examination of Basotho's ideas and responses to HIV/AIDS helps to firmly establish HIV as a kinship disease and to turn the analytical lens back on the importance of care and the role of the caregiver.

CHAPTER FIVE

INFECTED KIN: AN ECOLOGICAL APPROACH TO BASOTHO'S PERCEPTIONS, KNOWLEDGE, BELIEFS, AND RESPONSES

Lebo's story

In the summer of 2007 my husband, Will became immediately enamored with Lebo, then a chunky, energetic toddler of 18 months who was living in MCS's Safe Home. He was overly enthusiastic and energetic, and we had to keep a close eye on him because he would "play" too roughly with the other babies, and sometimes end up bowling them over. He was very vocal, and loved to be tossed into the air, tickled, and jostled. We all loved Lebo, probably in part because he was so robust, and reminded us of what we expected babies to be like.

However, Lebo had not always been this sturdy. When he arrived at the MCS Safe Home, barely a year old and weighing a mere 12 pounds, he and his six older siblings had been living with his grandmother, 'M'e Masello, for two months, since the death of their mother. He had just spent two weeks at the hospital and was being treated for TB. His first few months at MCS were rough. He had a chronic cough, diarrhea, and a very poor appetite. He was so reluctant to eat that he remained on a nasogastric tube for six weeks. He tested positive for HIV in early January of 2006 and started on ARVs a few days later. Finally, after a few months of treatment, he started to turn a corner.

By the time we arrived in Mokhotlong in June of 2007, he was the happy, bubbly, if slightly aggressive child I described above. A few months after we left that summer, 'M'e Nthabiseng emailed to tell us the good news that Lebo had been tested again for HIV and it was negative. They had checked and double-checked, and consulted with a visiting pediatrician from the United States. Finally, they decided to stop his treatment. The doctors guessed that perhaps his original positive result had been an error, or maybe his blood got mixed up in the lab. Either way, we were all delighted. For the first time in his young, but eventful, life Lebo's long-term future looked bright.

When I returned to Mokhotlong in 2008, I decided to go and visit Lebo, though he was no longer a MCS client. We entered the uncharacteristically dark and cramped rondavel where he was lying on a bed with his grandmother. There were two rondavels next to each other, but the second one had collapsed because of weather and poor upkeep, so the seven children and their grandmother were all sleeping in the one small rondavel, along with all their belongings which had to be moved from the collapsed home. Lebo seemed well enough, but he was despondent and had a cough that his grandmother said would not go away. He did not look malnourished, but had lost the extra weight that he had put on the previous year while at MCS – a fact I attributed to the activity level of toddlers. 'M'e Masello was herself unwell, and had to pause while speaking in order to catch her breath. When we left that day, I promised to bring Will with me next time for a visit.

Before I was able to return for the visit, I ran into 'M'e Masello and Lebo at the hospital, waiting in a long line to see the doctor for Lebo's chronic cough and stomach problems. I asked them to stop by MCS after their appointment, as I knew that all the

staff would love to see Lebo. When ‘M’e Nthabiseng saw him she was visibly worried. She knew that even HIV-negative children could deteriorate in the village setting, particularly if they did not have a healthy caregiver. But, his specific symptoms were worrisome. He was not underfed, he was just not thriving. She decided, since he was there, to have him take an HIV rapid test, just to make sure they had not made a mistake over a year ago when he was taken off his medication. The news was not good. The test was positive.

This particular test result was terribly disheartening. MCS takes in the most vulnerable children, so I had come to expect HIV-positive tests among children who were failing to thrive. In fact, a positive HIV test for a chronically ill child is the first step to recovery. But, Lebo represented the one who was “cured”. Of course, we did not really think he had been cured of HIV, but his false positive had given us a glimpse of what it would feel like if there was a permanent cure for this disease. His return to illness reinforced the current impossibility of this, and seemed even more unfair.

After this visit, Lebo became a MCS outreach client again, and was reinitiated on ART, but this time with the added complication of possible resistance by defaulting on his medication more than a year earlier. In addition, his (now deceased) grandmother’s deteriorating health added to the already significant challenge of good adherence in this remote, rural context. Pediatric HIV-treatment requires different doses of three antiretroviral medications (based on the weight of the child) taken at the same time once or twice per day plus a daily prophylactic and possible treatments for a variety of other opportunistic infections such as TB or thrush. Even a child with a healthy caregiver who

lives close to the clinic and near the main road will encounter various barriers to good adherence.

Lebo's story also highlights the role that chance encounters play in the positive, or negative, outcomes of children and families in this environment. If I had not run into Lebo at the hospital that day, he may have gone undiagnosed for even longer, lessening the chance that treatment would be successful. Given that his CD4 count was 13 percent - a very low percentage for a child - he likely did not have much time to spare. But, then again, his resilience over the years has proven him to be strong.

Lebo responded well to the restarted ART treatment. His grandmother reported that within weeks he started feeling better, had more energy, and was playing and running around with the other children. Indeed, I witnessed this return to health, as I observed the re-emergence of the old rambunctious Lebo being yelled at for one mischievous deed or another by his grandmother and older sisters.

I asked 'M'e Masello if other people in the village knew about Lebo's HIV status. She told me, "It is the disease of my family. I don't spread him all over here. I haven't told anyone, except those ones who I go to them, they are the ones who saw him there [at the clinic]." But she claimed that her reluctance to discuss his health would be the same regardless of what illness he was suffering from. "Everyone is not spreading [news of] their kids' diseases...Even when it's not HIV, you don't always say that. They just see me and I say I'm taking him to the checkup. I haven't said he's suffering from anything." Her reluctance to discuss Lebo's status is evidence not only of ongoing stigma, but of a general sense of privacy Basotho have about their health. It also

reinforces the many realms – both physical and emotional – in which kin-based care intersects with HIV.

This chapter will explore these – and other – issues emerging from the intersection of HIV and the particular cultural and geographical setting of Mokhotlong. First, I will address how AIDS education is pervasive, yet inconsistent, resulting in significant gaps in knowledge among the Basotho people. I will then examine how these often multiple sources of information have been translated into Basotho's actual knowledge about the illness and its impact on the body, once again with a focus on symptom management. Although the widespread availability and visible success of antiretroviral treatment have increased the credibility of the biomedical response to HIV/AIDS, misinformation and misconceptions about the disease continue to impact Basotho's knowledge and their responses to prevention and treatment. I will also explore the generational gap in knowledge that exists between young people and the elderly, particularly elderly caregivers. Although grandmothers and grandfathers in Lesotho are not suffering from HIV with nearly the same frequency as their children and grandchildren, they are largely responsible for the care of HIV-infected orphans (especially grandmothers); therefore, reducing the HIV knowledge gap among the elderly is of great importance.

This chapter will then delve into Basotho's perceptions and reactions towards prevention, testing, and treatment efforts – the three primary areas of intervention for HIV/AIDS across southern Africa. I will explore the strengths and challenges associated with condom use and partner faithfulness, with a focus on gender. I will also describe the culturally specific challenges that exist for the prevention of mother-to-child transmission such as breastfeeding practices, and disclosure of HIV-status. I will then explore trends

in HIV testing. My empirical evidence suggests that Basotho are testing in increasing numbers, but that barriers of gender, access, poverty, and culture persist, resulting in ongoing challenges for HIV-testing. Like testing, treatment has gained traction in recent years as many people have witnessed its transformative power. Yet, structural inequalities such as poverty and malnutrition, the sheer complexity of treatment, and barriers stemming from individual behaviors, the environment, and the healthcare setting and providers, continue to create challenges for access to treatment and good adherence to drug regimens. Finally, I will explore how these findings point simultaneously to a decrease in AIDS-related stigma and to its persistence, despite significant gains. Ultimately, this close exploration of Basotho's encounters with HIV helps to illuminate how it is understood as a social disease that impacts kin relations, and provides the context necessary to understanding caregiver challenges.

As medical anthropologists have advocated, diseases are not solved merely with biomedical treatment. Rather, they are mediated by culture, history, economics, politics, and time. As Morris (1998) and others have argued, we need to approach illness from a biocultural perspective that recognizes the multiple influences that impact the course of an illness. That said, not all illnesses are equal. Although the primary focus of this dissertation is on orphan care and the relationships between kin, ultimately, the current crisis in caregiving has come about because of the scale and longevity of the AIDS pandemic, and the specific ways it has played out in communities. Local responses to AIDS interventions impact orphans and orphan care because adult behavior affects both the health of caregivers and the health of the children in their care. However, using an

ecological approach to HIV/AIDS in Lesotho reveals a more embedded and fundamental relationship relationship between HIV and care that has greater implications.

The empirical evidence presented in this dissertation has emphasized the importance of sociality, and demonstrated the many ways in which Basotho privilege kinship and caregiving relationships. I have presented a historicized and contextualized micro-level view of the everyday interactions and negotiations Basotho make with regards to social organization, demographic patterns of household configuration, and beliefs and choices regarding health. In this chapter, these social patterns come to bear on the specific interactions Basotho have with HIV/AIDS information, their beliefs, and their experiences with prevention and treatment initiatives. It is in the individual stories that explore these social patterns that the theoretical orientation of HIV as a kinship disease is fully realized. Although research has long acknowledged the impact of HIV on personal relationships and on demographic changes at the household level, this research takes a more holistic approach in order to examine the intersections between HIV and kinship. HIV must not just be viewed as a disease that exists in its own realm and attaches onto social life and alters it in some ways. The scale of the AIDS pandemic in southern Africa means that HIV is no longer something that merely interacts with local environments, but rather, it is a fundamental part of shaping those local cultures. Basotho – both consciously and subconsciously – consider the physical and social ramifications of their beliefs and choices regarding HIV treatment and care. Navigation of these considerations is deeply constrained by structural inequalities such as poverty and sub-optimal medical care. HIV does not merely impact different aspects of social and family life in a haphazard or linear way. Rather, a dialectic relationship exists between HIV and

kinship whereby Basotho's beliefs and decision-making around HIV treatment and care are the result of constant feedback and interaction between the structural, biomedical and cultural implications of the disease at every level.

The findings presented in this chapter are at once hopeful and discouraging; they create both clarity and confusion. Health and social responses to HIV are improving, as is knowledge and access. Yet, HIV transmission rates continue to be extremely high. People are living longer with HIV, yet children are still dying undiagnosed. The stark juxtaposition of rural life and constantly changing medical regimens exemplifies the complexity and dynamic tension that requires close and careful attention. The contents of this chapter defy simple summary. If anything, the lesson to be learned here is just that: the various factors impacting children and families are numerous and complex. Yet understanding them can help to improve the responses that impact the health and well-being of Basotho.

Local perceptions of HIV/AIDS

The previous overview of Basotho's perceptions of illness in general, and their treatment seeking behaviors (see Chapter 4), was intended to put the following discussion about HIV/AIDS knowledge, beliefs, and responses into perspective. Information flow, opinions, and knowledge about HIV are highly variable across the population. This variation is stratified along lines of age, education, health, and eligibility for services. I will explore how information about HIV/AIDS flows, and the multiple sources of that information. I will then discuss how that information is translated into multiple – and sometimes contradictory – understandings of the physical impact HIV has on the body, as well as the different ways it is interpreted by various sub-groups within the population.

AIDS-related knowledge in Mokhotlong is pervasive, yet inconsistent, and methods of knowledge dissemination that could address the socially embedded nature of HIV are not being utilized to their fullest potential.

AIDS education, and knowledge about prevention and about the illness itself has been improving across Africa, but there still exist considerable gaps in knowledge that are stratified by wealth, education, and gender. In a study of nine African countries, Glick and Sahn found that, despite improvements, more than half of respondents were still unable to identify specific prevention behaviors (2007). Another South African study found that knowledge about disease etiology and modes of transmission were relatively high, but accurate knowledge about adherence and effectiveness of ART was still low (Nachega et al. 2005). Knowledge was lowest among rural Africans and women, and differences in knowledge were more pronounced with disparities in wealth and education (Glick and Sahn 2007). South African's with traditional beliefs about the cause of HIV had higher rates of misinformation about HIV/AIDS and were more likely to support social stigmatization about the disease (Kalichman and Simbayi 2004). As Mokhotlong is both rural, and poor, with low levels of education beyond primary school, it is likely that the responses of caregivers presented here correspond to the less informed population stratum in the region.

According to the 2009 Demographic and Health Survey (Lesotho Ministry of Health and Social Welfare 2010), all age groups within the population had high rates of knowledge about the existence of HIV/AIDS. However, this is hardly surprising given the pervasiveness of HIV across Lesotho. Moreover, this fact alone is not enough to positively impact prevention and treatment outcomes. In contrast to Glick and Sahn's

findings (2007), this survey showed that among adults (ages 15-49) women were more likely to have accurate knowledge about prevention. Both men and women showed improvement in knowledge compared to the demographic survey done in 2004. However, both men and women were less likely in the 2009 survey to agree to the statement that abstinence can reduce the risk of contracting HIV. Perhaps this reflects the fact that abstinence is both unrealistic and unreliable as a form of HIV prevention.

I observed inconsistent knowledge, which stems from the plurality of competing messages about HIV/AIDS, and the inconsistent pathways on which knowledge and education about the disease travels. There are multiple competing sources of information about HIV/AIDS that Basotho encounter on a daily basis. There are official sources such as government media campaigns, and unofficial sources such as informal discussions with neighbors. However, there are also ambiguous sources of information, such as a community run support groups, that blur the lines between official message and hearsay, biomedical knowledge and speculation. The result is a scattered and inconsistent flow of information that has created significant gaps in knowledge and confusion about the veracity of information about AIDS.

Media communication through radio, television, billboards, and posters is commonplace even in rural Mokhotlong. Although Basotho living in the outlying villages of Mokhotlong's camp town do not have electricity, and therefore do not have television, most people have occasional access to either their own, or a neighbor's battery powered radio. From these multiple sources, they are inundated with positive messages such as those from Lesotho's Know Your Status campaign, which encourages HIV testing. There are call-in shows where people discuss issues relating to HIV, and the

news often reports on issues relating to HIV treatment and care. News reports are not only positive. They also chronicle the failures of HIV programs and controversies regarding politicians and funding, such as the highly publicized failures of Mbeki's administration (Fassin 2007).

Reliable information about HIV also comes from patient interaction with various healthcare workers such as doctors, nurses, and Voluntary Counseling and Testing (VCT)⁸⁰ personnel, and through the mandatory adherence sessions that HIV-positive adults and caregivers of HIV-positive children are required to attend (although as we will later see with regards to ARV adherence, health care providers can also create barriers to treatment). Basotho also interact with social workers and employees of NGO's such as MCS, and often receive information about HIV in those contexts. However, information is abundant for those "therapeutic citizens" (Nguyen 2005) who are already connected to the network of providers by nature of their role as "ART patient" or "AIDS orphan" - labels they have likely accepted in order to claim eligibility for services. Those who fall outside of these categories are often excluded from these networks of resources, information, and support.

Most Basotho identify as Christian, therefore church activities and the sermons of pastors and church leaders are important and trusted sources of information about AIDS. African churches are poised to play a significant role as leaders in the response to HIV because of their pervasiveness (Hartwig et al. 2006; Campbell et al. 2011). Many African churches are only now emerging from their silence to respond to the HIV/AIDS crisis (Hartwig et al. 2006; Ruth Prince 2009). Churches can help by creating "supportive

⁸⁰ Voluntary Counselling and Testing counsellors are government trained employees that do pre- and post-test counselling, as well as perform and record the results of the HIV-tests. They are employed at every hospital and clinic.

social spaces”, challenging stigma, and supporting the care of people living with HIV and orphans (Campbell et al. 2011). However, churches also have the potential to foster HIV stigma through silence, moralizing messages, and by reinforcing gender ideologies that disempower women in their ability to negotiate for their own health (Hartwig et al. 2006; Campbell et al. 2011; Ruth Prince 2009; Parsitau 2009).

It is important – given the moral authority held by churches – that information is accurate and presented in a way that reduces stigma. ‘M’e Malefu, the village health worker and caregiver for two AIDS orphans, said she had heard her pastor speak many times about HIV. She said that pastors “talk in a positive way to solve this problem.” Her pastor focused on faithfulness: “They encourage Basotho not to be attracted to other people’s partners. Because, if it wasn’t there in your family and you go to another family, you will get it. And they encourage people to stay at their families, not to go to other people’s families.” Tsepiiso’s young mother agreed that they were spreading positive messages. She has heard them “encouraging people to know their status, if they realize that all people are dying.” Although none of the churchgoing Basotho I spoke with said they ever heard church leaders discuss HIV in a negative or overtly stigmatizing way, many of them said that it was not a frequent topic of conversation. Some said they never heard their pastor talk about it, while others said it was discussed in smaller groups, but not in the larger church services. In a conversation my research, Ausi Ntsoaki (NL), and I had with Matseli’s grandmother ‘M’e Maliehi (MN) and his grandfather Ntate Kanelo (KN) said they have heard the priest at their Catholic church discuss HIV; however, they praised him for not addressing it directly when children were present:

EB: And when you go to church, does the priest talk about HIV?

MN: Yes, nowadays, they talk about it.

NL: What do they say?
KN: They said you should respect it. Yes, because it is dangerous.
MN: And the priests are talking about it nowadays. Because they are encouraged to talk about it. Even at school or everywhere.
NL: So, *nkhono* what have you heard him say?
MN: Because there will be children in the church, he will not be talking directly.
KN: Indirectly.
MN: Yes.
EB: So, they don't like to talk in front of children?
KN: Yes, yes, 'M'e.
EB: Why?
MN: I don't know how Basotho are. They don't want their children to know.
EB: Do you think they should talk in front of the children?
KN: Ach, ah ah, they don't have that mind. Ach, I don't like it.
EB: But, then how will the children learn to protect themselves?
KN: When they are older.

Even the Ntho's, who cared for an HIV-positive child while living with three other children, would prefer that children were informed about HIV when they were older because their "minds" were not ready. A culture of silence surrounding issues of sexuality and illness create barriers for open communication about HIV, and thus create barriers for treatment, prevention, and the reduction of stigma.

Ntate (NM) and 'M'e Monatsi (MM), a young husband and wife team, are leaders of a local independent Christian church. They critically reflected on their past reluctance to openly discuss issues about HIV. Ntate Monatsi had recently returned from a training workshop with the Christian AIDS Bureau of Southern Africa (CABSA), where he had a transformative experience. Although they had both been tested, and were talking privately with individuals and families about HIV, Ntate Monatsi felt that they were only "waking up" now to the responsibility they had as a church to spread a Christian approach to HIV guided by principals of love, compassion, dignity, and hope. 'M'e Monatsi reflected, "You know, actually taking it into the church whereby the whole

congregation is there and talking about it seriously, it was our first time.” Both husband and wife felt that pastors were particularly well situated to impact the situation with HIV because they had “influence” and were “more trustworthy” than other community leaders such as chiefs. Ntate Monatsi eloquently described for me some of the problems with the way AIDS education had been done in the past:

We are working towards mobilizing the church, so they understand it. Mobilize. But, we haven't been doing it because we...we, actually didn't know we were ignoring it as well. Because, in fact, over and over and over, and people know if there is an HIV/AIDS workshop it's, ok, talk about sex a little bit, laugh a little bit, eat, and go home. Yeah. That's how it has been done. Also, there is one thing that, uh, coming from the training, that I realized there is, in the manual, there is a follow-up program. But, since the workshops have been run here nothing like that happened in order to strengthen the information that people have received. To, even also evaluate where they are at, you know? Nothing like that has happened. So, we would like to make a change...Because normally [the information] would come to us by, from people who are coming from the lowlands. And they will spend just a few days, and they are under pressure and they are leaving, and, you know, it's just like throwing a stone into the sea, you know?

The Monatsis' experience reinforces the literature that suggests that churches are late to address the issue of HIV/AIDS in their parishes. It also highlights the potential for both positive and negative contributions to AIDS education and stigma, and the need for prolonged engagement with the community.

AIDS education has not only been highly fractured, but reports of corruption, mishandled funds, and the spread of misinformation by community leaders and government officials has dominated the news, leading to mistrust, stigma, and fear. Church leaders recognize the need for improved AIDS education that is coordinated, comprehensive, and does not merely scratch the surface of the issues. Ntate Monatsi believes that if pastors and other community leaders were properly trained, they could be

instrumental in bringing this about. He noted, “If more church leaders could be trained - not just attend information workshops - but to be trained...we could be miles ahead by now.” However, church officials, like government officials, are individuals with their own beliefs, knowledge, and agendas. Their power over their parishioners is at once a potential resource, and a potential space for the spread of misinformation about HIV/AIDS. There is, therefore, a need for structured collaboration with church leaders to help spread positive and accurate information about HIV/AIDS in a way that is accessible to churchgoers. Community educators, like the Monatsi’s, possess local knowledge about the ways that HIV intersects with social and caregiving networks. They are thus positioned to educate local people in a way that does not threaten these important relationships.

Chiefs are also influential in shaping local responses to social crises because villagers who are under their domain still look to chiefs to resolve problems and establish social norms. The kingdom - and as a corollary to that, the chiefdom - still has considerable real and symbolic importance for Basotho. Chiefs are non-elected paid positions under the Ministry of Local Government and Chieftainship. They are divided into three tiers: principal chiefs responsible for an entire district, area chiefs responsible for ten or more villages, and village chiefs. They fulfill administrative responsibilities at the principal and area levels, and provide important social mediation and ceremonial officiating at the village level. Chiefs often referred clients to MCS, mediated discussions about caregiver rights between extended kin, and caregivers often sought the village chief's permission to send their children to the safe home. The continued importance of the chieftainship is a reflection of the strength of social networks, and

Basotho's embeddedness within kinship networks, clans, and villages. The structured nature of the chieftainship would be ideal for the proliferation of reliable AIDS education through a venue that is generally trusted by Basotho because it is a fundamental part of their social networks. Although one of the ministry's goals is "To contribute towards prevention, treatment and mitigating the impact of HIV and AIDS" (Lesotho Ministry of Local Government and Chieftainship 2012), the widespread impact of this effort was not evident in Mokhotlong. Although some of the caregivers I spoke with said they had attended a community meeting (or *pitso*) about HIV presented or organized by a chief, these efforts seemed to lack the necessary follow-up, consistency, and depth addressed earlier by Ntate Monatsi.

I spoke at length with Ntate Puseletso, a local village chief, about his role in the community, including his role as an AIDS educator. I met him through MCS because he was serving on the local board of the organization. However, from observing meetings with the local board at MCS, I did not get the impression that he or the other board members were particularly active in educating the community about HIV prevention or treatment. At one meeting, for example, the board members spent the majority of the time discussing whether or not they should get name tags made for the meetings, although they all knew each other well given their position as prominent leaders in a small community. When I asked Ntate Puseletso about his role in working towards improving the situation with HIV/AIDS in his villages, he knew the correct politicized language of development efforts, but was vague in terms of his actual accomplishments:

Oh, we do the normal things. Quite a lot really. Because we work hard for the welfare of our villages. That is inclusive of health issues, HIV etcetera. All those, we have to touch. Like, here, for instance, I have done quite a lot of things regarding HIV/AIDS in order to help my community. I did

trainings on...training of, um, teachers of HIV. I'm the trainer there. I've done a lot on counseling. I've also done a lot on communication for change. Change for communication. In fact, quite a lot of things, really, I've gone through. The establishment of a support group. That is what chiefs should put into account. So, those are the trainings that I've gone through and those are also the teachings that I'm training the community on.

Chiefs, like pastors, could be an important information resource as they have the cultural knowledge and perspective to sensitively address issues that impact kin and care.

However, both chiefs and pastors are powerful community leaders that have the potential to spread both positive and negative messages about HIV prevention and treatment.

In contrast to the informal AIDS education being provided by local cultural and religious institutions, formal AIDS education is now a regular part of school curricula. Education is positively correlated with HIV/AIDS knowledge (Glick and Sahn 2007). As primary education is now free in Lesotho, the majority of young people attend school until they are at least twelve or thirteen. At the local high school in Mokhotlong where my husband worked, students were required to take a Life Skills class, which included AIDS education – a program similar to a country-wide initiative in South African schools (Peltzer and Promtussananon 2003). Young people are the target of numerous AIDS education and prevention programs in Africa (Obasi et al. 2006; Campbell et al. 2005; Parsitau 2009; Esu-Williams et al. 2006). Yet, despite numerous interventions targeting African youth, rates of transmission remain high (Campbell et al. 2005). A simple scale-up of interventions targeting youth is insufficient – any response needs to be adjusted to address the localized, social implications of AIDS knowledge and associated behavioral changes.

Information about HIV is pervasive, yet it is inconsistent. Knowledge varies widely across the population, and the result is a patchwork of accurate and inaccurate

information, and significant gaps in knowledge based on various demographic characteristic, and also on chance encounters. MCS's managing director, Nthabiseng Lelimo (NL), outlined her perspective on information flows in rural communities and how multiple competing sources of information can cause confusion and impede behavior change:

NL: People who at least have gone to school, or have access to reading material on HIV, they kind of understand HIV, or even believe that there is...even though they don't change their behavior, they still believe there is HIV based on what information they get and see. But, people in the village who really don't have access to a lot of information, they depend on word of mouth, which can change from person to person. And also, HIV as it is, it's complicated because of the information and the way it changes from time to time...so I think people are kind of confused and that that leads to them thinking there's no HIV. You know. So, I think people in the village are confused. So, within that confusion, they still don't change anything. For them it's one of those sicknesses that maybe there's a cure, maybe there's no cure, that kind of thing. And, they still have their own cultural belief that the other related illnesses that people do get, for instance, like TB, they think it's the normal illnesses that can be cured.

EB: You don't think in the rural areas there have been any changes?

NL: Um, I think it's different from, the further you are from town, the more...you don't understand it and there's no change. But, the closer to town, it's kind of starting to see changes. But, it's...it's...the changes are really slow compared to the spread of HIV. But, there is change.

The significant knowledge gaps caused by inconsistent and contradictory flows of information create challenges for prevention, treatment, care, stigma reduction, and the reduction of HIV-transmission between adults and between mother and child. Culturally embedded institutions, such as churches and the chieftainship, are well poised to disseminate accurate information about HIV and possess the localized, cultural knowledge, to present that information in a way that recognizes the socially embedded nature of the disease. External sources of knowledge from international NGO's, or even government officials travelling from urban centers, cannot provide the long-term

engagement or localized knowledge necessary to help eradicate the inconsistencies that are pervasive in Mokhotlong.

Physical understandings of HIV/AIDS

The multiple sources that inform Basotho's AIDS knowledge, in conjunction with the tendency to focus on observable symptoms of illness, result in a fractured and fluctuating understanding of the physical implications of HIV/AIDS. Many of the caregivers and mothers I spoke with were either HIV-positive themselves, were caring for an HIV-positive child, or had cared for their sons and daughters during the late stages of their illness. Many of them had attended adherence sessions, and frequently visited clinics for check-ups and antiretroviral therapy. One would thus expect a fairly nuanced understanding of HIV's impact on the body, yet this was not the case. In their explanations of HIV, Basotho tended to combine their own experiences with what they had learned from the multiple competing sources of information about HIV/AIDS. This section is not intended reinforce ideas about rural Africans' ignorance regarding health issues. Rather, it is intended to highlight the ineffectiveness of AIDS education in providing people with clear and reliable information in a coordinated manner that reduces the confusion caused by multiple sources of contradictory information, as well as the inadequacy of existing sources of information in addressing the impact of HIV on networks of kin and care.

When asked to describe someone's illness, Basotho almost never name the illness, but instead focus on the symptoms the patient is experiencing – especially when discussing HIV. This reluctance is a reflection not only of a symptom-focused perspective of illness, but a strategy employed by Basotho in order to avoid threatening

networks of kin and care.⁸¹ Symptoms often mentioned for a patient with HIV included pain all over the body, pain in the chest and feet, swollen body and swollen stomach, diarrhea, vomiting, and wasting. The emphasis on symptoms helps Basotho to normalize HIV as something that is "like any other disease," – a phrase that was said to me on numerous occasions. Ntate Kanelo claims that HIV changes the color of the body, and can cause mouth sores, referring to oral thrush, a common opportunistic infection associated with HIV, particularly in breastfeeding children. Ntate Kalasi, an HIV-positive father of five, knew that HIV was sexually contracted and so extrapolated that it affected the male and female parts. 'M'e Maphonolo said she knew her aunt was HIV-positive based on her symptoms: "I have seen the symptoms that she was positive because I have heard that when people have diarrhea and it doesn't stop, even when people are getting sick and having a headache, and this goes together with diarrhea, they have that disease." In this statement, 'M'e Maphonolo reinforces the reliance on symptoms as well as the influence that word-of-mouth has on people's understandings of HIV.

The reliance on physical symptoms confused 77-year-old 'M'e Mamorena as to whether her daughter was actually suffering from HIV. She said "I didn't see anything when I was washing her. They said I should look at her hair. They said, when it's thin like that, she had that disease. I said, 'I don't know, when I looked at her body, I didn't see anything.'" Her inability to "see" anything made her doubt the existence of the illness. However, after her daughter passed away, she got herself tested just in case. The pervasiveness of HIV and the focus on multiple symptoms associated with HIV caused 77-year-old 'M'e Mapoloko to attribute all her problems to HIV, despite her age and the

⁸¹ See Chapter 4.

fact that her husband had been deceased for more than 20 years. When she was discussing her various ailments, from itchy armpits to a sore back, she said, "I think it is [HIV]. Because everyone can be suffering from it. If you are suffering from the nose or the ears, they are now itching, you are having HIV." When I told her most cases of HIV were sexually transmitted, she laughed and said, "I don't know if I have got it some years ago," implying, embarrassedly, that she had not been sexually active for some time.

Although the majority of caregivers focused on visible signs of HIV infection, a few mentioned its effect on the blood. HIV-infection causes "unclean" blood, and a few caregivers mentioned wearing gloves while caring for the sick so that if you have a cut your blood does not "meet" with someone else's. Ntate Kapo, one of the more knowledgeable caregivers I encountered, said HIV is "when the veins are not working properly" and it "stops people's blood, and the blood is not clean." When I asked him what happened once you contracted HIV, he surmised, "I think it sucks all the blood and that person will end up having no blood at all." Although blood was a substance occasionally discussed in relation to shared kinship, it was thought to be more figurative, and therefore, did not carry nearly as much weight as the implications of HIV transmission through shared milk.⁸²

Some caregivers did comprehend, in vague symptomatic terms, the basic relationship between HIV and AIDS. Those who had gone through the adherence sessions for ART patients and caregivers generally understood that AIDS was more severe than HIV, but were not able to explicitly connect AIDS with lowered CD4 count, or the inability for the immune system to fight illness in the body. 'M'e Maliehi expressed this vague understanding well when she said, "The most dangerous is AIDS.

⁸² See Chapter 3.

And HIV is when someone is infected. I don't know how to show the difference." Ntate Kalasi said he understood the difference between HIV and AIDS like this: "I heard that when you have HIV you have a small illness. But, when you have AIDS you have to take the big pills...You are still active, but you can be sick like other people, and still powerful [when you have HIV]." Ntate Kalasi is, himself, HIV-positive, but as of September 2009 he had not yet initiated ARVs. This understanding of HIV reflects his own view of his illness as "small" and himself as "powerful." Kotsi's grandfather, Ntate Kapo, generally understood the qualitative difference between HIV and AIDS but was incorrect in his belief that the drugs could cure HIV: "The difference of HIV is infection only. And AIDS is something else. I have heard that people who have AIDS don't survive, when it's AIDS. People who have HIV can be cured if they take the drugs. I just know in that way that it means like that." 'M'e Mapole tried to explain the difference, but was also mistaken in some of the details:

EB: What is the difference between HIV and AIDS?

ML: They say the difference is when that HIV...I don't know how, but, when it's high it's when people have HIV and AIDS. But, when they are patients who are not taking the drugs, there is a difference. But, when they are taking the drugs is when they are suffering from HIV and AIDS.

NL: What if they are not taking the drugs, they are the patients of what?

ML: When they are not taking the drugs, they are of HIV.

NL: What about when they are taking them?

ML: They are together.

The confusion among those like Ntate Kapo and 'M'e Mapole, who each attended three adherence sessions, indicates a need for clarification and reinforcement of key issues in order to deepen patients' and caregivers' comprehension. A deepened understanding could have an impact on the health of both adults and dependent children living with HIV/AIDS.

In my interviews with caregivers, if someone demonstrated an incorrect understanding of the biomedical facts regarding their health, I would ask them if they had any questions or if they would like clarification. I found myself on many occasions explaining the progression from HIV to AIDS, and the connection between CD4 count – a measure they were familiar with – and the body's inability to fight off infection. Caregivers often indicated a willingness and desire to learn, thus inadvertently indicating that other service providers were not adequately addressing their misconceptions or providing them with a venue where they felt comfortable asking questions.

For many Basotho, HIV was normalized by viewing it as an illness "like any other," even though most people understood that there was no cure. Nonetheless, many were still optimistic about the future. 'M'e Mamorena used the analogy of tying a rope to describe what the medication has done for her granddaughter Hopolang: "They have tied it. People [doctors] from the camp town, unless if she stops taking [the drugs]. From there, [the doctor] has tied it. I see that this thing was going to be increased if she was not given drugs. She was given drugs while she was still young. Now it's stable." I asked 'M'e Maliapeng, the HIV-positive caregiver for two young girls, what she learned at her adherence sessions. She replied: "Ah, I asked them whether after taking the pills the infection will go away. They said no. But, the virus will not have power to work on my body."

The visible and tangible success of ART gives people hope, even when they comprehend that there is no cure. 'M'e Mathabelang, one of the MCS outreach workers, told me she hoped doctors would find a cure in the near future. When Ntate Kalasi, HIV-positive father of five, asked me if I thought a cure was possible, I told him that I did

think so, and that many doctors were working on it. He responded, "But all people will be dead. They will all be gone." As a father of five young children, he and his co-infected wife have reason for concern about the future. Others optimistically viewed the change in those on medications as evidence that there was a cure. 'M'e Mapoloko witnessed such a dramatic change in her grandson, Joki that she told me there was a cure "if you are using the pills in a good way." Ntate Kapo also witnessed his grandson, Kotsi recover from near death after initiating ART. Like 'M'e Mamorena, he said the drugs "have stopped it" but also said he thought it was cured. Multiple conflicting sources of information were likely responsible for this confusion.

When Lebo's grandmother was informed (incorrectly) that his HIV-status was no longer positive, she was confused. She interpreted his changed status not as an error in the original diagnosis (or in the re-diagnosis, as was the actual case) but that his HIV had come and gone. I asked her if she understood why they had found him positive for the second time, she said, "Yes, I did, because firstly they told me that there was no cure for that disease. And I was so surprised when they said it has gone away. How has it gone away yet they say there is no cure for that because it's this disease?" Her confusion throughout this saga of multiple and conflicting diagnoses reinforced her tenuous understanding of how HIV impacts the body, and how treatment works to fight the virus.

In addition to misunderstandings about the impact of HIV on the body, many caregivers also held fundamental misconceptions about transmission, prevention, and the physical manifestations of HIV. These misconceptions stemmed from a combination of formal and informal information networks. Often, it was difficult for villagers, who access much of their information through informal chains of communication, to weigh

the veracity of varying sources. This multiplicity of sources leads to an understanding of HIV/AIDS that combines scientific and speculative sources of information. For example, there are still some, especially among the elderly, who question HIV's true identity, attributing it to distinctly Sesotho illnesses such as *kokoana* and *mokaola*, which have been around for decades. Yet, this belief does not necessarily prevent them from adhering to recommended treatments, as some of these same caregivers support the treatment of their HIV-positive grandchildren. As opposed to having Sesotho origins, one young HIV-positive widow and mother said she heard people in her community say that "AIDS is the disease made by *makhooa* [white people]," though she claims she did not personally believe this, and thought all Basotho should be tested. 'M'e Malefu, a village health worker, said, "Some are talking about the things that are not true. Like me, the first time when I heard about it, I thought maybe some black people have met some people with whom their blood did not go together. Their blood didn't go together. And I thought that this disease came from there." Although 'M'e Malefu claimed that she no longer believed in this concept, she seemed unsure.

In other cases, misinformation led to confusing ideas about transmission and prevention that could have had serious consequences for dependent children and the success of planned intervention strategies. For example, 24-year-old 'M'e Matsiu first told me a complicated story about HIV being caused by women having many abortions. She then added:

And they sleep with someone who has not been washed and later they will say, that person has *mahaе*. And when they go to the doctor, those *mahaе* [a type of vaginal discharge] go out from their female organs. And when they go to the doctor, and they get tested, they are found positive. And I just think those things are the ones making people to be positive.

In this case, she was referring to the ritual washing and shaving (*hlatsoa tsila*) that is done after a person cuts the band (*thapo*) that signifies the end of their period of mourning after the death of a close kin member. Rumors are also common that claim that HIV is caused by the buffer used in HIV testing, and that condoms have worms that cause HIV⁸³. In all of these examples, informal information networks led to varying, often contradictory misconceptions about HIV that could potentially impact the quality of decision-making by patients and caregivers.

Elderly people in Lesotho are often poorly informed about HIV/AIDS compared to younger members of the community. In part, this is because they are not targeted for prevention and testing efforts as they are predominantly beyond their sexual prime and are therefore less likely to contract the illness.⁸⁴ The cumulative and competing sources of information, the reinforcement of this knowledge by their peers, and the de-emphasis on targeted education for elderly Basotho, places this demographic group among those most likely to be misinformed about HIV/AIDS. Given that the elderly, particularly grandmothers, are primarily responsible for the care of orphans, community-based responses that help to reduce the gap in knowledge in order to improve caregiving practices for orphaned children living with HIV are needed.

The elderly view HIV/AIDS, somewhat correctly, as a young person's disease. For most young Basotho, HIV is a lived reality that has always been a part of their public

⁸³ I will examine the fears about condom use in my discussion of prevention methods below.

⁸⁴ Data on HIV-prevalence among the elderly is limited. UNAIDS, one of the primary sources of global AIDS statistics, only provides age-specific data for people under 50. Studies have shown that, in the last decade, HIV-rates for those between 50 and 60 years of age are still extremely high. According to data from 2004, Basotho men in their fifties had an HIV-prevalence rate of approximately 16%. However, in a South African study from 2008, the HIV-prevalence rate for men and women over 60 was 3.5% and 1.9% respectively, suggesting that the rate drops precipitously after the age of 60. However, the current generation of HIV-positive adults is aging with the general population, and living longer because of ARVs, so research on the needs of this population group is needed (Negin and Cumming 2010).

health consciousness. In contrast, elderly Basotho bring with them a history of interactions with health, illness, and public health responses that color and shape their understanding of this newest public health crisis. Matseli's grandfather, Ntate Kanelo, said many people were infected because of sex. His wife, 'M'e Maliehi, responded, "I don't know what causes that for young people. It is true that even old people have it, but not like young people." Because it is sexually transmitted, she assumed it excluded elderly. 'M'e Masekha, Thapo's grandmother, also equated sexual risk with younger people. She told me that young people should use condoms when having sex. When my research assistant, Ausi Ntsoaki, asked whether she should also use condoms, she replied, "No, 'M'e. I'm no longer doing that, since 2001." It is true that elderly Basotho are less likely to contract HIV, however, many grandmothers and grandfathers are still sexually active. They are also more reluctant to use condoms because, as 'M'e Mapoloko said, "We have not grown up using those things." The current population of HIV-positive adults is living longer because of ART, adding a new dimension to the management of the disease. New health problems are emerging as the challenges of HIV are amplified by chronic illnesses associated with old age (Negin et al. 2011; Negin and Cumming 2010). The near absence of HIV programs targeting elderly people in southern Africa ignores the real risks and challenges they face both as patients and caregivers.

One recurring theme in my discussions with elderly Basotho was denial or discomfort in talking about HIV. Although there were significant gaps and errors in elderly Basotho's knowledge about HIV, the appearance of knowing very little often masked discomfort with the subject, insecurity about the validity of their knowledge, and

a desire to disconnect the illness from their networks of kin and care.⁸⁵ When I first asked about HIV, many elderly caregivers would agree to discuss it, but warned me that they knew very little. 'M'e Mapoloko, the primary caregiver for HIV-positive Joki, told me, "There is nothing I know." Nkhabu's grandmother, 'M'e Marefiloe, also denied knowing anything. I told her just to answer as best she could and she replied, "I don't want to lie." However, over the course of our discussions, they both revealed a deeper knowledge than they had first admitted.

In the following conversation, 'M'e Matlotliso (MM), Kotsi's blind and elderly great-grandmother, humorously revealed her discomfort discussing HIV and her insecurity about the veracity of her HIV knowledge, while also revealing the pervasiveness of informal conversations about HIV in the community:

EB: Have you heard people talk about HIV and AIDS?

MM: *Ach*, no, 'M'e, because I haven't gone to the clinic. I have heard people saying AIDS, AIDS, AIDS, and I'm always asking them, what is it this AIDS? Where does it appear from on the person? I don't know it. *Kanete* [I swear]. I don't know it. [laughs]

EB: Did you know that it's a disease?

MM: Yes, I know that it's a disease, but I don't know it. And I'm always asking them, every day to tell me what it is. [laugh]

EB: From what you know, do you think it's a big problem in Lesotho?

MM: Yes, they say it makes Basotho suffer, when I hear them.

EB: Do you know how people get HIV?

MM: Ah ah, I don't know. That's why I'm saying I'm always asking them to tell me.

EB: Oh. Do you know anyone who has HIV?

MM: Ah ah. At all, I don't know. I don't know at all.

EB: When you hear people talking about it, does it seem like people want to keep it a secret, or do they talk about it openly?

MM: They just talk about it. Saying, this and this and this and this, but I don't hear what they are talking about. Mmm.

EB: And, do you think, from what you've heard, do people treat others with HIV differently?

MM: I said, I don't know, because I've just heard people, but they are not talking to me, saying, some have run away from the clinic, what and what and

⁸⁵ Chapter 4 discusses the denial of knowledge regarding illness more broadly.

what, maybe they have AIDS, and they run away when they are told to do something at the clinic. So, ah...

EB: Nkhono, do you want to know what HIV is?

MM: *Ach*, 'M'e, no.

It's unclear whether Me Matlotliso actually knew very little about HIV. Although her great-grandson was HIV-positive, he lived with his grandfather ('M'e Matlotliso's son) in an adjacent home. With her limited mobility and vision, she may, indeed, have not witnessed him taking his medication. However, she likely knew that he visited the clinic with his grandfather every month, or perhaps overheard his grandfather calling for him at seven in the morning and evening each day to take his medications. It seems unlikely that she actually knew as little as she claimed, but she clearly had no interest in discussing the matter with me.

Like 'M'e Matlotliso, other caregivers claimed ignorance at first, but over time revealed extensive knowledge and deeply-held opinions about HIV transmission, treatment, and prevention. When I told 'M'e Mamorena, great-grandmother and primary caregiver for HIV-positive Hopolang, that I wanted to ask her what she knew about HIV, she responded, "I won't answer. I don't know it. It's my first time to hear about it this year." 'M'e Mamorena did not attend adherence sessions for Hopolang because she was unable to reach the clinic due to severe arthritis in her knees and back. However, it would be nearly impossible for even the most remote villager to not know about HIV until 2008, as the rate of infection at that time had already plateaued at around 23 percent in Lesotho, and 'M'e Mamorena had been caring for her infected daughter prior to her death. She said she frequently heard people talking about "AIDS, AIDS, AIDS, I'm always asking what is this AIDS?" Yet, because it is associated with sex, people told her, "Ah *nkhono*, it's not a disease that you can know." This merely reaffirms the ebb and flow

of misinformation that circulates among the elderly. Nonetheless, she chose to get an HIV test after her daughter passed away because she had been caring for her with without gloves, indicating at least some knowledge and awareness about the disease.

Unlike her original assertion that she knew nothing about HIV/AIDS, ‘M’e Mamorena ultimately revealed a great deal of information and misinformation. She knew HIV was transmitted sexually, and that treatment is for life, but it is not a cure. She said that everyone should go for counseling and know their status. She had also heard that condoms (*khohlopo*, literally, gum boots) prevent HIV, but wanted to know if they harbored worms that caused HIV - a common misapprehension about condoms. She also discussed two Sesotho illnesses, and was unsure if they were synonymous with AIDS. The first, *mofetse*, she described as a disease suffered by women that causes soft bones. The second, *mokaola*, she described as causing sores on the chest and a black rash. At first she told me that people were wrong to say that *mokaola* was the same as AIDS, but later admitted that she was unsure. In contrast, 7-year-old Hopolang, with the help of her 10-year-old sister, were able to follow her complicated and ever-changing ART regimen, though sometimes Hopolang forgot in the mornings because she was excited to get to school. ‘M’e Mamorena proudly boasted about her granddaughter’s knowledge:

When it’s time for her to take the pills, she will be calling Ntate Khosoane.⁸⁶ If Ntate Khosoane can say its 7, she will come back to the house running, saying bring my pills, my pills. And sometimes she just takes them because she knows how to take them. And she knows that she’s supposed to take the full pill in the morning, and in the evening, she’s supposed to take the half. And she will be saying, “give me half, half, half, half”. She knows them exactly. Even her medicines, she will be asking for the teaspoon [of bactrim⁸⁷]. The problem is in the morning when in a hurry to go to school, she just runs to school.

⁸⁶ Ntate Khosoane is their neighbor who owns a working clock.

⁸⁷ Trimethoprim-sulfamethoxazole is the prophylactic (such as cotrimaxazole, or Bactrim) taken daily by ART patients in addition to ARVs in order to prevent opportunistic infections.

Even after telling me all of this, when I asked her what she thought *mokaola* was, she replied: "I think it's that HIV that I don't know." 'M'e Mamorena's denial is likely a coping mechanism that she employs to protect the close and loving relationship with her great-granddaughter, whom she also relies on for help.

Many elderly caregivers linked AIDS and *mokaola* as a way of connecting and making sense of their current experiences and knowledge with their past. *Mokaola* is a Sesotho illness that is sexually transmitted and was described to me as having a wide variety of symptoms including: genital sores, body rash (described alternatively as all over the body, small, and black), thinned hair, and genital discharge. Most of the caregivers that brought up *mokaola* acknowledged that it was sexually transmitted. Ntate Kapo said that a person who had *mokaola* was "bitten". When HIV first appeared in the community, many caregivers had heard that it was not a new disease at all, but rather, *mokaola*, which had been around for years. Although attributing a rise in HIV to a well-known local illness gives it continuity and makes it easier to comprehend, it also creates confusion. One of the dangers of conceptualizing HIV as an extension or expansion of *mokaola* is that it causes AIDS denialism. Ntate Kapo, who is one of the more knowledgeable elderly caregivers, said when HIV first appeared, he heard other people saying, "There is no such thing here. They were saying that. Saying mmm mmm. This is not HIV. They were saying it's *mokaola*. They say it's the disease that we know – same as in the past." 'M'e Marefiloe told me that many people now understand that what people are suffering from is, in fact, HIV, not *mokaola*. I asked her what she thought, and she said, "I don't know." She found it easier to comprehend when it was an illness that resonated with her experience; she said, "Now that it has an English name I don't

know anything about it."

The isolation of elderly Basotho from knowledge and support networks is of grave concern because of their primary role as caregivers. Elderly Basotho, particularly grandmothers, bear the brunt of caregiving responsibilities associated with the AIDS crisis. They perform essential, life-saving tasks such as administering complicated drug regimens, and taking dependent adults and children to the clinic or hospital when needed. Elderly people in Lesotho are also respected as important leaders in their communities, both informally, and in official capacities such as religious leaders and chiefs. Thus, elderly Basotho could act as an established and trustworthy source of guidance for the rest of the community. Educating elderly Basotho could be an important step in improving care for AIDS patients and strengthen AIDS education for younger generations of Basotho.

HIV/AIDS interventions and everyday practice

The following section will explore the everyday experiences of Basotho as they interact with the many prevention, testing and treatment services for HIV. In particular, I focus on those areas of prevention, testing, and treatment that most directly implicate networks of kin and care. These experiences reinforce the socially embedded nature of HIV/AIDS, and shed light on the biocultural landscape within which caregivers negotiate new household configurations and patterns of orphan care.

Prevention

Basotho regularly encounter educational and biomedical interventions designed to prevent the spread of HIV between sexual partners and between mother and child. Not surprisingly, local responses to prevention efforts have been mixed, as evidenced by the

continued high rates of new infections in the region (Kelly et al. 2006). Ethnographic evidence about the implementation of the popular ABC model of prevention (abstinence, be faithful, "condomize") indicates that interventions targeting behavior change have been the least effective in addressing the challenges of HIV prevention because they fail to address the biocultural aspects of HIV (Parker 2001).

There are three areas where prevention efforts intersect most directly with kinship networks: condom use, partner infidelity, and the prevention of mother-to-child transmission (PMTCT). All three of these prevention areas threaten the most basic social relationships because they not only implicate the nature and strength of these relationships, but the fundamental definition of what it means to be a wife, a husband, a mother and a caregiver. Each of these prevention areas also sheds light on culturally constructed notions of gender and sexuality, and the ways in which married women, in particular, have limited ability to protect themselves from contracting HIV. This section will explore each of these areas of prevention insofar as they shed light on the explicit and implicit tensions that exist between sociality and health.

Condom use has been the widespread focus of prevention efforts across Africa for the simple reason that condoms are inexpensive, easy to distribute, and easy to use. However, interventions that ignored the cultural implications of condom use for both men and women have largely failed (Campbell et al. 2005; Booth 2004; Jemmott et al. 2007). My own empirical evidence on Basotho attitudes about condoms confirms that, on their own, they are currently not a reliable prevention method for Basotho. Condom use threatens the strength of marriage by implying infidelity and denies the possibility of conception in a culture where parenthood remains an important rite of passage and

children are highly valued household members. The continued spread of misinformation about condoms and an emphasis on men's dislike for condoms masks the social implications of condom use on marriage, parenthood, and gendered power imbalances.

The Sesotho word for condom is *khohlopo*, literally meaning gumboot⁸⁸. Basotho also regularly refer to condoms in English, but more often use the abbreviation "CD" as a way of avoiding using the actual word⁸⁹. Inconsistent condom use is not an issue of availability, even in rural Mokhotlong. Male condoms are widely distributed in Lesotho. They are free and available at clinics, hospitals, government offices and even on a small table inside the bank in Mokhotlong. They are also for sale at local shops and grocery stores. Female condoms are not nearly as ubiquitous, but are occasionally available at clinics and hospitals. At a village health worker training session that I attended, every attendee received a box of condoms to hand out in their community. I once saw the driver of a government truck hand boxes of condoms out of the window to workers who were temporarily employed to fix a section of flooded road. One of the challenges of measuring condom usage, however, is that the only indication of use is through personal reporting. As 'M'e Nthabiseng says, "I think health issues are always complicated and not easy to measure. Because, for instance, if you want people to protect themselves, and you give them condoms, you are never going to see if they use them. All they will do, they will tell you [that they are using them]." Also, people may report condom use, and even though they are using condoms some of the time, they may not be using them every time. Lesotho's 2009 Demographic Health Survey (2010) found that only 65 percent of

⁸⁸ Gumboots are tall rubber boots worn by many Basotho, particularly shepherds. The use of *khohlopo* to refer to condoms is likely borrowed from the British term "rubbers" which refers to both boots and condoms.

⁸⁹ Further in this chapter, I will discuss the ways in which Basotho talk about HIV in order to avoid actually using the words HIV and AIDS as evidence of the stigma and discomfort that still surrounds the disease.

men and women reported condom use with a non-cohabitating partner. In contrast, only 24 percent of women, and 32 percent of men reported condom use with a spouse or cohabitating partner. As expected, condom usage for married women was very low, and education and urban residence were both positively correlated with condom use (Lesotho Ministry of Health and Social Welfare 2010). A more accurate measure of the likelihood of consistent condom usage is reflected in Basotho's attitudes about condoms, which range from positive acceptance toward their preventive usefulness to suspicion and dislike. Basotho's mixed feelings about condoms and condom use point to its inconsistency and unreliability as an HIV-prevention method.

The majority of Basotho, both young and old, at least comprehend that condoms are intended to prevent HIV infection, though some question their efficacy. 'M'e Masenate told me "if you can sleep with a man without CD's, there is something that can happen." Her young friend and neighbor, 'M'e Matsiu added, "Because you will not know their status and how they are living where they are living. And you just sleep with them without using a CD." When I asked 'M'e Maliapeng what she would tell her young niece when she was older about HIV prevention, she told me, "Hmm! This one is difficult. Because, the girls like to disobey, even if you have told them what not to do, they don't listen to you. It's better if we encourage them to use condoms." She dismissed abstinence as a realistic possibility.

In contrast, religious leaders like Ntate Monatsi preach about the importance of abstinence. When I asked him about condom use he told me he only encouraged it among married couples:

Ah, condom, yeah, it is recommended. We are ready to teach about condom in the church to encourage people who are in marriage but have tested and

could be running the risk of infection. So there we believe that the use of condom is fine. But, people who are not in marriage. Ah, abstinence. Yes. Yeah.

When I followed by asking him if he actually believed that people would do this – meaning abstinence - he misinterpreted my question to mean condom use. He responded: "Well, one realizes looking at the infection rate, and death rate, and how, you know, people are sick, you really can wonder if a condom is even making any difference. I don't think people are using the condom." Although he was willing to state that condoms were not widely used, he avoided the implication of infidelity that condom use inside marriage implies. The explicit conversations that would be necessary to address the challenges of consistent condom use and abstinence would likely give voice to the previously avoided topic of marital fidelity.

Whereas most people focused on the protection condoms afforded them personally, Kotsi's grandfather, Ntate Kapo, also noted that if he were infected, condoms would protect his partner as well: "Even me, if my things are not good, it helps me not to infect that person. On both sides, I should not find infection from the woman, or, me, I should not give it to her." Even one of the Sesotho doctors I spoke with, Ntate Leseko, encouraged condom usage, however, he did so in the context of misinformation about HIV-treatment and cures. He said:

Yes, it's good for people [to use condoms] who take a long time without using medicines because people delay to see that they are sick if they don't use medicines. Even when people are not sick, they must use some medicines to clean their bodies. And condoms are good, *kanete*, I encourage it, because people don't clean their bodies or their blood.

Ntate Leseko's patients were encouraged to use condoms, but this was based on the false assumption that if they were taking Sesotho medicines to regularly clean their blood, they

would be free of HIV and unable to pass it to their sexual partners.

Regardless of motivation, these positive attitudes towards condom usage in general do not appear to translate into consistent and widespread condom usage in the population, particularly among young and married people. 'M'e Maphonolo, the young HIV-positive mother of three and caregiver of her two orphaned brothers said she encouraged people to use condoms, but the spread of misinformation is making condom negotiation difficult:

EB: What have you heard people saying about condoms?

MM: Sometimes if I have a friend, and we share secrets, and she is telling me that 'My friend doesn't want to use a condom when we have sex.' And she is saying 'I don't know what to do.' I said, 'You should leave him'. I always encourage that if they refuse to use condoms they should leave them because they don't know whether [their partner] has it or not. They also don't know if they have it or not. No one is telling each other. It's better if you leave them.

EB: So, do you think a lot of people are using them, or no?

MM: Some people are using them, and some people are not using them.

EB: Have you ever heard people say things about condoms causing HIV?

MM: Yes, some of them, they don't like the way they are. They hate that oily stuff. They are saying where is it coming from and what is it for? They just think they are the ones causing the disease. And if you don't believe [in HIV], you will listen to them.

'M'e Maphonolo uncovers one of the essential paradoxes of HIV prevention. Too few people are being tested, and if they are tested they do not always disclose their status making it difficult to negotiate condom use. Although she is not explicitly advocating abstinence, she raises a logical paradox: she believes that you should leave anyone who will not use a condom or disclose their HIV status, yet many people do neither of those. This presents limited choices for young, sexually active Basotho both inside marriage and out.

In addition to the social difficulties of negotiating condom use, even among those who believe in their efficacy, there exist many negative beliefs about condoms that cause

confusion and distrust. One of the most common myths I heard repeatedly was that condoms cause HIV-infections. Many people repeated the rumor that condoms contain worms, and that these worms could pass from one person to another during intercourse. I was told that if I boiled a condom then put it out in the sun I would confirm this rumor, though when pressed, nobody had witnessed this firsthand. My research assistant, Ausi Ntsoaki, told me that she, too, had heard this rumor. In part to convince her of its falsity, and in part to be able to tell others that it was untrue with convincing authority, Ausi Ntsoaki and I performed this experiment. We boiled the condom for thirty minutes and left it in the sun for over an hour. Of course, nothing unusual happened, and we were able to report in future conversations that this was untrue as we had witnessed it for ourselves. Even young and generally knowledgeable 'M'e Matsiu said she was not sure what to believe, "I have heard people saying CD's have AIDS if you can use them for a long time. If you use them for a long time, you will end up being positive. And, I'm not sure whether that's true or not." Her friend, 'M'e Masenate assured her, "We could not be encouraged to use them if they were the ones causing it. I think they prevent it." She replied, "Yes, I'm always asking myself whether it is the truth or not. And I wasn't sure and I didn't know who will tell me the truth." Although she doubted the veracity of the rumor, she expressed difficulty in finding reliable sources of information.⁹⁰ I was surprised to find out later that these two young women, who spoke easily in front of each other about HIV, had never previously discussed it with each other.

A Voluntary Counseling and Testing (VCT) counselor from the hospital, 'M'e

⁹⁰ A highly publicized source of misinformation about HIV was occurred in 2005 when Jacob Zuma, then a prominent member of South Africa's ANC party and now the President of South Africa was accused of rape. Although he was acquitted of the crime, he admitted to having unprotected sex with the girl, whom he knew to be HIV-positive. He famously said he took a shower after intercourse to reduce his chances of contracting HIV (BBC News 2006).

Karabo, heard a range of other complaints about condoms in her counseling sessions, especially from men. Some men complained that they experienced pain in their kidney or liver while using condoms, which she dismissed as untrue. Some said that condoms did not fit their penises, while others complained that "they can't feel" while using condoms. 'M'e Matlai, a teacher and friend of my husband who had previously done HIV counseling group work for an NGO, once shared with me the well-known expression that "you can't eat wrapped sweets," which reinforces a general dislike of condoms, and the disarming humor with which they are dismissed.

Men's general dislike of condoms is closely linked to women's lack of power in negotiating condom use, particularly with their husbands. Married women are among the most at risk for HIV infection, in part, because condom negotiation between married partners is even more difficult than it is between unmarried partners (Clark 2004). As I discussed in Chapter 3, parenthood remains an important rite of passage for Basotho men and women, and the use of condoms prohibits conception. Many of the Basotho women I spoke with agreed that it would be difficult to ask your husband to use a condom. I asked newly married 'M'e Masenate if it would be possible to use condoms with her husband, and she answered in the hypothetical: "I don't think it's possible if you have your husband, unless you are still sleeping with other men, you can use them. But, not with your husband...Because sometimes the parents-in-law will say they want children. And you will not have children if you are using CD's." If a woman asks her husband to use a condom, she is not only denying them both the possibility of a child, but also implicitly expressing her suspicions of his infidelity, or alluding to her own infidelity. In this context, men's stated preference for condom-free sex avoids having to have difficult

conversations that could pose a threat to their marriages.

‘M’e Malefu, who separated from her husband years ago, said, "I don't want him to come back, because he will bring some diseases to me." Unlike younger women who often return to their natal homes, ‘M’e Malefu, 69, still lives in her husband's village where she has spent the majority of her adulthood. She would rather he not return to their marital home because she does not see condom negotiation as a possibility, and thus would have no way to protect herself. It also does not seem likely that he will return as they have been estranged for some time. In contrast, a young woman who worked with my husband was in a similar situation, but she was anxious to have her husband back home. He left for Durban, South Africa, three years ago while she was pregnant with her second child, and he never returned. She had been saving money to find him and bring him home, but she, too, was worried that she would not be able to protect herself. She tearfully told Will and me over lunch one day that she was worried she would contract HIV because she feared that he had been sleeping with prostitutes. She was grappling with the conundrum of trying to reunite her family, which could have potentially important emotional, material and social benefits, while protecting her health.

‘M’e Karabo, the VCT counselor at the hospital, confirmed that many women have trouble negotiating condom use with their husbands. She told me that women "are always coming here to ask for our assistance to talk to their husbands," and she counseled them on the goodness (*bohlokoa*) of condom use, even within marriage. If a couple wanted to conceive a child, ‘M’e Karabo encouraged them to work with the doctor to ensure that their CD4 count was high, and to determine the best time to conceive, so that they could limit their exposure to HIV infection by using condoms during the balance of

the month. 'M'e Karabo told me that because her husband worked in South Africa, they used condoms, but would employ this strategy when they decided to have a baby. The strategic use of condoms is particularly important for sero-discordant couples⁹¹, but also helps to prevent reinfection between sero-positive partners, which can accelerate the onset of AIDS (Schiltz and Sandfort 2000; Gottlieb et al. 2004).

Condom use has the potential to be one of the most effective methods of preventing HIV transmission because of cost, ease of use, and effectiveness. Basotho generally acknowledge that condoms prevent HIV, and many state that at least, in theory, they are useful as a protective method. However, condom use is inconsistent among Basotho and misinformation and myths about condoms are pervasive, even among young men and women who are generally well-versed in HIV prevention. Basotho rely on familiar tropes about the dangers of condoms as a tactic to avoid facing the social implications of condom use, especially among married couples. These allow people to avoid acknowledging more difficult barriers to condom because of their impact on people's social relationships. If a person asks their spouse to use a condom, they are denying the possibility of a child, and either admitting infidelity or accusing their partner of the same. Male aversion to condoms makes it particularly difficult for women to protect themselves inside marriage. Women are thus left with some difficult choices. They can attempt to protect themselves, which could both cause marital strife and deny them the possibility of a child, which is essential to their social value as an adult; or they can risk their long-term health in order to maintain their short-term social networks.

In addition to the importance of condom use, partner fidelity has been a major focus of prevention efforts in the region. Like condoms, faithfulness is not merely a

⁹¹ Sero-discordance is when one member of a couple is HIV-positive and the other is HIV-negative.

straightforward prevention method. Instead, it gets at the heart of people's intimate relationships, cultural attitudes toward concurrent partnerships, and it intersects with structural barriers to fidelity such as migrant labor. Although polygamy is permitted according to Sesotho kinship laws, it is not widely practiced. Men and women both uphold fidelity in marriage as the ideal, while also expressing the expectation that their partners – especially men – will have difficulty adhering to this standard. Cultural expectations of infidelity work against faithfulness as a viable prevention method. Yet, pervasive messages about “one love” and the explicit connection of HIV-infection to infidelity force Basotho to acknowledge the gap between idealized and practiced kin. They also create a culture of blame around issues of health that have the potential to disrupt kin relations by drawing attention to the pathways through which HIV spreads.

Current debates in both anthropology and biology center around the validity of concurrency theory, which argues that multiple, overlapping concurrent partnerships, which are common in southern Africa, connect a large number of people through sexual networks. This theoretically has facilitated the rapid spread of HIV in this region in a way that does not apply in cultures with non-concurrent multiple partnerships (Epstein 2007; Mah and Halperin 2010). Across southern Africa, public health messages stress the importance of “one love” or faithfulness to one's spouse or primary partner. However, admonitions against marital infidelity are challenged by the cultural expectation that men like to sleep with many women, as expressed by the Sesotho idiom “Men are like pumpkins, spreading everywhere” (*Monna ke mokopu oa nama*). In Lesotho, six percent of all women, and twenty-two percent of all men reported having two or more concurrent partnerships, and these self-reported numbers are likely lower than the reality (Lesotho

Ministry of Health and Social Welfare 2010). During one of the long drives out to visit a MCS client, two of the young female outreach workers told me adamantly that they believed 80 percent of men cheated on their wives. One of the outreach workers was married with two young children, while the other, who is HIV-positive, claimed that this was the reason she never wanted to get married at all. Of course, this statistic is purely speculation on their part, but it indicates their concerns as young women in Lesotho, and reinforces the cultural belief in men's infidelity.

'M'e Matlai, the young teacher whose husband had run away to South Africa and had not returned, said, "Here people have many partners. It is so bad. This life encourages the disease." Most women I spoke to focused on male infidelity, but 'M'e Matlai acknowledged that both men and women have sexual relationships outside of marriage. However, she viewed men as the catalyst for this behavior because they "leave their wives inside the house" and go look for other women. She told me that women were unfaithful because they needed something that their husbands were not providing, or they were lonely because they had been abandoned by their husbands. She said, "Women may need to be loved and cared for by their husbands." If men changed their behavior, she told me, women would also change. The Ntho's, Matseli's grandparents, also recognized women's infidelity as a means to increase their income. Ntate Kanelo said that it was difficult "for young people" to remain faithful because "they like money a lot, those people." His wife agreed, adding, "Even if they can give them a hundred rand, they are satisfied, because they are saying that they are increasing that which they are given by their husbands for a month."

A few individuals recognized broader structural factors as contributing to

infidelity; however, they were community leaders and educators who had received special training in HIV prevention and education. Ntate and 'M'e Monatsi, the pastors who had increased efforts in their church to educate their parishioners about HIV, said that people were making "a small change" when it came to fidelity, but that family separation as a result of migrant labor made this difficult. In addition to being a pastor, Ntate Monatsi sold coffins and transported home to Lesotho the bodies of Basotho who passed away in South Africa while at work. Again, pointing to men's inability to resist temptation, he said, "You know there is stubbornness, especially from the men's side, because there are so many women working on the farms. Yeah, they outnumber men." 'M'e Matlai, the peer educator, said that the situation could be improved if there were more jobs in Lesotho. She astutely recognized that, "A major problem of HIV is this problem of poverty." Speaking from personal experience, 'M'e Karabo, the VCT counselor, expressed that it was difficult to remain faithful when a couple was separated because of migrant work. She worried that her husband, who frequently took month-long trips to South Africa for work, was not able to remain faithful to her. Although she did not outwardly admit to me that her husband had been unfaithful, she said, "What makes my relationship difficult is this arrangement. Because I know, a man is not like a woman. When he feels that, he just meets a person. Mine I control. I can tell myself, no, I'm waiting for my husband, while he's not waiting for me." She is at an advantage because her education and training as a VCT counselor gives her the tools she needs to communicate with her husband, and to negotiate consistent condom use.

Many people suggested that faithfulness was a key factor in HIV prevention, though few provided any insight as to how this might be achieved. Ntate Kanelo offered,

"I should stay at my house, and not go to other people's." People often used such expressions as "visit" or "meet" as euphemisms for sex. 'M'e Malefu, a village health worker thought, " We can solve the problem if black people were going together not to be attracted to other men. Like taking this one and this one and this one. And I think the problem would be better," thus, unconsciously reinforcing the racist notion of HIV as an African problem spread by a culture of promiscuity. Tsepo's mother, who is HIV-positive, said that "people should stop having sex" though, no doubt she recognized this as an untenable solution. 'M'e Nthabiseng worried that the effectiveness of HIV treatment would only exacerbate the problem of infidelity that so many attribute to the spread of HIV:

Ah, I think people will continue to have new infections. I don't see people really changing to the situation where they are like, oh no, we have to stop new infections. Now that they have ARVs they see people coping. It's like, they found an answer. So, I think this country has a lot to...HIV, it's going to take a while to really, for new infections to be lower, or there be no new infections at all. The way people do things, behavior wise, aahhh, I don't know.

So far, 'M'e Nthabiseng is correct. Basotho are living longer because of ART, while the HIV-infection rate remains stable (UNAIDS 2010b).

It is difficult to assess, both from my own fieldwork, and from existing literature, the frequency of extramarital sexual encounters in the region. Some scholars warn that a focus on male infidelity misses the frequency of female infidelity. This often occurs in transactional partnerships where gift exchange or cash support is part of the arrangement (Hunter 2002; Kaufman 2004). These transactional relationships give women some agency in accessing resources (Leclerc-Madlala 2003). However, women with multiple concurrent partnerships are frequently unmarried. Yet, young married women remain the

highest at-risk group for HIV infection. Parikh (2007) moreover argues that the barrage of public health messages condemning extra-marital affairs in Uganda has had the unintended consequence of creating secrecy among married partners regarding their extramarital relationships, thus putting married women at greater risk of infection because it denies them the ability to protect themselves by knowing when their husbands are being unfaithful. What is clear is that in Lesotho men and women agree that there is a need for faithfulness in relationships, but that this has yet to be achieved. In addition, the expectation of infidelity in combination with inconsistent condom use limits the ability for both men and women to protect themselves from HIV infection from their long-term partners.

One of the paradoxes of increased attention on partner fidelity is that an already frowned-upon, albeit accepted, practice – infidelity – is now further fraught with the blame and stigma of HIV-infection. People are reluctant to disclose their HIV-status to their partners. The joint stigma of HIV and infidelity thus amplify one another. Admitting infidelity no longer simply means the disappointing one's spouse – it has the potential to implicate the unfaithful partner with infecting both their spouse and children. This does not imply that messages regarding faithfulness need to be removed from dialogues about HIV-prevention. Rather, prevention efforts must recognize the potential that messages about fidelity may reduce partner communication, decrease the likelihood of disclosure, and increase HIV-stigma by making infidelity coterminous with the spread of illness to one's kin.

The vertical transmission of HIV (from mother-to-child) is also fraught with stigma, blame, and silence, because of the painful ways it implicates mothers in the

illness of their children, threatening the health of the child and the sacred bond between mother-and-child. Although men are equally responsible for the HIV-status of their children, they are distanced by the physical realities of mother-to-child transmission, and the close physical bond that exists between mothers and infants. This issue is particularly sensitive because HIV can be transmitted in utero, during birthing, and through shared breast milk – a substance that is key in constituting and maintaining affection between mothers, children, and siblings.

Although the majority of my interviews took place with the caregivers of orphaned children, I also conducted 22 in-depth interviews over the course of the year with seven mothers trying to prevent the vertical transmission of HIV to their unborn or nursing babies. In addition, I observed the delivery of services to MCS's PMTCT (prevention of mother-to-child transmission) clients for several months, and also observed numerous PMTCT clinic visits. The prevention of mother-to-child transmission is one of the more successfully targeted areas of preventive intervention because it is a relatively simple intervention that is highly successful in reducing the rate of transmission. According to the WHO, without intervention, the risk of mother-to-child transmission ranges from 15 to 45 percent. However, with specific interventions in breastfeeding populations, the risk of transmission can be reduced to less than 5 percent (WHO 2012). Because of the ease and import of intervention, PMTCT has received a great deal of attention and funding from international donors.

In 2003, the Lesotho government launched a program aimed specifically at the improvement of PMTCT services, with the ultimate goal of reaching 100 percent of HIV-positive pregnant women during their pre-natal clinic visits. According to a UNAIDS

Lesotho Country Report (2010b), PMTCT interventions in Lesotho have resulted in marked improvement in transmission rates. Between 2004 and 2008 the number of facilities providing PMTCT services in Lesotho went from nine to 180. In 2004 only 2,764 HIV-positive pregnant women were tested for HIV as compared to 37,159 in 2009. The proportion of pregnant women and newborn infants receiving ARVs around the time of birth also increased (UNAIDS 2010b). These heartening improvements signal the potential for both enhanced maternal health, and the reduction of mother-to-child transmission. Effective PMTCT has the potential to greatly benefit the current crisis in caregiving by reducing the number of orphans through improved maternal health, as well as the challenges of orphan care associated with HIV-positive children.

In Lesotho, pregnant women regularly visit clinics for pre-natal care. This treatment-seeking behavior has facilitated the implementation of PMCTC services, including HIV-testing. In theory, all HIV-testing is voluntary; however, in practice pregnant women are rarely given a choice. 'M'e Matsiu was tested during her pregnancy as a matter of routine. I asked her if she could have refused if she wanted to, and she said, "I was so afraid...Because it was my first time to get tested. And I was asking myself what is going to happen...I asked them first whether I can refuse or not, and they said no, especially when people are in that condition [pregnant]." 'M'e Mahlompho tested during her pregnancy as well, though she was also reluctant. She said, "I didn't want to, but they said I must be tested." 'M'e Karabo the VCT counselor confirmed the experiences of these women by admitting that she does not give pregnant women a choice: "Now, it is a matter of must, for pregnancy." Officially, HIV testing, even among pregnant women, is required to be voluntary (Government of Lesotho 2004). However,

in practice, pregnant women do not feel as though testing is voluntary, and VCT policies are not enforced. The power of structure of patient-caregiver interactions, as well as the pervasive lack of questioning by Basotho patients, reinforces this unequal dynamic. The gendered dynamics at play here effectively mean that there is *de facto* mandatory testing for the majority of women of childbearing age, even as men are reluctant to test. If a pregnant woman wants to assure that she does not have to receive an HIV-test, she would have to avoid pre-natal care altogether. PMTCT is an essential program for the reduction HIV-positive children, and testing is an essential part of that. However, widespread testing of pregnant women threatens women's health autonomy, and reinforces a gender dynamic where women are made responsible for the health of the family, while men are distanced from their role in the transmission of HIV from mother-to-child.

Breastfeeding is one of the most contested and discussed issue related to PMTCT because it is a highly visible activity, and it is central to Basotho's ideas about care and childrearing. Milk is not merely nourishing, but it is also a key substance that creates important and lasting bonds between mother and child, as well as between siblings. Formula feeding is associated with lower HIV rates, however in many parts of southern Africa, clean water sources are not reliable, and pose a danger to infant mortality because of malnutrition and diarrhea (Oladokun et al. 2010; Coutsoydis 2001), and the high cost of formula is prohibitive.⁹² In many parts of southern Africa, a mother who is seen feeding her child formula is exposed to HIV-related stigma (Doherty 2011). Because of the risk of malnutrition and diarrhea, mixed feeding, meaning a combination of breast milk and formula or other foods and liquids, is not recommended. It is common for

⁹² When I was in Lesotho, a bottle of formula lasting two weeks cost approximately 150 Rand, or 15 USD. This far exceeds the cash availability of most families.

Basotho to feed their children other foods such as sugar water or *lesheleshele* (porridge) after they are a few months old, even though mixed feeding has been associated with increased HIV infection (Coutsoudis 2001). PMTCT patients are counseled not to practice mixed feeding, but it is difficult to monitor. It is also difficult to keep up with PMTCT recommendations for healthcare providers and mothers. In 2009, the WHO changed their breastfeeding recommendations from exclusive breastfeeding for six months followed by rapid weaning, to continued breastfeeding for one year even after other foods have been introduced (WHO 2009). The risk of malnutrition drastically increases if a child is weaned at six months, because of the continued importance of milk in the face of food insecurity.

Monitoring exclusive breastfeeding is also a challenge because of the unreliability of self-reporting. Although MCS is one of the few organizations that do provide formula under some circumstances, 'M'e Nthabiseng worries that some women only ask for formula because it is free, but that they are not committed to weaning.⁹³ There is no way to verify what the child is actually being fed. As 'M'e Nthabiseng jokingly told me, "You can't always go there and squeeze milk out of them." Ultimately, women want what is best for their children, but they are coping with competing sources of information and intense social pressure, as well as poverty and hunger – all of which create magnified challenges for safe infant feeding practices.

The ideal scenario for successful PMTCT is that a woman voluntarily tests for

⁹³ Many NGO's will not provide funding for formula because of its cost and the difficulty of monitoring its usage. Because MCS obtains over half of its funding from MCSF, its parent foundation based in the United States, a large proportion of its funds do not come with restrictions. MCS makes bi-weekly home visits for its clients on formula, thus they are able to carefully monitor that bottles are being prepared properly and water is being boiled. In addition, Lesotho's water is relatively clean and reliable. Orphans under the age of one are provided with formula by MCS, as are some PMTCT clients, based on the age of the child and health of the mother.

HIV at her first pre-natal visit, begins taking AZT at 28 weeks gestation, delivers her baby at the hospital and receives the appropriate treatment at the time of birth, breastfeeds exclusively for six months, then introduces food and continues to breastfeed until the child's first birthday. These measures drastically reduce the viral load of the mother at the time of birth, thereby reducing the chance that she will transmit HIV to her child during labor. During this time, the woman should carefully monitor her own health and have access to a healthy and varied diet. However, there are numerous structural challenges that create complications for the realization of this hypothetical scenario. Women often have poor knowledge about their date of conception which delays the onset of treatment, and they may live far from the hospital so they are unable to travel once labor has started. This is complicated by a tendency for HIV-positive women to go into labor early (Steer 2005). Some women cope with this by going to the hospital around the eighth month of pregnancy, as there is housing at the hospital for women waiting to go into labor. However, this potentially month-long (or more) absence can be problematic for women who have caregiving and other responsibilities at home. The clinics cope with this by giving some women a minimum package, called the Mother/Baby package, which was introduced in Lesotho in 2007. This package includes all the necessary medications and detailed instructions for women to self-administer the ARVs until they are able to get to the hospital. These are still not widely distributed because of training and supply issues.

Monitoring the status of exposed infants is also complex. In addition to the variety of ways infants can be exposed to HIV (during gestation, labor, and breastfeeding), the basic antibody test used on adults (the rapid test) does not accurately

determine HIV-status among children younger than 18 months because the mother's antibodies can be present in the child until that time, resulting in a false positive. Therefore, children require a DNA/PCR blood test, which does not give immediate results, as the blood sample must be sent to the laboratory at the district hospital for analysis, which can take several months. MCS outreach workers routinely checked their client's health booklets (*bukana*) to ensure that a child's status was being properly monitored by the clinic or hospital. They often found mistakes, or found that a child's test results had not been properly recorded in their health booklet. This becomes more problematic if the child is orphaned, because the mother is an important source of information when the health booklet records are incomplete. On one occasion, the clinic lost the HIV-test results of one young mother who was pregnant with twins. Even though she gave birth at the hospital, she did not receive treatment. Both twins contracted HIV and one of them died before her first birthday. This woman's husband blamed her for the sickness of the children, and she faced numerous caregiving challenges because of her daughters' multiple hospitalizations. These kinds of structural barriers do not only impact health, but also disrupt networks of kin and care.

Non-disclosure of HIV-status also creates a significant barrier for PMTCT. Effective PMTCT requires a woman to take a number of steps to protect her child. Many of these steps, such as breastfeeding and taking medication, are made easier by the support of family, and make adherence difficult if a woman has not disclosed her HIV-status to those with whom she is living. One young woman was pregnant with her third child, though one had been a stillbirth, and the other, a 3-year-old, was HIV-positive. She was living with her mother-in-law, to whom she had not disclosed her status.

Because of this, she was unable to deliver at the hospital and did not receive the basic package to take at home, and the child was infected. Several months later, when I visited the family after the mother had disclosed her status, the grandmother repeated several times that she did not know the mother was supposed to go to the hospital, implying that she would have supported the mother if she had known. In this situation, the woman was attempting to balance a tenuous relationship with her mother-in-law and the health of her children.

‘M’e Karabelo, an HIV-positive outreach worker, decided to get tested in 2005 after the death of her four-month-old baby. She married an HIV-positive man in 2009, and told me that she wanted to have another child. She was hopeful that with the knowledge she had gained as an outreach worker, and since she had started ARVs, she would be able to prevent transmitting the virus to her child. She recently gave birth to a beautiful baby boy, Limpho, who is healthy and thriving at 6 months of age. For ‘M’e Karabelo, PMTCT education was a key factor in avoiding the loss of another child. However, she was connected to up-to-date and accurate sources of information through her job that few other women can access.

Women’s participation in efforts to prevent mother-to-child transmission must be contextualized by the structural, cultural and social factors that influence them. The very acts that are key to the process of establishing relatedness and nurturing life (such as sex, birth, breastfeeding, and caring) are also those that are responsible for the transmission of HIV. These factors are complicated by the biocultural landscape in which they exist.

Testing

HIV-testing, like other areas of HIV prevention, is subject to its own set of

challenges that emerge from both cultural and structural barriers. Although attitudes to testing seem increasingly positive, there are particular barriers to testing that create limitations for its universal use. In particular, cultural attitudes about masculinity that view illness and treatment seeking as a sign of weakness intersect with the cultural barriers to testing that are amplified for men, who interact far less with the healthcare system. Men's reluctance to test until their sickness has become advanced makes transmission to their partners more likely, and this in turn increases the likelihood of transmission from mother-to-child. Stigma about HIV intersects with cultural ideals about masculinity that put men and women at increased risk. Kinship relationships are deeply impacted by the gendered imbalance in testing and because of the social and economic impact of men's illness and premature death.

HIV testing in Lesotho is available in a variety of venues and is – at least in theory – voluntary, though this is not the case with PMTCT patients. VCT counselors like 'M'e Karabo work at hospitals, clinics, and with organizations like New Start that have mobile testing units that visit towns, villages, and are often present at community gatherings such as HIV-awareness events or other celebrations. Every hospital and clinic has a designated VCT office where HIV-testing and pre- and post-test counseling are done. VCT counselors also visit the inpatient wards at hospitals and do limited outreach and follow-up in the rural areas. VCT testing ideally involves pre-test counseling, a rapid test where a drop of blood is placed on a small strip, and post-test counseling where counselors discuss the implications of a positive test, and preventive practices in the case of a negative test.

By 2008, Basotho's perceptions about HIV-testing were generally positive, and

many recognized that it had made great strides in terms of public acceptance. Most people I spoke with felt that an increasing number of Basotho were testing, and they often invoked the language of the government's national testing campaign that encouraged everyone to "Know Your Status". Young 'M'e Matshepo's sentiments reflected this change: "People were encouraged to get tested and to know their status. But, people refused to do that. Not like now when they go to the clinic voluntarily." The pastor's wife, 'M'e Monatsi, attributed this change in behavior to a change in attitude. She said, "More people now are getting tested. They now have the courage." This courage seemed to stem from the normalization of testing, of knowing one's status, and even of HIV itself. 'M'e Nthabiseng witnessed this normalization both among MCS clients and in the broader community:

I think, within our clients, very few cases of people saying, 'no I don't want to test'. Everyone that comes to us for support, and if we talk about HIV/AIDS testing, they are willing to test. It's just the way, they are willing to test, but the impact of the results, you can't see that much, because even if it's HIV/AIDS-positive, they still have babies...But, then they still test. So, I would say within our clients, testing for HIV, it's not a big deal. I wouldn't think it's an issue. But, generally, I think people are starting to really test. Because you can just see by looking outside Lerato Center where they get HIV drugs and stuff, there are a ton of people every Monday and Wednesday to draw CD4, that's one of the signs that people are starting to act towards HIV and their own health.

Despite people's willingness to test, however, she noted that this does not necessarily translate into changed behavior in terms of prevention, in part due to the continued importance of children. As Smith (2004) demonstrates in Nigeria, cultural conceptions of parenthood and its continued importance means that AIDS knowledge does not necessarily translate into effective prevention behavior, and this impacts men's and women's ability to negotiate safe sex differently.

There are a variety of reasons why testing has become more normalized, and thus less stigmatized, in the broader population. Ntate Puseletso, the village chief, believed that education led to increased testing: "Originally people feared to test. But, with knowledge, there was no fear. Why? Because they were educated enough, you see. So, they got tested." In addition, prior to the availability of ART, there was little personal incentive to knowing one's status. However, as 'M'e Karabo, the VCT counselor noted, people were willing to test because they were now able to receive treatment if the test was positive: "I can say that nowadays there are more people testing rather than before. Because now...there are so many ARVs, so they are testing because they know that they will get the help." All of these factors intersect to create a positive environment for HIV-testing: more people are being tested and treated, fewer people are dying of AIDS, stigma is decreased, further increasing Basotho's willingness to test.

Previously, people tested primarily when encouraged or coerced during interactions with the health care establishment such as during pre-natal care or hospitalization. However, now there are a variety of other common routes to testing. Some people simply decide that they would like to be tested and go to the clinic or hospital on their own. Others are encouraged by local support groups who go door-to-door. 'M'e Maliapeng said she was encouraged to test by her friend who was HIV-positive herself and noticed that 'M'e Maliapeng had lost weight. Many people who cared for an HIV-positive adult or child had been tested to ensure that they had not been exposed during caregiving activities. The pastor and his wife, 'M'e and Ntate Monatsi, tested so that they could encourage their congregation to test without hypocrisy. 'M'e Monatsi insightfully noted, "If you want to talk to someone about it, having you yourself

gone under it. Knowing the experience of being there waiting for the results, how it feels. So, then you can talk to other people about it." 'M'e Malefu told me that she went with the other local village health workers for testing so that, like the Monatsi's, they could lead by example.

The decision to be tested involves a variety of calculations and pressures on the individual: social pressure to know one's status, a feeling of being at risk of infection, the desire to protect a partner or child, and finally, a desire to know one's status. Individual experiences with the actual test vary widely based on expectations and perceived risk. Tsepiso's mother, 'M'e Matsepiso, seemed as though she expected her test to be positive because her son had become very ill and was in hospital, so she was prepared for the result. I asked her what the testing experience was like for her and she told me:

There was no problem. Even when they were saying, I'm having it, I didn't care. I just said, I will take it like other diseases. I will take it like when we are suffering from common cold. Yes, and people when they were saying it's there. I just said, I'm going to take it easily, like anything. And when they told me that I'm infected, I told them, you will give me pills and I will be ok. And they laughed at me.

Perhaps their laughter was an indication that her easygoing attitude was unusual. 'M'e Karabo, the VCT counselor, affirmed that the sickest individuals were often most accepting of their positive test results because they were expected. In contrast, she told me that those who thought they were healthy were much more troubled by a positive test result: "Sometimes they will be angry, sometimes they will cry, sometimes they are refusing their status. Maybe when you see that you are HIV-positive, you say, no this is not my status. Because sometimes they, when maybe he or she feels fat, they think that being fat, it means..." She hesitated to find the right words, so I asked, "They look healthy so it can't be them?" and she replied emphatically, "Yes, yes!"

Despite the increase in testing, not all demographic groups are testing in equal numbers. Women have a great number of interactions with a variety of health services through pre-natal visits, childbirth, routine well-baby care activities such as immunizations, and when their children are sick. They are also the frequent target of HIV-testing campaigns as part of PMTCT intervention strategies across sub-Saharan Africa (Mills et al. 2012). This increases both their opportunity and likelihood of undergoing an HIV-test. Unlike their female counterparts, Basotho men interact primarily with the health system only when they themselves are sick, and they are more likely to seek biomedical treatment only once their disease is more advanced, which decreases treatment effectiveness (Mills et al. 2012; Johannessen 2011). It may be that women were initially reluctant to test, but that over time, repeated interactions with the health system increased their opportunities for testing, and normalized their expectations about it.

There are also cultural ideals about masculinity that preclude men from receiving medical treatment and voluntarily testing for HIV – particularly when they are still feeling healthy. As the pastor, Ntate Monatsi said, “Men are supposed to be strong, and not just go [to the clinic] for each and every thing that is coming up.” The outreach worker, ‘M’e Karabelo told me that men continue to be tested less because of this reliance on symptoms: “They believe that if you are going to doctor, it’s like you are weak. You have to be strong even if you are still sick. You have to wait until if it’s bad, until it’s bad, you can come to doctor. But, if it’s pain, you can do something, you can cure itself.” Unfortunately, HIV-patients often do not present with symptoms until their viral load is very high, which increases the risk of infecting sexual partners, and lowers

treatment success rates.

Another MCS outreach worker, 'M'e Mathabelang, invokes both culture and lower regularity of health care interactions to explain why men do not test: "The problem is the culture of Basotho, it makes people not to feel like [testing], especially the men. They feel like they are not the women, they won't go to the clinics usually like the women." Some women felt that men were reluctant to test because of fear. 'M'e Karabo, the VCT counselor, observed that perhaps men were afraid because a positive test would reveal their infidelities: "I don't know why. Maybe it's because they know that they are the one who is always coming out for, maybe for prostitution." 'M'e Masekha ventured that men were afraid of having to become medicalized. She told me, "They don't like it at all. Even when they are sick and you encourage them to get tested, they will just go and consult the doctor and come back...They are afraid...afraid. And they think when they get there they will test positive and they will go for the checkup every day." In this case, she focused on the negatives of treatment over the result of the test itself.

'M'e Mahlompho's story reinforces how men's reluctance to test has a negative impact on the physical and material health of the family and community. 'M'e Mahlompho had two children and was pregnant with her third child when her husband, who had been feeling sick for many months, became increasingly ill and had to stop working. In addition to caring for her children, she was nursing her bedridden husband, and trying to earn extra money for her family in secret, because her husband did not approve of her selling homemade brooms in town. She learned of her HIV-positive status during prenatal care, and encouraged her husband to test, but he refused, even though she had disclosed her positive status to him. After several months passed, once he

was already showing signs of the later stages of AIDS, he finally agreed to test, but he passed away before receiving treatment. 'M'e Mahlompho noted a dramatic improvement in her own health since receiving treatment, and lamented that perhaps her husband would have lived if he had agreed to test earlier. When I asked if she was angry with him, she laughed and told me, "There was no use to be angry." Ntate Kapo's brother was in the opposite situation. His wife had died recently without knowing her status, and he was showing signs of illness as well. I asked Ntate Kapo, who is knowledgeable about HIV because of his role as a caregiver, if he had encouraged his brother to test. He said, "It's not something that he can do. Ah ah. I know him. I know how he is...He's someone who doesn't listen to other people's encouragements." In both of these cases, family members seemed to accept men's dislike of medical interventions – particularly HIV tests – as inevitable, despite the high cost of remaining untested. These social tensions were so pronounced that Ntate Kapo declined to speak with his brother about it.

The outreach worker, 'M'e Karabelo's story is interesting because in her case, her husband's fear of testing and increased medical intervention led him to proclaim his positive status before it was even confirmed. 'M'e Karabelo, who has known her status for several years, became engaged in 2009 after a brief courtship with a man she had reconnected with from her childhood. Before she agreed to marry him, she told him of her HIV status. At first, he was incredulous, asking her, "Are you lying to me?" But, she showed him her health booklet and her medications, and finally he revealed that he, too, was positive. She was skeptical because when she asked to see his health booklet he said he had tested but had not received a CD4 count or any medications. After a few months of marriage, he asked her if she wanted to have a baby. At this point, she insisted on

having him tested to make sure his CD4 count was high in order to help prevent reinfection and mother-to-child transmission. He finally admitted he had been lying when he previously told her he was HIV-positive. Perhaps he was merely trying to demonstrate to her that he still wanted to marry her despite her status, or perhaps he suspected that his status was positive based on his symptoms. Either way, he preferred to lie to his future wife about his status rather than submit to testing. When he finally did test, 'M'e Karabelo accompanied him to the hospital. She expressed relief to me at finally confirming his HIV-positive status, "I was worried about him because I see him. He is not healthy." After this he initiated treatment and she gave birth to a healthy baby boy.

In discussing Basotho men's reluctance to undergo HIV testing, Ntate Monatsi, who was at one time himself reluctant to test, emphasized Basotho masculinity as a primary factor: "I think it has a lot to do with our upbringing." At this, his wife interjected and he agreed that men have "the hardened heart." He pessimistically added, "Sometimes the argument is, whether you die by AIDS or you die by gunshot, or whatever, the end result is death." This poignant acceptance of one's mortality is especially relevant in a country with a low life expectancy and a high rate of illness. A MCS outreach worker, 'M'e Mathabelang, was more optimistic about the future of HIV-testing for men: "I think maybe they will end up, because there are men who are now on the ART and they can teach others and tell them. Maybe they will go, I think." The many examples of men I encountered who had been tested, some by themselves, some with their wives, is evidence of this trend towards increased male testing, which will help to protect women and children through lower transmission rates, and lowered viral loads.

Gender is not the only barrier to HIV-testing. In the rural mountainous district of

Mokhotlong, there are numerous other social and structural barriers to testing that result in low testing rates, improper testing procedures, and increased stigma. In order to understand the testing experience, I went to the district hospital to receive an HIV-test. However, it took five trips to the hospital before I was able to obtain a test because I was unable to locate the whereabouts of the counselors. The challenges I faced in obtaining an HIV test would likely be insurmountable for Basotho living in the outlying villages who would have to overcome the inconvenience, cost, and fear of testing to merely arrive at the district hospital. Although these challenges were discouraging, they were not surprising. I was surprised, however, at how anxious I felt sitting in the waiting room, and how my stomach churned while I waited a few minutes before the little line showed up on the testing strip. This experience reinforced for me the importance of reducing barriers to test-taking, including physical barriers, and extensive VCT counselor training.

HIV-related stigma also presents a significant barrier to testing, because it is a visible activity that requires a person to go to the hospital or clinic and wait publicly in line. Stigma is relevant only insofar as people fear its impact on their social relationships – thus connecting it firmly to kinship and caring. In a small, rural, community, it is unlikely that you could go to your local health facility without encountering someone you knew. Many people said they were not bothered by this, but some were reluctant to test for this reason. One young MCS client said her friend did not get tested at the clinic because she thought that “people in the rural areas are silly.” Instead, she was tested by someone she knew who worked at a local NGO. For this same reason, ‘M’e Nthabiseng encourages the caregivers and family members of MCS clients, as well as all MCS staff, to let her test them, as she is a trained counselor. I was in her office one day when she

was setting up a testing kit. One of the house mothers (*Bo''M'e*) came in with a baby that I thought was going to be tested. Instead, 'M'e Nthabiseng sent me out of the room with the baby in order to test the house mother. 'M'e Nthabiseng said she sometimes wondered if MCS should offer HIV-testing to the general public:

I kind of see people coming individually, feeling comfortable to come to MCS and get counseling, and tested. So, if we had an HIV counseling center, I think I have a strong belief that that would accommodate more people who would rather not go to the hospital, but come here. And I think it's also because there is also a queue at the hospital, and you know, you talk to people you don't know. So, I think people are coming to MCS because they know who to talk to and the services are faster.

However, when I asked her if this was in MCS's five-year-plan, she keenly recognized that if MCS were to become a testing center, it would lose the exclusivity and sense of anonymity that currently makes it a comfortable place for clients and employees to get tested.

These physical and economic barriers to HIV-testing only serve to reinforce cultural ones such as reliance on symptoms as an indication of illness. Ntate Kalasi told me that he was reluctant to get tested, but his wife encouraged him so he finally went. He admitted, "If people don't feel sick, they don't like to know about their status." I asked him if he thought they were afraid, and he told me:

Yes, that is the most important thing, but still they want to feel pain before. Because the nurses like to ask people when they see them coughing. And they will ask many questions, this and that and that, and then ask them about their status. And if they say no, the nurses will ask them, 'why have you not tested?' and they will not have answers. They will only go if they feel pain.

This is particularly true for men, as seeking treatment when healthy is seen as a sign of weakness.

Testing is an important initial step in reducing the alarmingly high HIV-rates in

Lesotho, thus efforts to reduce barriers to testing are paramount. Like other intervention strategies for HIV, Basotho's decisions to test or not test are deeply influenced by their social networks, and they are caught in the complex web of biocultural interactions.

There is a dialectic relationship between testing and kinship because testing decisions are measured against their impact on kin, while kinship relationships influence both men and women's testing decisions. These social factors are mediated by structural imbalances that unequally restrict Basotho's ability to test by providing women with increased opportunities, while reinforcing men's cultural proclivities against testing. Like all areas of HIV, these complex factors have ripple effects which radiate outwards to influence the most basic aspects of kinship and caregiving.

Treatment

The development and provision of free antiretroviral drugs has been the most important step in achieve effective HIV treatment, and is an important element of HIV care. Successful treatment, both in terms of an individual's biomedical response and adherence to medication, impacts the health of HIV-positive individuals, and enables HIV-positive parents and caregivers to provide effective care to dependents. Once a patient overcomes the barriers leading to HIV-treatment, such as those that constrain them from undergoing HIV testing, there are a host of other challenges that arise. Under ideal conditions, ART reduces a patient's viral load, reducing the chance of vertical and horizontal transmission and increasing life expectancy. However, this idealistic view of treatment, which focuses solely on the biomedical and not on the cultural aspects of illness, ignores the many challenges and barriers to successful treatment. These barriers can be grouped into three distinct sources: structural inequalities in society, factors

related to the patient and their environment, and factors related to the healthcare system and providers. All of these barriers impact both patients' health and the challenges that caregivers face. Caregivers impact the treatment outcomes of orphans in their care because they are the prime decision-makers and executors of the everyday tasks of caring. One of the most interesting findings emerging from this data is that caregivers who have witnessed the transformative powers of treatment are more likely to adhere to the complex biomedical regimes required of ART patients. Thus, AIDS does not merely impact the provision of care; care impacts people's fundamental ideas about AIDS.

There is evidence that widespread treatment of HIV through antiretroviral therapy in poor countries with high rates of infection could be the saving grace of the AIDS pandemic. Schwartlander et al.(2011) argue for ARV treatment as prevention. This is a current trend in biomedical approaches to AIDS interventions. However, there are numerous structural inequalities that stem from limited access, poverty, and treatment complexity, which patients must overcome before they are able to receive services and utilize them effectively. In Lesotho, an adult's eligibility for ART is determined by CD4 count, which, according to government standards, has to be less than 250 for patients to begin treatment. However, CD4 machines are expensive and volatile instruments and are prone to breaking, with repair times of up to two months. According to the lab technician at the Mokhotlong Hospital, the CD4 machine was broken four times for a total of three to four months during 2008. When CD4 machines are unavailable, ART eligibility is determined by clinical symptoms. According to the WHO (2010), an HIV-positive individual with clinical signs of stage 3 or 4 is eligible to begin ART. This method of diagnosis is sub-optimal because CD4 counts often decrease before a patient presents

clinical symptoms, meaning that some eligible patients in need of ART do not receive it until the disease progresses.⁹⁴ Treatment according to clinical symptoms does have the benefit of allowing individuals to begin treatment without having to wait for a blood sample to be analyzed. However, this places a greater diagnostic burden on healthcare providers. On several occasions the nurses were unclear about how to diagnose clinical symptoms. For example, one patient was diagnosed as stage 3 because of TB co-infection, and therefore was started on ART. However, his cough went away after two weeks, putting him at stage 1, but he had to stay on treatment since he had already started. Treatment options are limited and each line of treatment has limited effectiveness for each patient. Therefore, starting ART early can shorten the amount of time during which available treatments will work effectively.

Like other aspects of HIV prevention and care, those who are educated about HIV treatment, or who have been in close contact with an ART patient, are more likely to have a positive view of HIV treatment. Many of the caregivers I spoke with had witnessed their children or grandchildren escape from the brink of death after receiving ARVs. For example, Thapo's grandmother described her grandson's rapid recovery after starting ART:

Kanete [I swear], he was better after he started and it was on the second month, 2007. And on the 4th month, he gained weight. The 3rd and the 4th month passed, and he was a healthy child, and living well. He has been healthy since that time...He was sick. He was having diarrhea and vomiting, diarrhea and vomiting, and it is gone up to now.

Lebo's grandmother also noted the dramatic transformation her grandson made after initiating treatment: "He is doing well and now he is becoming fat compared to before.

⁹⁴ I once encountered a woman at a clinic visit whose CD4 came back as 36 but who was presenting no symptoms. Since anyone with a CD4 count less than 250 is eligible for ART, her viral load must have been extremely high. She was lucky to be alive, let alone healthy.

And he took a long time vomiting and having diarrhea, not eating anything, saying, ‘I’m full, I’m full’ always. And he’s no longer tired like he was. And he’s always playing and he’s strong.” ‘M’e Mamorena, who also saw the health of her granddaughter, Hopolang, drastically improve with treatment, told me that HIV-positive people should “run to the doctors” in order to stabilize the illness so that “it will not go anywhere.” There are too many success stories like these to recount, though it bears remembering that the caregivers with whom I was acquainted were already predisposed to express positive sentiments about ART because their association with MCS implicitly indicated a willingness to undergo testing and to seek treatment when necessary, even if the motivation to do so was to receive MCS’s services.

The widespread availability of free ART in Lesotho and the high HIV-prevalence rate means that most Basotho caregivers will have witnessed the transformative power of treatment at close range. Nonetheless, there are still some who refuse HIV-treatment because of the very real likelihood of side-effects, the need for a lifetime of sustained medicalization, and fear of stigma. Some Basotho continue to seek treatment from Sesotho doctors, because as Ntate Kapo told me, they are “Basotho-sotho-sotho,” implying that only very traditional Basotho would refuse treatment from the “English” doctors. Both of the traditional healers with whom I spoke confirmed that they treated many patients for HIV with Sesotho medicines. Ntate Leseko said he gave patients a green medicine that tasted like chili, which is found only in KwaZulu Natal, and some pills which caused them to gain weight and manage their symptoms. I asked if some of his patients also used ARVs in addition to his treatment, and he told me that his patients “don’t use those.” He later revealed, however, that he thought ARVs could be effective,

but that they were not stored or prepared properly: “I think, if things from the hospital can help, the problem is they are not cared for in a good way. For example, their cars are always in a hurry. And, it’s hot where they are kept. Medicines don’t want hot according to my knowledge. And to be shaken like that...I don’t trust them.” He told me about a client who was taking the Sesotho medicines he prescribed for HIV and was doing well, but was encouraged by his son who worked in health care to begin ART. After doing so, he became sick. It is likely that he was initially sick from the side-effects of ARVs, or that his viral load was low, but this only served to confirm Ntate Leseko’s mistrust of biomedical treatment for HIV.

One of the reasons Basotho might turn to the simpler treatments offered by Sesotho doctors is because biomedical HIV treatment consists of a complex and constantly evolving combination of medications with complicated dosing regimens, an large number of pills, the need for ongoing tests, unpleasant side-effects, and frequent medication changes (Nachega et al. 2004; Orrell et al. 2003). These complexities create barriers to successful treatment, and are reinforced by structural impediments that impact personnel training, and the efficient delivery of information, services, and supplies. In order to illustrate some of the challenges to successful HIV treatment in rural Lesotho, I will draw primarily from ethnographic observations I conducted at four different rural clinics⁹⁵. ART patients have monthly clinic appointments where their symptoms are monitored, and they receive medication. At the district hospital’s compound in Mokhotlong, the Lerato Center is the designated facility for HIV-positive patients on ART and those who have not yet started treatment – these patients are designated as pre-

⁹⁵ I did not interview these patients; therefore, I will only provide examples in the form of field notes where relevant.

ART. This facility services HIV patients daily. In the rural clinics, there are specific days designated for ART and pre-ART patients. Regular HIV care is provided primarily by nurses, though patients are referred to the doctor in order to treat more complex

Table 5.1 – Sex distribution of clinic sample (2009)

Sex	Frequency	Percent
Female	70	59.8%
Male	46	39.3%
Unknown	1	0.9%
Total	117	100.0%

opportunistic infections. Over the course of several ART days at four rural clinics I observed the interactions between healthcare providers and 117 ART and pre-ART patients (see Tables 5:1, 5:2, and 5:3 for an analysis of the demographic distribution of the patients by sex, age, and HIV-status). This allowed me to directly observe both

Table 5.2 – Age distribution stratified by sex, clinic sample (2009)

	Adults (over 18)		Children (18 and under)	
	Percentage	Frequency	Percentage	Frequency
Female	65.8%	48	50.0%	22
Male	34.2%	25	50.0%	22
Totals	62.4%	73	37.6%	44

successful treatments and the barriers to treatment from all of the demographic groups. The results demonstrate that treatment and adherence to ART are impacted by a variety of factors: structural inequalities, the complex nature of HIV treatment in this cultural context, the patient and their environment, and the healthcare system and providers (see

Tables 5:4, 5:5 for the frequency and types of barriers observed during clinic observations). The following section analyses examples from each of these barrier categories in order to illustrate the range of treatment challenges that exist.

Table 5.3 – HIV status of patients, clinic sample (2009)

HIV-status	Percentage	Frequency
HIV-positive	88.9%	104
Exposed infant	10.3%	12
Unknown	0.8%	1

Table 5.4 – Patient or environment generated barrier, clinic sample (2009)

	YES		NO	
	%	n	%	n
Environment	3.4	4	96.6	113
Poverty	10.3	12	89.7	105
Individual	17.1	20	82.9	97
Treatment confusion	4.3	5	95.7	112
Circumstantial	20.5	24	79.5	93
None	58.1	68	41.9	49

Once a patient is deemed ready to being ART, the clinic decides on a course of treatment. Currently in Lesotho, only the first line of ARV treatment is readily available throughout the country. If a patient is experiencing treatment failure, a nurse or doctor can appeal to a medical board in the capital city of Maseru to begin the much more expensive second line of ARB treatment, which is not yet available in generic form. At the current time, because antiretroviral medication has only been widely available in

Lesotho since 2004 (UNAIDS 2010b), there are still few people who are in need of second-line treatment. However, access to generic second line drugs will soon emerge as a critical issue, particularly given the challenges of good adherence in this rural context.

Table 5.5 – Healthcare generated barriers, clinic sample (2009)

	YES		NO	
	%	n	%	n
Difficult diagnosis	13.7	16	86.3	101
Healthcare provider error	13.7	16	86.3	101
Resource problem	15.4	18	84.6	99
None	65.8	77	34.2	40

Poverty also serves to exacerbate the treatment of an already-complex illness (Ncama et al. 2008; Bikaako-Kajura et al. 2006). In addition to the cost of the medication itself (although in many African countries, including Lesotho, ART is now free), patients lack money for transportation (Hardon et al. 2007), struggle to buy the foods necessary to promote good health while on treatment (Watt et al. 2009), and cannot afford to take time off work in order to attend clinic appointments (Hardon et al. 2007). Issues of limited access also prevent successful treatment (Crane et al. 2006). Structural factors such as few clinics, limited transportation, a lack of well-trained staff (Hardon et al. 2007), and limited treatment options in the developing world (Nam et al. 2008) can also have a negative impact on treatment outcomes.

Food shortages and malnutrition were noted for several patients in the clinic sample, particularly among the children. Malnutrition is exacerbated by illness as those with more advanced HIV/AIDS or TB co-infection often have a poor appetite.

Malnutrition is treated with a ready-to-use therapeutic food (RUTF) called Plumpy Nut, a pouch of peanut butter-like paste that contains all the necessary fats, proteins and nutrients for weight gain. Field notes from my clinic observations highlight these challenges for a 17-month-old HIV-positive child, who was not yet on ART:

This child has been vomiting for two weeks every day after taking medication. Has very bad sores in the mouth. Not on ARVs. Child not breastfeeding or eating. The child is stage 4 because she is severely malnourished and has thrush and herpes. The child needs ARVs soon. For now she's trying Plumpy Nut to see if she'll eat it but she cannot eat it probably because of the sores in her mouth. Child is referred to the hospital and she is very malnourished. During the clinic visit the mother was crying and said it was because they have no money for the hospital.

In this case, the child was suffering from the effects of poverty, severe illness, and a difficult diagnosis with multiple serious opportunistic infections. These kinds of complicated and multilayered cases are common and difficult to address.

Individual, or patient-generated, barriers to treatment were also frequently observed at the clinics. These treatment barriers could be easily categorized as mere non-compliance or indifference on the part of the patient. However, even when a patient refuses to take the medication as instructed, there are underlying causes such as fear, stigma, or a lack of education that motivate such non-compliance.

Other patients, such as the following middle-aged woman, seemed to suffer merely from forgetfulness coupled with a lack of understanding of the importance of the medication for her recovery:

CD4 in May was 218, but they didn't start ARVs because the woman was complaining that she could not remember to take the medications so the nurse told her to bring one of her children -- her oldest is 19 -- so they could support her but she did not do that. She is saying she will remember to take them. They are finding a calendar for her to check off the days to try to help her to remember.

In this case, the nurses devised a system to help her improve her chances of good adherence. In addition, she was told to return in two weeks instead of the usual monthly appointment interval so that they could monitor her adherence more carefully.

Individual barriers to adherence that impact a dependent child are even more complicated because the child is unable to care for themselves. On the clinic days that I observed, only two out of 44 children (18 years of age or under) were not accompanied by a caregiver. In one case, an 18-year-old girl came in with her own baby, and in the other, a grandmother, who normally accompanied the female patient, was sick. Five children were not accompanied by their primary caregiver. However, several of the caregivers noted the reason for poor adherence as being related to a change in caregivers over the course of the month. For complicated drug regimens, a consistent caregiver is extremely important, and in this sample, a change in caregivers was a significant cause of poor adherence among children. Additionally, some children seemed to be in the care of a reluctant relative, and therefore, the quality of care they received was lower. One 13-year-old girl, who contracted HIV as an infant, came in on two separate occasions with her aunt, who was her primary caregiver:

Patient has been on ARVs for over two years. She was doing poorly a month ago. Dr. N is worried she is failing her 1st line treatment. May need 2nd line but that is difficult to get. Also, need to be sure she can have good adherence before switching. Coughing especially when sleeping. The child looks very sick. The child is extremely wasted. She looks like she's about eight years old. Her adherence is also very poor (93 percent, 57 percent, 83 percent). The aunt denies failing to give her any meds even though it is obvious that she has been missing them.

I later learned that this patient passed away six months after this visit, reinforcing the importance of willing and informed caregivers.

In comparison to more complex barriers to treatment such as that just described, cases of treatment confusion are generally more clear-cut and easy to resolve. For example, one elderly male patient was unable to read the label on the box correctly. Another woman was taking half of each required dose. These mistakes are usually cleared up quickly because patients are asked at each visit to explain to the nurses how to take their medication. However, treatment confusion rarely stands alone as the only barrier to adherence, and underlying issues such as lack of education must be addressed.

Finally, the most frequent reason for patient-generated barriers to adherence stemmed from various circumstances that were beyond people's control. Many of the patients missed doses because they did not bring their medication with them when travelling, and ended up staying longer than expected. In these situations, the nurses encouraged the patients to bring their medication everywhere with them in case they were unable to return home in time. Several of the male patients said they went to find animals that strayed too far while grazing and were unable to get back in time to take their medications. Others merely forgot to bring their remaining medication to their clinic visit, so their adherence could not be verified. These circumstantial events do not signify chronic adherence problems with any given individual, but they are frequent enough that they need to be targeted through culturally appropriate interventions. In addition, the ways in which certain environments create conditions that are more prone to such circumstantial barriers must also be addressed.

The number of times that I observed problems generated by the healthcare system or its providers was alarmingly high. Like the treatment barriers caused by the patient or their environment, the examination of these barriers should not be seen as a way of

placing blame on the nurses or HIV-counselors, but as an indication of broader structural problems that need to be addressed in order to promote good adherence. Barriers generated by the healthcare system and providers included cases with difficult diagnoses, healthcare provider errors, and resource problems.⁹⁶

In one of the more complicated cases a patient had a false negative HIV-test. Although she had tested negative, she was symptomatically presenting as someone in stage 3, and ready to start ART:

Her whole tongue is covered in white sores. It looks like very bad oral thrush. The woman has been coughing every day since August [it is November]. Weight loss. Dr. N thinks also TB. The woman tested negative recently but is presenting exactly like she is positive. Rash, extremely bad thrush. Dr. N is starting to treat her like she is HIV-positive and having her get a CD4 count. When patient was told that she probably is infected she hardly reacted to this news.

The nurse had not thought of this treatment on previous visits, and it took the visiting doctor to decide on this course of treatment.

In other cases, the treatment was more straightforward, but the nurses made wrong decisions that could have been avoided. For example, some medications require additional testing for liver function and hemoglobin levels. Although these tests are routine with certain medications, they vary with patient sex and age, and the retesting schedules are complicated and vary from drug to drug. Healthcare providers frequently forgot to perform required supporting tests during my observations, or they were simply too busy to do them when necessary.

⁹⁶ Treatment for patients with HIV and TB co-infection is particularly complicated. In addition to negative drug interactions and the pill burden of being on both treatments at once, the timing of co-treatment is extremely sensitive. A wrong decision with co-infected patients can lead to serious illness or death (Michailidis et al. 2005) putting increased pressure on healthcare providers. These complex treatment decisions are exacerbated in a setting where delivery of goods and services, personnel training and routine testing is difficult. These factors lead to errors by the patients and healthcare providers, and are central to the treatment challenges faced by Basotho.

In several circumstances, the nurses merely failed to write down the medications on the ART chart, making assessment of adherence at the next visit impossible. Most of the time this was caused by the nurses being visibly overworked, however, on a few occasions the nurses were not busy but merely neglected to find the charts for a patient, which are usually left in a pile out of order and are identified by a complicated numbering system. Some of the clinics employ “expert patients.” These are ART patients who, for a small stipend, help prepare the patients by pulling their charts and weighing them prior to the patient seeing the nurse. These kinds of support systems are crucial to helping make the nurses jobs easier and to counteract the complacency that can come from being overburdened and overworked.

When a patient needs to be tested, they are sent to the counseling center on the same compound where a government trained counselor is required to provide comprehensive pre- and post-test counseling. A 42-year-old male patient came in with his 40-year-old wife and 20-month-old child. The wife did not appear to understand why they were at the clinic, and it was eventually revealed that the husband, who had been on ART for several months, had not disclosed his status to his wife. Obviously nervous, he brought her to the appointment as a way of informing her of his status so that she could get tested. The man had poor adherence, likely because he had not disclosed his status to his wife and was forced to take his medication in secret and without support. The man left after his visit and the wife and child went to the counseling center to get tested. Unfortunately, the mother and child both came back with positive tests. The nurse asked if the counselor had told her about HIV and what she had to do next, and she said the counselor had only tested her. It was late in the day, and it is likely the counselor wanted

to go home. In this case, it is a failure on the part of the counselor who did not do her job, adding further trauma to the experience of this woman.

Resource problems were the most frequent, and also the most frustrating problem that impacted adherence, as they are difficult to remedy, and indicate the deeper issues with the political economic structure of the healthcare system. In addition to the aforementioned problems with the diagnostic machines, medical supplies at the clinics were often intermittent, forcing the nurses to provide sub-optimal treatment to the patients. In some cases, there was a shortage of ARVs and patients either had to switch medication, shorten their time between visits, or for those being initiated, begin a treatment regimen that was not optimal for them. ARVs can have very strong side-effects, and choosing the correct treatment is of critical importance and should not be determined by supply chain issues. In other cases, patients were unable to start the best treatment for them because the necessary supporting materials, such as a pregnancy test, buffer for the hemoglobin machine, or even batteries, were not available.⁹⁷

It is also important to emphasize the positive role which healthcare providers often play in the lives of patients. Several of the above examples demonstrated the caring and creative ways in which healthcare providers sought to mediate the adherence problems of the patients. However, the high number of problems generated from the healthcare setting merely emphasizes the need for increased support and training for healthcare providers, and increased monitoring of the healthcare system, in order to decrease the barriers and increase the overall effectiveness of the system.

⁹⁷ ARVs have patient-specific considerations. For example, Tenofovir is a popular drug for adults because of its low toxicity. However, Tenofovir can also negatively impact the liver; therefore a liver function test must be done prior to beginning this medication. Similarly, additional tests are required with many of the drugs, creating more opportunities for resource shortages.

In order for treatment to be successful, a patient must respond well to biomedical intervention, and must also overcome multiple structural, cultural, and individual hurdles. Early concerns about introducing ART in developing countries centered around the inability for an individual to adhere to complex ARV regimens (Lucas et al. 1999). However, this individualistic approach ignores the structural barriers to treatment such as poverty, limited transportation and infrastructure, cost, and a lack of integration between testing and treatment (Mukherjee et al. 2006). It also ignores the centrality of kin-based care. As these examples have shown, barriers to treatment stem from multiple complex factors: structural barriers; biocultural barriers that are intensified by the complexity of HIV treatment; and the environment, the individual, and the healthcare system and providers. Some NGO's, such as Partner's In Health (PIH), use a comprehensive coordinated response to help mitigate the barriers to treatment. The PIH model attempts to alleviate the costs of treatment by providing free health care to HIV patients, assists with transportation and food costs, uses direct observed therapy to help with drug adherence, and recommends that clinics and hospitals provide HIV care in the same facilities as primary care (Mukherjee et al. 2006). Though successful, this model requires considerable up-front costs and a large staff. Interventions should attempt to minimize the multiple barriers to treatment using a similar comprehensive and coordinated strategy, but in a way that mobilizes existing community support systems such as community-based organizations and village health workers. Intervention strategies that continue to ignore the broader structural barriers to treatment, and focus solely on biomedical interventions, ignore the biocultural realities that will continue to limit the success of ART.

***“An illness just like anything else”*: Signs of stigma reduction**

A final, yet pervasive challenge that is present in all aspects of HIV management, from caregiving to treatment, is HIV-related stigma. Stigma does not have meaning outside of its social context. The mere existence of stigma is evidence of the intersection between HIV and kinship because stigma is, by definition, the fear of negative social ramifications and their impact on networks of kin and care. One of the most promising signs of stigma reduction for HIV is implied in Basotho’s characterization of the illness. In contrast to the past, where HIV was a swift and highly visible killer, the availability of treatment has allowed HIV-positive Basotho to live a relatively healthy and stable life for many years. As Ntate Kanelo noted, people still talk about HIV, but the tenor of their conversations has changed because, he says, “There is something helping people to get better. There were many people dying in the past.” Because of this, many Basotho, such as Tseviso’s mother, explained to me that HIV was “an illness just like anything else”. ‘M’e Nthabiseng expressed these same sentiments about her adopted daughter, Tseli, by calling her illness “normal.” This attitude was pervasive among patients and their caregivers, and is an important sign, not only of stigma reduction, but of coping mechanisms that help people to live positively.

Another important sign of stigma reduction takes shape in the increased communication about HIV between kin. Only a few years ago, many caregivers reported that their children, the parents of the orphans now in their care, did not know (or at least did not disclose) their HIV status. Prior to the availability of ART, there was little incentive for being tested or disclosing, since a positive diagnosis was equated with

illness, ostracization, and certain death. However, because of the availability of ART and the pervasiveness of HIV in Lesotho, the lines of communication have opened up.

According to the VCT counselor 'M'e Karabo, couples are increasingly getting tested together. In contrast to those caregivers whose children died without their status being known, now many caregivers have cared for their children and helped to administer and support ART. Many couples, such as the Ntho's, told me that they encouraged each other to get tested, and went to the counseling center together. While speaking with 'M'e Maliehi about HIV, her husband came home part way through the interview. I paused and asked if they were comfortable doing the interview together given the sensitive topic, and they both agreed that it was fine. In contrast, on a previous occasion, Ntate Kanelo entered the home while I was discussing issues surrounding birthing practices with 'M'e Maliehi, and in this instance, both husband and wife thought it better to discuss these things separately. 'M'e Maphonolo told me that she was comfortable with her friend remaining in her home while MCS was counseling her on PMTCT because, she said, "She is someone I trust. I have seen that she doesn't care. There is nothing that she will not do with me." I also discussed HIV issues with 'M'e Masenate, the young caregiver of Tebello, and her neighbor, 'M'e Matsiu. Afterwards, I asked them if they had ever discussed these issues before together, and they said this was the first time. However, their willingness to do so, and their apparent comfort level during the interview, indicated a desire for safe venues to have these conversations. A need for facilitated conversations about HIV issues was reinforced when near the end of my fieldwork several caregivers thanked me for speaking with them. 'M'e Malefu, the village health worker and caregiver said, "Thank you, because you have made me to be wise about things I wasn't

aware of.” ‘M’e Mapole, the caregiver for chronically ill Letlo thanked me, saying, “Thank you because when we are talking it is like you are also counseling me.” There is evidently a degree of latent willingness to talk about HIV that may be maximized if the proper format for conversations is fostered. Clearly, providing safe venues for people to discuss HIV with their peers needs to be prioritized in order to educate people and foster community support.

One potential venue for facilitating such conversations could be through patient support groups where patient supporters (*batsihetsi*) provide physical and material support for people living with HIV/AIDS. Several of the grandmothers with whom I spoke were members of such support groups, which are usually organized at the village or community level by chiefs or through church groups. They would bring soap, do laundry, or help cook and bathe patients, often in the late stages of AIDS when these daily tasks become difficult. Although increasing communication about HIV/AIDS is not currently central to these groups’ mission, there is the potential to utilize these established forums for helping to foster improved AIDS education and staunch the proliferating sources of competing information.

Stigma reduction was also signaled by everyday interactions between people. Prior to the widespread availability of ARVs, fear and a lack of knowledge ostracized people living with AIDS. For example, in a South African household survey, 26 percent of respondents said they would not be willing to share a meal, 18 percent would not sleep in the same room, and 6 percent would not speak with a person they knew to be HIV-positive (Kalichman and Simbayi 2004). However, my empirical evidence suggests that this is no longer the case, at least in Lesotho. ‘M’e Maphonolo said that in the past,

people did not want to share things like *joala* (Sesotho home brewed beer) and porridge, because it requires eating from the same basin. Although she admits that while some people still do not want to share, most people are comfortable sharing food, even if they are aware of someone's HIV-positive status. She told me, "They know that they will not infect them. They can only be infected by blood. You cannot be infected by saliva. I have seen other people not caring because they say it's the disease all over the world, and how will people know that they will not suffer from it?" As she implies here, the pervasiveness of HIV in Lesotho has resulted in the reduction of stigma, perhaps because interacting with HIV-positive people is unavoidable, or perhaps because increased interaction with HIV-positive people helps to reduce fear and increase knowledge. Shared food is an important mechanism for creating and maintaining social relationships. As previous examples have demonstrated, the refusal to share food can be a powerful tool in weakening social networks. In this context, a willingness to share food with HIV-positive individuals is an important sign of stigma reduction that carries with it broader implications about networks of kin and care.

Despite these encouraging signs of stigma reduction in Lesotho, stigma remains a major barrier for HIV/AIDS interventions targeting all areas of HIV prevention, testing and treatment. In addition to the many examples of ongoing stigma throughout this dissertation, one of the most pervasive signs of ongoing stigma is evident in Basotho's reluctance to speak the name of the illness. Even when discussing HIV with those who knew I was aware of their status, or the status of the child in their care, they were still hesitant to say HIV or AIDS, and would find other ways of referring to the illness. As I previously noted, many people would refer to it as "that disease" or "it." One

grandmother referred to it as “the illness of H” while another called it “the disease for the youth.” Even ‘M’e Maliapeng, who told me voluntarily about her status, still denied at first that her husband died of HIV, saying it was TB, and only later admitted that he had tested positive. Others, when asked about a loved one’s illness, would focus on the symptoms of the patient in question, rather than actually identifying HIV as the problem. HIV is seldom written on death certificates, or openly acknowledged as the cause of death by family members and friends at funerals.

This general silence surrounding HIV is typical for Basotho, and extends itself more broadly to issues of general health, the body, and sexuality. It is possible that Basotho’s reluctance to discuss HIV may be less about HIV-specific stigma and more a reflection of this general practice of silence. However, this silence may impact HIV-related stigma specifically by slowing the reduction of stigma, or preventing typical methods of knowledge sharing such as community groups from being effective in educating people about prevention and treatment of HIV.

Conclusion: HIV as a kinship disease

The HIV/AIDS landscape in Lesotho is complex and pervades every aspect of life. Prevention, testing and treatment messages and services intersect with each other and impact Basotho’s conflicting knowledge about disease etiology, behavior and perceptions. Many of the examples presented here implicate kin and care in both direct and indirect ways. In making decisions about prevention, testing, and treatment, caregivers are grappling with competing messages and pervasive, if declining, stigma. It is within this context that caregivers conduct daily negotiations about the costs and

benefits of their actions on the health of children in their care, and on their broader social networks.

Intervention efforts focused on prevention, testing and treatment also connect the broader AIDS pandemic to the everyday beliefs and choices of individuals, families and communities. In addition, the ethnographic examples that I have cited illuminate the often fuzzy connections between everyday experiences and broader structural processes. In making these connections between everyday life and the continued spread of HIV in Lesotho, this research confirms the multiple intersections between HIV and kinship. By understanding how HIV impacts the social fabric of everyday life, we can then see how it has fundamentally changed the structure and role of caregiving relationships in Lesotho. The following chapter will examine how HIV has also changed the demographic makeup of the family by focusing on the important role of the caregiver, while moving away from idealized notions of patrilineality. However, the ways in which Basotho negotiate for the care of orphans still exists firmly within the familiar tropes of lineal ideals, even as caregiving practices emerge as increasingly flexible and central to Basotho notions of kinship.

CHAPTER SIX

“THEY ARE ALL DOING THEIR BEST”: ORPHANS, CAREGIVER BURDEN, AND THE SHIFTING GENDERED LANDSCAPE

‘M’e Matau’s story

‘M’e Matau is in her 60’s, although she can’t quite remember the year in which she was born. If you ask *nkhono*⁹⁸ who is the head of the household and responsible for the four orphans in her care, she will name her son who lives next door with his wife and children. But, the day-to-day caregiving arrangements in this family are more complicated, and reflect the flexible and fluid responses to the care of children that is prevalent in Lesotho.

I was introduced to ‘M’e Matau through one of her orphaned grandsons, Tsepi, who became a MCS client in 2006. ‘M’e Matau had been living with Tsepi since his birth, because her daughter, Lehala, had come to live there with her children when her husband went to the lowlands for work. Lehala claimed that her in-laws were not taking good care of her or the children. When Lehala became sick, ‘M’e Matau cared for her until she died of AIDS-related illness in late 2005. Lehala and her husband, whom she had divorced before her death, and who is also now deceased, had four children, but the fourth died of “cold” as an infant –possibly an opportunistic infection related to undiagnosed and untreated HIV. ‘M’e Matau was caring for the mother and child during their illnesses until the mother passed away and the child went into the MCS safe home.

⁹⁸ Sesotho for grandmother

When Tsepi first came to the safe home in January of 2006, he had a CD4 of 16%, well below the threshold for beginning ARV treatment.⁹⁹ He spent nine months in the safe home where he tested positive for HIV, and began antiretroviral treatment (ART). He has been an outreach client ever since he was discharged, and is now a thriving and rambunctious 5-year-old.

In addition to caring for Tsepi's mother and her children, 'M'e Matau is also caring for the orphaned child of another daughter. Of 'M'e Matau's five children, three have died, but the third – a son – had no children. For the majority of the year, 'M'e Matau lives only with Tsepi and the other orphaned granddaughter. Tsepi's two brothers – ages 5 and 10 – live in the nearest town, Mapholaneng, with a non-biological relative whom she calls a son-in-law. The older boy is attending school in Mapholaneng. However, during school breaks, the boys return to the village to live with 'M'e Matau, and she and her son are ultimately responsible for them, both in terms of kin obligations and care.

'M'e Matau has support in her village. Her son and daughter-in-law share the caregiving responsibilities. In fact, it is common to see Tsepi, wearing his best outfit - matching jeans and a patch-worked jean jacket – come to town for his clinic appointments with his aunt, as *nkhono* is often working in the fields. As my research assistant, Ausi Ntsoaki, and I talked with her one sunny afternoon, her son's children ran in and out of her rondavel with Tsepi, who complained that they were bothering him. His *nkhono* told him that she would beat them and that they should go outside and play away from the rondavel so she could talk to her guests. A moment later we saw him chasing

⁹⁹ Among children, CD4 is measured in percentages in order to increase accuracy. Adults are measured with a CD4 count. In Lesotho, a child has to have a CD4 of 25 percent or less in order to begin ARVs. An adult has to have a CD4 of 250 or less in order to begin ARVs.

some children with a shovel full of rocks and dirt, though he was too small to launch these missiles very far.

I asked 'M'e Matau about the situation with Tsepi's paternal grandparents. She said that after her daughter died, the paternal grandparents sent her a letter asking for the children. However, she would not give them up because she feared they would not take good care of them, since they had shown themselves unable or unwilling to care for her daughter and grandchildren when their father was working in the lowlands. She said, "They said they would not lose their babies, they are theirs, but we didn't agree with them because they haven't taken responsibility before. They were just without a home." She also disagreed with her daughter's in-laws about the identity of the children, who belong to her clan, and share her last name. She said, "No, I didn't agree with them because these are my children...I said, you didn't pay bridewealth". In the current economy, with the loss of migrant labor jobs, it is common for couples to marry without bridewealth. Moreover, many paternal grandparents claim responsibility for their grandchildren even when this is the case. However, 'M'e Matau wanted to keep the children, and therefore used the institution of bridewealth as a way of justifying her decision.¹⁰⁰ She claimed that their paternal grandparents did not really want the children because "they just talk." She believed that their motivation were purely economic, "They just want to eat with them. They just want these children to work for them." However, although there was obvious affection between the children and their grandmother, she also liked having them around because they were useful, a fact she did not mind admitting. She said, "I like them to help me because I have been caring for them."

¹⁰⁰ For a thorough discussion of bridewealth practices in Lesotho see Chapter 3.

‘M’e Matau’s family situation includes many of the elements of care and shared responsibility common to Basotho families. In this case, one person is the formal head of household while the day-to-day care was provided by a variety of others. While her son was ultimately responsible for making important decisions for all family members, caregiving responsibilities were shared by ‘M’e Matau her daughter-in-law, and the family of the “son-in-law” living in Mapholaneng. It is expected that children, particularly female children, will help around the house and with tasks such as fetching water and collecting wood. Male children are expected to help in the fields and with the care of animals. Indeed, the circulation of children, especially the movement of girls to live with elderly female relatives, is more often explained by the need for assistance with daily chores than because of affection or the desire for companionship (Goody 1984). However, this does not indicate any lack of affection between adults and children, but rather these arrangements indicate an acceptance of the economic advantage of children in this agricultural society, and a tendency to focus on the physical aspects of caregiving relationships.

With the loss of viable caregivers resulting from AIDS-related illness and death, the increase in AIDS orphans has made crisis fostering much more common than previously was the case (Townsend and Dawes 2004). However, a history of child fostering in Lesotho provides a model from which people can understand and legitimate the care for children, and the form and function that such care should take. In addition to kin-based care being the preferred model of care for orphans, it is also often the only option in rural areas such as Mokhotlong where institutionalized care is limited. Basotho like ‘M’e Matau, who lived with her grandmother until she was 15-years-old,

contextualize the movement of children with their own experiences, and reinterpret it to accommodate emerging fostering practices required by the crisis in caregiving caused by HIV/AIDS. This reinterpretation helps caregivers to make sense of the physical realities of caring for children who often have significant health concerns, adding an additional element of difficulty to crisis fostering (Oleke et al. 2006).

These demographic shifts necessitate a reinterpretation of the roles and relationships of caregivers within the Basotho family, which is in theory, driven largely by principles of patrilineality (Murray 1981). As the orphan population increases and the adult population decreases families have had to adjust to changing configurations of people within their households. They appear to be adapting by capitalizing on the flexibility and fluidity of household membership and the normalcy of child circulation in order to understand this new order within the context of the old rules. For example, even though she was a maternal relative, 'M'e Matau used the rules of patrilineal descent, and the importance of bridewealth payments, to justify her claim to her grandchildren. Despite that she is a maternal grandmother, 'M'e Matau uses the idealized rules of patrilineal descent to justify her caregiving situation. The same rules are ignored in other families when the paternal grandparents are providing care even though bridewealth was not paid. The result is that extended families remain able to provide the best possible care for children without completely overturning the social order. Notwithstanding this inherent flexibility, the slight bending and reinterpretation of previous social practices is slowly changing the makeup of Basotho families, and in turn changing Basotho's broader ideas about kinship. The result is a system of caregiving that is increasingly flexible in order to incorporate a broad understanding of care within the ideal of patrilineality.

In this chapter, I will examine the physical aspects of care: from the fluidity and movement of children in and out of households to the day-to-day challenges of care, in the context of a history of child fostering practices. Past and current fostering practices highlight the important relationship between the elderly and the young – especially between children and their grandmothers. HIV infection rates in Lesotho began to rise in the mid-1990s, peaking in the early 2000's (UNAIDS 2010b); therefore HIV-infection is much less prevalent among the elderly in Lesotho than among other adult age groups. In some ways has strengthened intergenerational relationships because grandparents are often the only family members able to care for orphaned children. While the increasingly strong bond between grandchildren and grandparents (grandmothers in particular) can be seen as a positive consequence of these demographic shifts, they often place great strain on elderly caregivers, as their responsibilities are very demanding because of the additional carework that HIV necessitates. The shifting demographic landscape is also changing the role that men play as caregivers, and the potential they have as an important caregiving resource for orphans. Although the caregiving relationship is still often mutually beneficial, caregivers have the added responsibility of dealing with frequent visits to the clinic and hospital, complicated drug regimens, the management of opportunistic infections and malnutrition, and responsibility for an increased number of family members. These new challenges caused by crisis fostering are redefining the definition of adulthood, particularly for the elderly, whose new responsibilities challenge their physical and economic capabilities at later stages of life.

As HIV can be seen as a kinship disease, so are people's solutions related to kinship. This chapter will provide an overview of the type of movements and changes

that are occurring among Basotho and examine the new kinship structures that are forming as a result of the demographic shifts caused by HIV. One significant change is that gender has emerged as a fundamentally malleable resource that can be modified and utilized to respond to these demographic shifts. The overview of caregiving that follows confirms that fostering has always been dominated by females. However, because of a caregiver shortage and the increase in crisis fostering, gender malleability is used by Basotho to justify an emerging population of male caregivers. The flexibility in gender constructs can be used to make claims that both reinforce and depart from previously existing cultural gendered norms. For example, one man can be denied care of an orphan because he is a man, while another man is granted caregiving duties because he is “like a woman”. Gender’s malleability has contributed to an overall shift in the concept of gender within the patrilineal system regarding the locality of care.

I argue that Basotho have maintained an ideal of patrilineality, while in practice there has been a gradual shift towards increasing care by maternal relatives. Paradoxically, Basotho explain this shift in caregiving largely by invoking the rules of patrilineal descent. The process of negotiation and justification that occurs when a family is deciding the locality of care for orphans highlights continued adherence to idealized principles of patrilineal descent. At the family level, the result has been considerable flexibility in caregiving patterns so that children are placed with the relative most willing and able to provide them with the best possible care.¹⁰¹ At the structural level, there has been an increase in matrilocal care that remains to be understood as part of a patrilineal

¹⁰¹ Interestingly, this widening of kinship obligations is not the standard response to demographic change. Renne (2003) notices that kinship obligations among the Yoruba, particularly among educated people in Etika, are narrowing, and a preference for fostering close, biological kin has emerged in place of broader networks of fostering.

system of fosterage. In this case, gender is used as a social negotiation tool that is two-sided: it both reinforces and subverts idealized gendered norms.

While these structural changes are still being understood within the patrilineal context, I suspect that there will be a normative shift away from the current ideal of patrilineality – at least when it comes to caring practices. The beginning of this shift is evident in the experiences of caregivers, and in the negotiations and justifications they give for the children in their care, which I explore in this chapter. At the local level, this structural map will provide a greater understanding of the changes occurring within families and households in rural Lesotho as a result of HIV. At a broader level, this exploration provides insight into the ways that kinship structures change incrementally and over time as a result of a major social disruption. As exceptional behavior becomes normalized, conceptions about what is considered ideal gradually change, lessening the gap between ideal and practice.

The gap that exists between Basotho's kinship ideology and their caring practices can be, in part, explained by the differentiation Bourdieu (1977) makes between "official" and "practical" kin. Whereas "official kin" is the representation of kinship for the public sphere by the group as a whole, "practical kin" is "directed towards the satisfaction of the practical interests of an individual or group of individuals". In this case, it is in the interest of the health and well-being of an increasing number of children to live with their maternal kin. As many kinship theorists have demonstrated (Franklin and McKinnon 2001; Carsten 2000b; Holý 1996), relatedness is processual and embedded in a particular historical, socio-economic, and geopolitical context. As

Hutchinson notes regarding the Nuer (2000), physical objects such as paper, guns, and money, can change the way people are related to each other. Illness can do this as well.

In Lesotho's case, the HIV/AIDS crisis, which was precipitated in part by other contextual factors such as migrant labor, has altered the relationships between kin. As a result, carework has increasingly shifted to the maternal family. However, I take this argument one step further. As Comaroff (1985) notes in her critique of Bourdieu, practice does not merely reinforce power structures, it provides the opportunity for resistance as well. Ortner (1995) further suggests that the resistance vs. domination binary is a false one as it is not a matter of either domination or resistance. Instead, Basotho are simultaneously resisting *and* submitting to deeply embedded societal norms as a strategy for coping with the pressures of the emerging orphan population.

Caregivers in Lesotho are negotiating their practice of resistance in the form of matrilocal care using the tools available to them. That is, they are using the official rules of the dominant power hierarchy – patrilineal descent – in order to ensure that children are well cared for. As Bourdieu asserts, “all solutions are acceptable so long as they are expressed in genealogical language” (1977:37). In this way, potential caregivers are able to resist ascribed patrilocal patterns of care, but they do so in a way that maintains the dominant ideals of relatedness, while demonstrating the flexibility of gender constructs.

The privilege and challenge of children: Child fostering practices in Lesotho

The normalcy and frequency of child fostering in Basotho households is immediately apparent. Children regularly live with various relatives throughout their childhood on both the paternal and maternal sides. Because I was married and of childbearing age, people often assumed I had children, and thought it natural that I would

leave them in America to come to Lesotho to do my work, as many parents in Lesotho leave their children with relatives to work in the lowlands of Lesotho or in South Africa (Lesotho Bureau of Statistics 2007b). Children are generally seen as assets to a household both in terms of companionship and for assistance with the many chores associated with rural subsistence farming and village life. Studies from across Africa have attested to the many functions of fostering, including providing assistance for foster parents (Renne 1993; Bledsoe 1989; Goody 1984; Leinaweaver 2007; Page 1989). As Bray (2003) notes, defining housework in a southern African context as child labor does not take into account the cultural view of this type of work as an essential part of household membership and social learning. Although Hunter focuses on romantic love, he urges us to think about love in a way that recognizes “love’s expression in practical acts of cooperation and mutual assistance” (2010:15). Hunter’s notion of “provider love” is useful in thinking not only about intimate sexual relationships, but about caregiving relationships as well (2010). Although some fostering relationships are ambiguous in terms of the balance between labor and care (Leinaweaver 2007; Bledsoe 1990), the majority of adults in Lesotho remembered their childhood fostering experiences as overwhelmingly positive. Basotho children also enjoy a great deal of leisure time. Although many caregivers spoke about the assistance that their foster children provided, I more often than not observed children playing with their friends rather than working.

Zimmerman et al define carework as “the multifaceted labor that produces the daily living conditions that make basic human health and well-being possible” (2006:3). The authors specifically include human health in order to capture the nursing, nurturing, and caring tasks common to many women globally. Similarly, day-to-day caregiving in

Lesotho has historically been, and remains, a primarily female domain (Robson et al. 2006). Thus, the caregivers with whom I worked over the year were primarily women, and the ethnographic examples that detail the experiences of female caregivers throughout this dissertation reflect this reality.

The widespread fostering practices that have helped to find homes within the extended network of kin for many orphaned Basotho children are not new. Current fostering practices are part of a long tradition of fostering that many caregivers experienced as children themselves. As Alber (2004) notes about fostering in Benin, the elderly view the process as a circular exchange that benefits individuals both at the beginning and end of their lives. Children often go to live with other relatives when their mothers are trying to wean them, and sometimes they stay for years. Of the 21 caregivers I interviewed extensively, at least 12 of them spoke about living for some time with another relative when they were children, the majority of them maternal or paternal grandmothers, but a few with aunts or with both of their grandparents. In all of these cases, only one could be considered crisis fostering (the mother died) and one was because the mother went away for work. The rest lived with relatives for mutually beneficial reasons which included company, love, affection, and assistance. When I asked 'M'e Mapole why she went to live with her grandmother as a child she said, "She didn't have any children living with her. And my mother said she should take care of me so that I could help her when I grew up." Her mother sought to create a bond of affection that would solidify the mutual assistance between grandmother and granddaughter. Most of the caregivers have very fond memories of living with their grandmothers. 'M'e Mapoloko remembers, "My grandmother loved me and I loved her too... [Grandmothers]

were taking good care of the children because they loved them. They were asking a girl, what do you need?”

The function of many of these fostering relationships was to provide someone to help the elderly relative with daily chores and with work in the fields. ‘M’e Matau lived with her maternal grandmother until she was fifteen. She viewed her purpose in going as work-related, but she remembers her time there fondly:

EB: And why did you end up living with your grandmother?

MM: I was living with her because she was the mother of my mother. And I think they liked me to stay with her to fetch some water for her.

EB: When you moved there, did you ask to move there or did *nkhono* ask you to come?

MM: Yes, she asked for me to live with her.

EB: And, do you know why she asked for you?

MM: Ah, I don’t know. I thought maybe she wanted me to fetch water for her.

EB: How did you feel when your parents told you that you were going to stay with your grandmother?

MM: Ach, I liked living with my grandmother...When I was living with my grandmother she was telling me some stories and riddles. And it was nice and when I went to school, I was telling the other children what I had learned from my grandmother. I told them stories and riddles.

Me’ Matau moved back home at fifteen because her grandmother passed away. Like ‘M’e Matau, other caregivers’ recollection of their childhoods in the homes of their grandmothers is almost unanimously positive. This rich tradition of fostering and the memory of positive childhood experiences has contributed to the current environment where fostering is widespread and viewed as normative. Current fostering practices, which are shaped by HIV/AIDS, are thus both a continuation of, and a departure from this malleable system of care.

The concept of fostering allows for the temporary and flexible movement of children between households. However, as Walmsley (2008) noted of child circulation in Ecuador, close social and material ties reinforced through fostering do not obviate kin ties

based on biology, even when biology is not conceived of in the same way. An American couple that was working at an NGO in Mokhotlong experienced these temporary patterns of care firsthand with devastating results. They were caring for four orphaned infants of various ages whose extended families did not have the ability or desire to care for them at that time. In all of the four cases, the parents had passed away and the extended families declined to care for the children. After the couple and children had been living together for six months, the Americans sought to adopt the children in order to obtain passports for them and bring them back to the United States. However, the adoption process necessitated that the families sign letters saying that they were transferring all rights and responsibilities to the couple. Although the families had not wanted the children at the time the couple took them into their home, and none had been visited by their relatives during that period, three of the four families were unwilling to sign the letters. These families would have been content to have the couple live in Lesotho and raise the children as their own; however, the concept of signing away the children permanently was incoherent within the local system of child fostering that works well to support caregivers and protect children.

It was not difficult for me to locate families composed of children from various parts of the extended family network. However, the importance of ethnographic fieldwork became evident in the difficulties that I encountered working to uncover the emotional nature of the relationship between children and their non-parental caregivers. For example, it was common for caregivers to answer questions about the benefits of caring for children with material or economic answers that detailed the chores with which the children assisted. This, in part, comes from the way Basotho understand the question

(it would be odd to ask a Basotho if they loved someone or not), but it also comes from the economic importance of children in agricultural societies (Bledsoe 1989). However, through extended observation of the interaction between caregivers and children, I witnessed actions and expressions of feeling that indicate a strong emotional connection between the majority of caregivers and the children. Love was a major theme that recurred throughout my conversations with caregivers. However, this love and affection must be understood through its local and culturally mediated lens, and is connected to the role of the caregiver. A good caregiver was often described as “having love”. Or, as Ntate Kapo’s mother said of him, “I can see that it’s his heart.” In light of Basotho’s tendency to focus on the physical over the emotional in interviews, ethnographic methods allowed me to witness this special bond. Basotho’s concept of love is influenced by emotional attachment, and shaped by cultural ideas about loving relationships that include the social importance of children, filial responsibility, the social expectation of kin-based care, and the demonstration of love through physical acts of caregiving. Affection in this social context is not merely an emotion that exists between two individuals, but it is part of a social norm that has helped to protect children orphaned by AIDS.

One major factor that facilitates the care of children within the family network is the strong bond that exists between the young and the elderly. Anthropologists have long written about the closeness of alternate generations (Lévi-Strauss 1969; Radcliffe-Brown and Forde 1951). Grandmothers often care for their grandchildren or great nieces and nephews for reasons borne out of both necessity and mutual help. However, the relationship between the young and the elderly goes beyond the practical or the necessary

to include a strong bond of affection and love.

‘M’e Maliehi, the grandmother of Matseli, claims that love and experience make old people more fit to care for children.

The young people don’t know how to take care of a family...Like you small girls [addressing me and Ausi Ntsoaki] if you are sent somewhere you will just take a long time being there. Like going at Janteu [a place for shopping] the sun will set while you are still there not knowing what the kids will eat. But me, I will be here always.

When I asked her why old people were more willing to provide care for an orphan, she claimed “It’s because the old people have love.” She demonstrated this love repeatedly for her grandson Matseli. When we told ‘M’e Maliehi that Matseli would be returning from the safe home after spending almost a year there, she stood up and danced and sang “*o tla fihla, o tla fihla, abuti oa ka, o tla fihla*” [he is arriving, he is arriving, my boy, he is arriving]. She then cooked a special meal for him when he came home.

‘M’e Masello and her youngest grandson Lebo were also strongly attached. Lebo refused to let anyone else feed him or take him to the bathroom. She told me with

Figure 6.1 – Lebo with his grandmother, ‘M’e Masello



frustration, “When he is with the sister at the water tap, and when he wants to go kaka, he will not tell the sisters. He will just come straight to me and tell me that he wants to go to the bathroom. Sometimes he just poops on himself. And I ask him, why have you done that yet you were still with your sisters. He says, ‘I didn’t want to tell them’. And I become angry... Like even when eating, he wants me to help him, not anyone else. He doesn’t want to feed himself.” She worried about what he would do when it was time for him to go to school.

Grandmothers are also notorious among Basotho for spoiling their grandchildren.¹⁰² This is in contrast to other cultures such as the Baatombu in Benin who widely practice fostering because parents are viewed as not being strict enough with their own children (Alber 2004). ‘M’e Marefiloe claimed that the decrease in voluntary fostering was because parents did not want their children to be spoiled by their grandmothers. Ntate Kapo, who lived with his two grandsons, described the relationship they had with their great-grandmother who lived next door.

EB: Do you think it’s easy for grandparents to love their grandchildren like it’s their own children?

KM: Yes. They treat them the same way, kanete...And they sometimes spoil [*ba thefisa*] them, the grandmothers. They spoil them, they say, ‘come here, the child of my child, come here the child of my child’. And sometimes, I have beaten the child because he has done wrong, and the grandmother will be on his side. Yes, and say, ‘Ah ah, I don’t want you to do this to my child’. And the children like that about their grandmothers because they know that they fight for them anywhere...The grandmothers are loved by the children at lot. And they also love the children. They will call them and say, come and visit me. And the children, I have realized that they like the grandmothers a lot. And these small children, they like to go to the grandmother and talk with her. They like to say, ‘*Nkhono*, this and this and this and this and this...’ And yesterday, they were singing *mohobelo* [a dance for men] for her. And they were saying, ‘*Ntate*, look at us, we are dancing’ and I said, ‘tell your grandmother to *lilietisa* [ululate]. And she did it and they were very happy. It was very nice.

¹⁰² See also (Renne 2003).

Many caregivers, young and old alike, felt that younger women who were still caring for their own children would be less able to care for an orphan properly. 'M'e Maliehi commented, "The children who are not his or hers will always be working hard. Like, if they are two girls, let's say one is hers and one is not hers, the one who is not hers will always wake up early and do things for the other. And her daughter will do things when she likes." However, when I asked her if there were any people in her village doing this, she said "Ach, no," as if it were more a cultural stereotype of poor caregiving than a common occurrence. 'M'e Mahlompho, a young women and PMTCT client, was very pessimistic about the ability for other young women to care for orphans. She said, "Ach, they don't treat them in a good way...The way they talk, they will show you that it's not the real child of that family. And the way they dress, they're not clean, but their own children will be clean." These testimonies reinforce the belief that the elderly are best able to provide a loving and caring home for orphaned children. Recognizing these stereotypes of adequate and inadequate care helps to identify the ideal in caregiving. For Basotho, stories of good care focus on material things that help a child to appear clean and healthy. Inadequate care is discussed in terms that emphasize dirtiness, lack of food, overly hard work, and preferential treatment for some children over others.

The Basotho's love for children, and particularly the love between grandparents and grandchildren has been an important protective factor in supporting orphans (Ansell and van Blerk 2004; Young and Ansell 2003). Grandparents increasingly find themselves the only viable caregivers because of AIDS-related illness and death. The cultural expectation of affection between grandmothers and grandchildren helps to protect and maintain strong intergenerational bonds during this difficult time. In a way,

this cultural ideal not only promotes affection, but helps to justify living arrangements outside the patrilineal system. Because of this, a disproportionate number of grandmothers are providing care for their orphaned grandchildren. Often this care requires them to work beyond their physical capabilities, thus creating loving but vulnerable homes for children.

In addition to the strong intergenerational bond that exists in Lesotho, the emphasis on social parents over biological ones helps to protect orphans from abandonment.¹⁰³ Basotho children blend easily from one household to the next, and find loving and caring environments outside of their natal homes. During interviews, caregivers responded that they would provide children with care equal to, or better than, the non-orphaned children living in the household. 'M'e Masekha said that if she could only send one child to school it would be the orphan because they have no parents. Pity is equated with empathy and love, and people often characterize their positive and loving relationships as having shared pity. Other caregivers gave a more balanced view of the quality of care, claiming that some caregivers provide good care to orphans and others do not. 'M'e Masenate, the young caregiver for her husband's nephew Tebello, expressed pessimism that caregivers still living with their own young children could care for orphans with equal attention: "The fact that people are not the same and some people take good care of the children, but some do not take good care. Ach, *kanete*. Like people who already have children and they would not take good care of the other children like their own children." I then asked her if she would have problems with Tebello once her own children were born, and she said she would not as long as her husband was still working. Although in reality, these caregivers may be exaggerating their ability to treat all children

¹⁰³ See chapter 3.

as equals, it demonstrates the cultural ideal in caregiving, which places little importance on the proximity of the relationship between child and caregiver, and values generosity and empathy.

Basotho view child fostering not only as a moral good, but also as a responsibility they have, particularly towards kin members. 'M'e Mapoloko said of living with Joki, "It is important the pity that I have shown to him and to God to take care of this child. Because he doesn't have his parents." However, 'M'e Masenate, who lived with her grandmother growing up and is now caring for Tebello, believed that fostering was occurring less freely than in the past. She claimed, "There was no orphanage in those years and they just knew that if my daughter dies, I will just take care of her children. And it was a necessity." However, the MCS safe home is the only type of institutionalized care available in the entire district of Mokhotlong, and it is used primarily for rehabilitation until family reunification is possible. Despite 'M'e Masenate's experience with Tebello in the safe home, options for institutional care are still limited.

Perhaps 'M'e Masenate's altered view of fostering practices is reflective of the fact that the nature of fostering has changed, so it no longer resembles the form it used to take. The amount of crisis fostering and the reduction in available caregivers has compromised the ability for families to foster children voluntarily. Networks of care are strained and often saturated, so children are no longer being sent to their grandmothers for companionship or help. If there is a healthy grandmother within the family, she is likely already providing care for a child in need.

The experiences of caregivers examined thus far have been primarily focused on

women because they are providing the majority of care. However, in this section, I will also focus on the role that men do play as caregivers as evidence of the gap that exists between ideal and practice. The strong cultural ideal that prefers female caregivers could ignore a potentially important resource in male caregivers that might help to alleviate the current crisis in caregiving. The following examples reinforce the flexibility of gender constructs as a resource that can be strategically deployed in negotiating for the care of orphans.

This gender gap becomes evident if you ask Basotho who makes a good caregiver for children. The unanimous answer is that women provide the best care. One middle-aged woman summarized the cultural ideal of the gendered division of labor like this: “The job of women is to take care of the children and to cook and do all the cleaning in the house and gather wood. We wash the babies and wash the clothes for them. The father’s duties are to plow the field and do any other jobs that can bring in money to the household.” In reality, I observed many women partaking in typically “male” activities, such as doing contract work for the government and working in the fields. Another elderly grandmother told me, “The mothers are the ones taking care of the babies. There are few fathers who can...If the orphans can stay only with the father, you would not find them clean. They would always be dirty. But with the mothers, they will always be clean.” Although good male caregivers are less common, they do exist (as, of course, do inadequate female caregivers).

Of the 21 caregivers I worked with, only four were men. Of these three men, one grandfather lived with his grandchildren, but his wife provided the majority of daily care. Ntate Kalasi, a father of five, provided the daily care for his children because he had a

physical disability that limited his mobility, so his wife had to work outside the home. However, in the mornings and evenings, his wife did the cooking and cleaning. Ntate Lekhetho, whose wife was deceased, cared for four of his six children prior to his arrest for murder in 2009. Ntate Kapo cared for his two grandsons on his own.

The gendered nature of carework was reinforced in a discussion I had with Ntate Kapo. Ntate Kapo's wife had left him when their two children were very young. He raised his two children primarily on his own with his mother's help. When his daughter returned to his home a few years ago dying of HIV, he knew how to care for her two young sons, one of whom, Kotsi, was also HIV-positive. Ntate Kapo still lived next door to his mother, but she was blind, and although the boys loved to visit with her and talk to her, she could not provide for them on a daily basis. One day when Ausi Ntsoaki and I drove over an hour on our motorbike to see Ntate Kapo, he was not there. We found his mother carefully using her hands to follow a wire that he had put up between her house and the latrine. When I asked 'M'e Matlotliso about Ntate Kapo's relationship with the boys, she said:

Yes, he is taking good care of them, and they are two boys. And he's taking very good care of them, *kanete*. Very good care. He is like a woman in the household. He is cooking and he wakes up early to fetch some water and he washes them and the older brother goes to school.

I asked Ntate Kapo about his role as caregiver, and he also commented on the gendered nature of his responsibilities:

EB: So you raised both your children by yourself?

KM: Yes.

EB: That is why you are so good at raising Kotsi and his brother?

KM: That's it. Because it seems like I'm his mother and he doesn't know his mother. He just knows that his mother is me. Sometimes he asks me, he says, 'Ntate, are you my mother?' But I tell him, no, your mother is Pulane. And he asks, 'Where is she? Where has she gone? What will she bring for me when she

comes back?’ And he’s young, he doesn’t understand when people are saying his mother is dead....And now I’m telling you, he can’t go away from me. And when I go, he will just come after me, and he won’t leave me alone.

EB: He likes to be with you all the time?

KM: Yes.

EB: Why do you think he thinks you’re his mother?

KM: It’s because he has seen that I am taking care of him, and I’m taking good care, and I’m cooking, and I’m giving him food, and I wash clothes for him, I’m doing everything with him, and I sleep with him in the bed.

Caregiving is so intertwined with gender that Kotsi equates care with motherhood.

Despite the strength of this cultural ideal, there are men, like Ntate Kapo, providing excellent care for children.

Ntate Lekhetho, in contrast, was left to care for his six children after the death of his wife, two of whom were still babies. For a while, Reamohetse, the youngest of these and a MCS client, was living with her aunt, who lived in the same village. But, because of family conflict, she moved back home with her father. Her father was anxious for reconciliation because he noticed that she was unhappy and losing weight. He appealed to me for affirmation: “I think you have seen her now when she’s living with a man. It’s not like when she’s living with a woman. And she has changed a lot since she came from her aunt’s. Because the aunt was taking good care of her.” His sister-in-law, however, did not think it was because he was a man, but thought that, although he loved his children, he was lazy. She said that it was not difficult to cook and clean and care for children and that a man should be able to do it, an opinion that goes against the normal gendered division of labor. Though several female caregivers expressed the inability for men to provide good care, Ntate Lekhetho’s sister-in-law’s attitude towards male caregiving reflects the slow change in popular opinion, based on the increasing presence of good caregivers like Ntate Kapo. However, emerging male caregiving practices also

reflect the malleability of gender as a resource that can be deployed in different ways depending on circumstances and need. In discussing intervention strategies (Chapter 7), I will elaborate on the potential benefits of harnessing willing male caregivers as a way of alleviating the burden of care on elderly female caregivers.

Crisis fostering and the AIDS burden

I encountered many families living in mixed households of various configurations, not only among MCS clients, but also in the broader community. However, because of my association with MCS, many of the families with whom I became close were not fostering children voluntarily, but because of a crisis in the community or family (Page 1989). Crisis fostering is not voluntary, but it is necessitated by emergency situations such as divorce, illness, or death (Page 1989). These factors exacerbate the challenges of caring for orphans in a resource-poor community like Mokhotlong. The burden from crisis fostering is further exacerbated by the special needs of an HIV-positive child whose care puts physical, emotional and material strain on caregivers (Heymann et al. 2007; Heymann and Kidman 2009; Singh et al. 2011; Kimemia 2006; Kipp et al. 2006). This section will explore caregivers' experiences with crisis fostering and the burden on caregivers specific to the needs of an HIV-positive child.

Seventy-seven-year-old 'M'e Mamorena was originally reluctant to care for Hopolang, a 5-year-old HIV-positive girl, and her 10-year-old sister. She was old and has very limited mobility because of a bad back and knees. The girls' father was 'M'e Mamorena's grandson – so she was the paternal great-grandmother. He had disappeared and the mother and girls were living with 'M'e Mamorena when the mother died of HIV-

related opportunistic infections. At the mother's funeral, 'M'e Mamorena implored the mother's family to care for the girls: "I said, take these children, *banabeso* [plural term of endearment], because you can see that I'm sick and I'm old. And I don't have the energy to support these children. They said they wouldn't take the children because when their child is gone, everything is gone." Although 'M'e Mamorena initially did not want to care for the girls, she cannot imagine her life without them now:

MN: Ah, there was going to be no life. Maybe I would have died. Because there was no one to take care of me. I was going to die inside this house. I'm just living because of these children. I'm only surviving because of them. They can do laundry, gather wood, cook papa, wash the dishes, and fetch some water. They are helping me a lot. They help a lot.

The mother's family did not want the children, so they said that they belonged to the father's family, even though bridewealth was never exchanged. The rules of Sesotho culture are once again interpreted in a way that suits the family's desires – in this case, to refuse responsibility for the children rather than accept it.

'M'e Masello is the 77-year-old grandmother whose grandson had passed away from a brain aneurism. She lived in one small rondavel with seven grandchildren ranging from ages two to sixteen. Although 'M'e Masello was very attached to her grandchildren, particularly the youngest, Lebo, who was on ART, her ailing health made caring for them difficult. She had severe chronic asthma which put her in the hospital for extended stays twice while I was in Mokhotlong. During these times the children lived alone. Ausi Ntsoaki and I went to check up on them during one of her hospital stays, and Lebo was sitting on the ground, filthy, shoving food in his mouth, while his older sister was playing with her friends nearby. Although 'M'e Masello was sometimes helped by relatives living in a nearby village, she needed more daily support than she was receiving.

MCS helped her with food for Lebo and money for transportation to the clinic. She also received the 200 Maloti (equivalent to about \$20) all people over the age of 70 receive monthly from the Lesotho government.¹⁰⁴ Ideally, she would not be the primary caregiver for the children, but there was no one else. She worried about what would happen to them when she died. Sadly, I was informed a few months ago that ‘M’e Masello had died. Lebo is now living with paternal relatives. He is no longer visited by MCS outreach staff, but still receives money for transportation.

The challenges that stem from insufficient resources or the illness of caregivers and children are prevalent when rates of crisis fostering are high. Ideally, child fostering practices are characterized by mutually beneficial circumstances for the caregiver and the child. However, crisis fostering can result in the movement of children to households that are forced to stretch their resources in order care for the child (Page 1989). I discussed with MCS’ managing director ‘M’e Nthabiseng the possibility that family members might not want to care for children because they were HIV-positive. However, she thought that any reluctance was more likely related to limited household resources:

People don’t really want to take care of smaller children. Especially if it’s your brother’s kid, or something like that. They do it, but very reluctantly. I wouldn’t say it’s because of HIV, I think it’s just because of the load you already have. But, I don’t know. I’m assuming, because they never say, “Oh I don’t want to take this kid because it’s HIV positive.” But you see, “Oh, how am I gonna feed this baby?” “Oh, I already have my kids”. Things like that. That’s what I see being the factor in people caring for other siblings’ kids, or extended family’s kids. It’s hard to justify if it’s stigma, or just because of poverty. Because you really don’t have anything to provide for extra kids in your household.

‘M’e Nthabiseng is unconsciously identifying crisis fostering, and attributes the reluctance to care for children to a lack of resources. As death and illness among the

¹⁰⁴ In early 2012, this amount rose to 250 Maloti.

adult population rise as a result of HIV, and crisis fostering becomes more prevalent, the need for interventions to support caregivers becomes more important.

Familial affection in conjunction with the expectation that extended kin will care for orphans, helps to protect children from abandonment or institutionalization.

However, HIV has limited the number of healthy and available caregivers, and children like Lebo and his siblings often find themselves in loving but struggling and unstable homes. Patterns of care are similar for children orphaned for any reason; however, AIDS has been the primary cause for a dramatic increase in the number of orphans. Crisis fostering is preferred to abandonment or institutionalization in most cases, but it marks a decrease in the quality of care that orphans are receiving. As Cheney (2010) notes, kin do not want to be relieved of their filial responsibility, they want to be relieved of their poverty. The emergence of matrilineal care must be understood as firmly embedded in a particular context that is at once open to kin-based fosterage, but is also constrained by this pervasive health crisis.

Lesotho has high rates of malnutrition resulting from food shortages and food insecurity, and these rates have risen over the past ten years (Lesotho Ministry of Health and Social Welfare 2005). Thus, it is not surprising that Basotho place high importance on the physical aspects of care. When caregivers were asked about what a child needs for proper growth and development, they emphasized food, clothing and cleanliness. 'M'e Marefiloe said, "For a child to develop normally, they need to eat well, yes. They need to eat well, and to be washed. Like washing her clothes and washing her. And the child will be looking good, if I'm feeding her well, and taking good care of her. Yes." This is evident when children came to town for their appointments at the hospital, or when they

went to their local clinics, they were always clean and wearing their best clothes. One Friday, while visiting Letlo, we counted his pills and found that he was going to run out of antiretroviral medication before his next appointment, which was set for the weekend when the clinic would be closed. We advised his grandmother, 'M'e Mapole, to take him to the clinic that day; however, because we had come by motorcycle, we were not able to give them a ride. Instead of setting off for town immediately, which took them about two hours by foot and taxi, his grandmother insisted on bathing him, even though the child looked and smelled perfectly clean. She spent the better part of an hour getting water from the tap and heating it up for his bath. 'M'e Mapole took excellent care of Letlo. She was extremely diligent about keeping him clean; not only for his benefit, but as an outward sign to others that she was an adequate caregiver.

Although I encountered many examples of excellent care – many of which I have already detailed – not all caregivers were able to care for the children without support. Caregivers providing inadequate care can generally be divided into two categories: those who lack resources and means and those who are neglectful. In my observations, the majority of children that were receiving inadequate care fell into the former category. In many of these cases, the caregiver had the desire, but not the means or physical capacity to provide for the child. For example, elderly caregivers, like Lebo's grandmother, struggled because of old age and deteriorating health. The village environment can also be very harsh for children with weak immune systems, particularly the cold winter months. It was common for children who had been rehabilitated in the safe home to become ill shortly after returning to their villages because they had become accustomed to a warm, sterile environment, and a diet high in protein. During my fieldwork, Matseli

and Lerato, both HIV-positive, and both at the safe home for over six months, had to be hospitalized shortly after their return home because they struggled with the adjustment to the new environment – this, despite having loving and dedicated caregivers.

Structural barriers such as poverty, and resultant malnutrition, inadequate transportation, and a shortage of material goods such as household supplies and clothing, also create challenges for caregivers. For example, Sebetsi, age 3, is the youngest of four children. Their mother passed away a year after Sebetsi's birth, and the children then lived with their father. He often received contract work from the government to repair roads, providing essential income for the family. However, this meant that the children, the oldest of whom is ten years old, were left by themselves during the day. I visited them three or four times with the outreach workers and they were always playing by themselves, unbathed, and with torn clothing. Sebetsi's father worked hard to care for his children, and the challenges he faced were not a result of neglect, but rather, circumstances relating to poverty and a diminished network of support.

Malnutrition is also a major problem relating to poverty that rarely indicates neglect or indifference. Most malnourished children are lacking sufficient protein because it is costly. Exacerbating this is the fact that children with undiagnosed HIV or TB can have lowered appetite, and will often fail to thrive regardless of what they are being fed. For this reason, MCS's nutritional assistance consists mainly of milk or formula and protein in the form of soy, beans, peas, and canned fish, and at the hospitals and clinics malnutrition is treated with Plumpy Nut, a peanut-butter like paste high in protein, fat, and nutrients.

Poverty, in part caused by the decline in Lesotho's remittance economy, has resulted in a decrease in household income. As a result, families struggle financially to care for their own children, let alone any additional children under their care. When discussing the challenges of orphan care, poverty was the most common problem mentioned by caregivers. Specifically, caregivers frequently mentioned that there was not enough money for food, clothes, shoes, Vaseline, soap, candles, and school fees. I also observed many families struggling with the high costs of funerals. Many caregivers were willing to provide care, but struggled with the expenses associated with childrearing. 'M'e Matloane, a young mother and caregiver for three orphans - her husband's nieces and nephews - said, "Sometimes we go a long time without having any food. And some things like clothes and shoes, and you see that they are not good and I don't have money to buy new ones, and they delay to have them". Although it is common to experience cash and protein shortages, it is rare for people to go without food altogether. The majority of people are able to borrow maize to make *papa* from neighbors or family members on the basis that they will pay back in kind at a future date.

In addition to the challenges of caregiving associated with poverty, structural violence, and crisis fostering, HIV adds a complex and challenging layer to the duties and responsibilities of caregivers. Fortunately, in Lesotho, ARVs and TB medication are free, as are medications for orphans. However, the costs of transportation to clinic visits, proximity to health facilities, and other familial responsibilities are often prohibitive factors for caregivers. Of the 21 caregivers I worked with closely, eleven were caring for HIV-positive children (nine of these were orphans, and two were being cared for by their mothers). As of February 2010, 21.6 percent of the 366 children in MCS's database were

confirmed HIV-positive, while the status of another 30 percent was unknown. The staggering reality of these statistics is keenly felt by Basotho, where HIV is present in most homes. 'M'e Masello related an increase in orphans to her frequent attendance at funerals:

MP: There are many more [orphans] now. There were not many people dying in the past. But nowadays, week after week, we have a funeral. Week after week, week after week, we just bury many people. Not one person.

EB: Why do you think there are so many orphans today?

MP: Because of the death of their parents. And they die, like if it's a woman who dies first, the husband will come after. And if it's the husband who dies first, the wife will come after.

Others noted the frequency of grandmothers caring for orphans in their own villages.

The majority of caregivers attributed the increase in the number of orphans to AIDS, as they were confronted with the evidence of this trend on a daily basis.

Caring for a child with acute HIV or associated opportunistic illnesses such as TB, oral thrush, malnutrition, diarrhea, and severe rash is physically and emotionally draining, and limits the ability for a caregiver to maintain employment, complete housework, work in the fields, and care for other children. In addition, the health of the child is often directly related to the health of their caregiver. An able bodied caregiver is able provide better care. In the case of HIV-positive mothers and children, an undiagnosed and untreated mother often indicated an undiagnosed and untreated child. I repeatedly witnessed the illness and nutrition of the mother and child deteriorating in tandem. Because of this, caregivers frequently began to care for children at the height of their illnesses, shortly after the death of their mothers. 'M'e Mapoloko described what it was like caring for Joki before he was receiving treatment and assistance:

It's difficult to take care of the babies. It's difficult, and he was very sick, Joki...Yes, 'M'e. He wasn't [healthy] like this. He had a rash. And he had a

swollen face like he still has now. He was coughing. He was crying during the day and night. He was scratching himself. And he had diarrhea...Ah, it was difficult, because I was not sleeping during the day and night.

The burden of 24-hour care would be difficult for anyone, let alone an elderly woman of 77.

'M'e Masello came to care for Lebo at the height of his illness, and had to spend three months at the hospital, leaving his brothers and sisters at home. In the children's ward at the hospital overworked nurses only provide assistance with the doctors' rounds, and administer medication and treatments; they do not provide everyday care.

Therefore, a caregiver must be present at all times to feed, bathe, and generally care for them. The 'M'e Masello describes her experience:

He was very sick. He nearly died. He was just like that... And we were admitted at the hospital for this many months [holding up fingers], three. And I asked for support at the babies house [MCS] not knowing what I'm going to do to feed him because I didn't have anything. He grew up there. He was very sick, *kanete*.

Without MCS's help, 'M'e Masello would have not been able to buy food while at the hospital or pay for her hospital bill. Her meager pension of 200 Maloti per month was not enough to provide for her household, even without considering the special needs of a child like Lebo.

'M'e Masekha also described her experience caring for Thapo when he was very ill. Thapo came to his grandmother several years ago, before HIV-patients had access to treatment. She keenly felt the stigma of others and was forced to care for the child by herself.

MS: *Kanete*, I'm happy. I was not expecting him to survive. He wasn't looking like a person.

NL: Was he very sick?

MS: He had marasmas [severe malnutrition]. And he was not looking good. I could not wash him in front of other people. I was even afraid to take off his clothes in front of other people. And I was very patient and it was helpful to me.

Fortunately, with treatment and nutritional support, Thapo is thriving. His grandmother takes excellent care of him, but she also now has the support of other relatives for whom HIV/AIDS is more familiar, and thus, less frightening.

Several of the caregivers with whom I worked also cared for their daughters during the late stages of their illness. Their daughters would leave their husbands' villages because they were not being properly cared for during their illness. They then returned to their natal homes in order to receive care, often with a sick child accompanying them. Kotsi, Tsepi, Thapo, Hopolang, and Matseli all returned with their mothers to their natal homes, and all of their mothers died shortly afterwards. Caregivers recounted these experiences as being particularly challenging. Thapo and his mother came to live with 'M'e Masekha when they were both very ill. She describes this difficult experience as if she was caring for two babies:

EB: And what was it like caring for his mother?

MS: It was difficult. She had vomiting and diarrhea, vomiting, diarrhea...Because she had diarrhea and I was supposed to wash her like a small child. I was just washing her again and again and again. Changing the clothes time and time again...Because they came both sick, I didn't know what to do. I was still taking them to Sesotho doctors. She passed away because there was no one helping me to take her to the doctors. She was very sick... She didn't have time...

EB: Was it a lot of extra work for you while she was sick?

MS: Yes, it was difficult, because they were both wearing the nappies, and I was changing them both. I was changing the mother, then changing the baby, then changing the baby, then changing the mother, even at night. Even at night.

This level of care is made profoundly difficult by the challenges of village life where there is no electricity, no running water in the homes, and transportation is limited.

Sadly, by the time Thapo's mother arrived home, she was too sick to recover. Many of

the mothers died shortly after their arrival at home. Ntate Kapo's describes the death of his daughter, Kotsi's mother:

His mother was married, and she got divorced, and she came back home. She was sick, and she came back sick. And when she arrived here, I took her to Mokhotlong Hospital. Her stomach was swollen, her stomach was swollen. And when she arrived at the hospital, she was not able to do anything, and she was not taking the drugs correctly. And when I arrived there to see her, the nurses told me that my daughter is not taking the drugs and she refuses to take them. And she said she wants to go to her home. *Kanete*, when I arrived there I saw her that she wants to fight, she wants to go home, and she wants the nurses to give her the pills to take home. They don't work on a swollen stomach. They just gave her pills only. *Kanete*, I agreed, they discharged her and she came back home. And she arrived at home and took three days, and she was not helpful, even when we were taking her, I asked some people to take her until she arrived down there at the road, and I asked some men to help me to carry her...to help me to carry her home. She was carried when she arrived home, and she took three days only, ah ah, there were two, and on the third day she died. And I passed the message to the parents on the father's side, but they didn't come when I buried her and I cut the *thapo*¹⁰⁵. And they didn't come even now.

'M'e Matlotliso, Ntate Kapo's mother, praised her son for the care he took of his daughter during her illness. Ntate Kapo was very close with his daughter, whom he had raised on his own after being deserted by his wife. She said he cared for her until her death: "She died in his hands. Yes, she died in his hands, the girl." The tension that exists between the maternal and paternal sides of the family is exacerbated by illness, and by the affinal kin's failure to properly care for their sons' wives. In several cases, it was used as justification on the maternal side of the family to assert their right to the children.

Once a child is stable and generally healthy, adhering to a complex medication regimen and attending doctor's visits is a significant challenge as well. Chapter 5 provides a nuanced overview of adherence challenges with ARVs, but I will briefly

¹⁰⁵ *Thapo* is a strip of black cloth that mourners wear around their necks. It is cut approximately a month after the funeral. The time of wearing the cloth varies with families, but a month is typical.

examine the challenges specific to caregivers with regards to HIV treatment here. 'M'e Nthabiseng provided the following insight into caregivers' adherence challenges:

I think the hardest part is understanding the use of medication, and what this medication does to these kids. Because sometimes they think it's like, ok, they treat if you have a cold. Because sometimes a kid would have one particular illness, and maybe through the process where they go see doctor, whatever, and they end up starting ARVs. So, if that one particular illness - for instance if there was rash, or anything - upon starting medication if that rash kind of goes away, they kind of feel like, "oh, that treat's rash". So, they don't understand that this is the lifetime, these are the doses, do take the meds, we need to come for appointments. So, I think this is kind of confusing, especially when there are pills and you take half in the morning, I mean half at night, you take one in the morning. One of them you take once at night. It's like...especially with elderly people, illiterate people, it's hard to deal with this medication. Adherence - it's hard. It's really hard. But, I think people are trying their best.

Care for an HIV-positive child who is responding well to treatment consists of twice-daily medication of various dosages at the same time every day, as well as a monthly visit to the clinic. Of course, there are also innumerable problems associated with HIV that require additional treatment and care, and these things complicate the job of a caregiver. Many caregivers unwittingly make mistakes, and with ARVs, these mistakes can be fatal.

An 8-year-old MCS client passed away unexpectedly. Although the immediate cause of her death was not confirmed, her medication had been changed from three separate ARVs to a combination of three medications in one pill called Triomune. The combined three-in-one pill is designed to help improve adherence, but in this case, the family thought they were supposed to continue with the old medication as well, and for four days doubled her dose. It is likely that she was not taking the double dosage for long enough to overdose, but this error underscores the types of challenges that loving caregivers face in caring for HIV-positive children. I was with the outreach team the day we took her body from the mortuary back to her village. She was wrapped in a blanket in

the trunk of the SUV. Her calm looking face was covered with the blanket and I kept looking back to ensure it she not come unwrapped. Her family had prepared a rondavel to receive her body – it was cleaned and emptied of all furniture. I could hear her older sister wailing in an adjacent rondavel. We paid our respects to the family and left. It was a heartbreaking and unnerving scene, and one that repeats itself too often in this country. This family was in mourning, and had clearly cared for and loved this child for 8 years – a long time for an HIV-positive child to live considering the recent availability of ARVs. As ‘M’e Nthabiseng said, people are trying their best, but at times the complexity of the illness and the treatment in this environment creates insurmountable challenges for caregivers.

In addition to the physical challenges of caring for an HIV-positive child, there is an emotional toll that can get overlooked as the child’s physical needs get priority. A sick child requires more nurturing and emotional investment on the part of caregivers. However, the sad reality is that many of them die, and more will die during childhood even if there are dramatic changes in the availability of biomedical treatment in southern Africa. Despite this, caregivers continue to invest emotionally in children. It is encouraging to note that many caregivers understand that HIV is incurable, yet they are very attached to the children in their care. Letlo’s grandmother, for example, has not tried to remain distant in any way, despite her grandson’s HIV-status and the severe chronic respiratory problems that will likely shorten his life. I witnessed this closeness on many occasions.

Matseli’s grandparents felt a great loss when he passed away unexpectedly. His grandmother expressed her surprise, “He wasn’t even very sick. He didn’t lose any

weight. He was playing. I was getting Sesotho clothes for him so we could take his photo...And he was so clever.” However, they do not seem to regret the energy and love they invested in him during his short life. His grandmother ‘M’e Maliehi thinks of him fondly. She said she remembered him often in the morning because he used to wake up and call out to his sister Pompene. And when ‘M’e Maliehi would ask his sister to go out early to boil the water, he would call from his bed “Go out! Go out!” I asked if it made her happy to remember him she said, “Yes, really, we remember his words, they are still in our hearts. He would be saying, “*Ntate? Ntate? Ntate?*”... Yes, he was making us happy.”

Kotsi’s grandfather, Ntate Kapo, described how distraught he was when Kotsi was admitted to the hospital: “The most difficult thing is this disease that he has. He had been sick and I lost hope. I lost hope when he left here.” Fortunately, Kotsi, now four-years-old, is thriving under the excellent care and love of his grandfather. On one visit I observed him playing energetically outside his home near where we were talking; he picked up a stick and was trying to knock some leaves off a tree with it. Every so often Kotsi took a break from playing to stand by his grandfather and put his hand on his knee to momentarily connect with him then returned to playing. Kotsi loves to go everywhere with his grandfather. They have a sweet relationship that clearly brings both of them a great deal of joy. Like Ntate Kapo, Kotsi’s great-grandmother thought he was not going to live. She, too, was thankful for his good health: “Yes, now he is doing well, he is a man. And even now if he comes, he likes talking. He talks, *jooo!* He is not like when he was taken to the camp at the hospital. Ah, and that time, we were saying that he was leaving us. But, when he came from the hospital, and [MCS] helped him, ah ah, he is a

child, *kanete*.” If Kotsi had died, life would have been simpler for his family, but clearly the bond they have with him is strong and mutually beneficial, despite his likely life-shortening illness.

The majority of these examples described the many difficulties and hardships that could lead to sub-optimal care for children. Sadly, I did encounter a few cases where neglect and indifference contributed to the illness of the child. Lesotho’s Child and Gender Protection Unit (CGPU) is part of the police department (Lesotho Mounted Police Services) and is responsible for dealing with cases of abuse and neglect. However, outside of the Maseru district, the ability for the CGPU to adequately respond to community needs in rural areas is limited by a lack of places of safety, like MCS’s safe home (UNICEF 2009b). I only encountered police intervention in child abuse and neglect three times: once because MCS referred a 2-year-old boy to CGPU whose grandmother ceased taking him to his ART appointments; and twice because of abandonment where the police were attempting to locate the childrens’ mothers to take them to court. In both of these latter cases, the children stayed temporarily at the MCS safe home, the only temporary residential facility for children in the district. Extended kin usually handle such cases, with intervention or mediation by chiefs.¹⁰⁶ In cases of abuse and neglect, kin-based solutions are not only culturally salient, but are often the only option.

One young boy, Reanetse came to the MCS safe home in 2007. He was extremely ill with undiagnosed HIV. He was treated for almost a year and returned to his home a happy, energetic, and healthy young boy. However, even though MCS paid for

¹⁰⁶ Referrals to MCS often come with a letter from the chief, asking for help and giving permission for the child to be placed in the safe home if necessary.

his transportation to the hospital to receive his medication, his grandmother often failed to come, and even when she did, she did not adhere to his medication regimen. 'M'e Nthabiseng sent the police to talk to the grandmother and Reanetse's older sister about taking better care of him, but this tactic failed to work. Several months later, I checked at the clinic to see if Reanetse had been receiving his medication. He had not. Unless someone else intervened on his behalf, Reanetse would not live for long without his medication. Even if he did restart his medication, having defaulted several times in the past would severely impact the medication's effectiveness, and put him at risk of developing resistance.

I met 7-year-old Amohelang in the neighboring district of Thaba Tseka. She had severe untreated oral thrush with open sores all over her lips and tongue.¹⁰⁷ She was on ARVs and when we counted her medication in order to ensure she had enough to get to the next appointment, varying amounts of dirt-covered pills remained. As I discussed in Chapter 3, Basotho are normally very careful about keeping their homes clean. However, in Sabina's rondavel, there were hundreds of flies all over the walls, and a large pile of dirty dishes also covered in flies. Her grandmother was there, and seemed not to notice the unkempt condition of the home. Given these rare outward signs of neglect, and considering that even the most loving and well intentioned caregivers have trouble adhering to the complex ARV treatment schedule, it is doubtful that Sabina was receiving her medications correctly. One assumes that if there were other capable family members aware of her situation, she would not be living with her grandmother.

¹⁰⁷ Oral thrush is an opportunistic infection associated with HIV that results in sores around and inside the mouth.

None of the caregivers I spoke with admitted to doing a poor job of caring for the children themselves, yet they were able to point to other caregivers who they felt were inadequate, reinforcing their conception of a culturally acceptable standard of care for children. Although people expected children to do work around the house, if a child was required to do too much work, or if the caregiver was perceived as being lazy, others were highly critical. Nkhabu's grandmother, 'M'e Marefiloe, who provided well for Nkhabu, but was an alcoholic, was critical of Nkhabu's other grandmother who was caring for Nkhabu's two brothers. She said, "Those boys are gathering wood, and the grandmother is not doing that. She would rather take the roof of her house to make a fire, and it's these children who gather the wood. And they are fetching some water." Basotho have a balanced expectation of children's work, and this expectation helps to protect children from overwork through social pressure.

The physical, material, and emotional challenges of care for an HIV-positive adult or child are profound. Caregivers' challenges are exacerbated by structural issues such as poverty, and access to medical treatment, and by the complexity of treating HIV¹⁰⁸. Kin-based care is both a culturally salient continuation of a history of fostering, and a necessity given the prevalence of HIV in Lesotho. However, fostering practices have shifted to cope with the changing demographic makeup of the family caused by HIV towards a model that favors and justifies increasing matrilocal care within idealized notions of patrilineality.

Ideal versus practice: Patrilineal descent and matrilocal caring practices

The majority of fostering arrangements in Lesotho are made within the extended

¹⁰⁸ The biocultural issues that stem from the intersection of illness and culture are more fully explored in Chapter 5.

network of kin. Although I encountered a few examples of children living with non-kin, it is extremely rare. Despite the flexibility in household makeup in Lesotho, there are rules that guide the decision making process when determining caregivers. As discussed in Chapter 3, in theory, if bridewealth is paid, the father's family has the responsibility for, and privilege of, caring for the children born to their sons. Children may live with their mother's relatives if it is mutually beneficial, but if a child of married parents is orphaned, it is technically the father's family who is responsible for finding that child a home (Murray 1981). Basotho still hold strong ideals with regards to patrilineal inheritance, marriage practices, and the ownership of children. Yet, as Alber notes in his study of child fostering in Benin, the lived experiences of people are "more flexible and varied than the rules suggest" (2004:36). Most Basotho are surprisingly flexible when it comes to the locality of care, and agree that it is best to look at the family situation to ascertain the best environment for a child. Frequently, the mother's family is found to be better equipped to care for a child, which is contrary to the "official" rules of fosterage within the patrilineal system (Murray 1981). Of the 21 caregivers I worked closely with, 13 of them were caring for children of a female relative. The most striking aspect of this emerging system of care is the way in which matrilocal care is being negotiated within the patrilineal system, as potential caregivers are using the rules of patrilineal marriage and descent to make claims for children outside of the patrilineage. As contemporary kinship theorists such as Borneman (1997) and Butler (2002) suggest, people adapt and stretch rules in order to privilege the quality of care over other more rigid aspects of kinship, such as descent and alliance.

Deciding on a home for a child is often a complex process of negotiations between family members on both sides. This is exacerbated by the crisis that frequently precedes orphanhood, such as the death of a parent. If a maternal relative believes that they are best able to care for a child, they often invoke the rules of patrilineality in order to make their case. For example, if a husband never paid bridewealth, or had left his wife, these will be used as arguments against the presumed rights of the paternal family. However, these same circumstances can be ignored if the paternal family is providing adequate care for the children. Maternal relatives justified their rights as caregivers by emphasizing the legitimate pathways to matrilineal care within a patrilineal system, namely, mutually beneficial caring relationships for companionship and household assistance.

The following examples demonstrate some of the ways caregivers negotiate for children using the rules of patrilineality in order to justify alternative care patterns. As discussed above, several maternal relatives (mostly grandmothers) came to care for their daughters' children because the mothers brought their children with them when they returned to their natal homes during their illnesses. After mothers died, the grandmothers would often keep the children on the grounds that the paternal family had failed to care for their daughter while she was sick, or because the paternal family had no interest in the children. For example, Kotsi's mother had returned home during her illness, and passed away in her father's arms. I asked Ntate Kapo about following kinship rules in a general sense, and unprovoked, he used the opportunity to explain why it was his right to care for Kotsi and his brother:

And now let's say their mother came with them and she was very sick, do you hear? Let me tell you. Her marriage was already not good. She was not living

well when she was coming here. And I was the one looking after her until I took her to the doctors and she died. And after she died, I called her parents-in-law [*babohali*], but they did not come. And I did all the things by myself. And they came after some months saying they are coming to take the children, and I asked them, ‘The children of whom? Because you did not even pay *likhomo*.’ Because they did not even come when their mother died. And they went back without anything. They didn’t have anything to do. They would not take me to the court because they did not pay *likhomo*.

Kotsi’s paternal grandparents were not able to make a legitimate claim for him and his brother because they did not pay bridewealth according to Sesotho custom, and they did not take care of their mother when she was sick. Although most people negotiate care without involving the courts, it is a possibility, and Ntate Kapo is comforted that the paternal relatives do not have this option. Ntate Kapo is extremely close with his two grandsons, and would fight to keep them if their paternal grandparents tried to make a competing claim. Yet, he is still angry with them for their failure to care for his daughter, to pay bridewealth, and to show the proper respect at the time of her death. As Feeley-Harnik (2008) notes, burials are key to creating and maintaining social relationships. The paternal family’s failure to attend their daughter-in-law’s funeral helped Ntate Kapo to justify his claim to her sons.

Ntate Kapo is an advocate for following the rules of “Sesotho culture”. He believes that orphaned children should go to their father’s side. Curious about this viewpoint given his current living arrangements, I inquired about situations where matrilineal care is allowed within the bounds of patrilineal descent:

EB: So, are there any situations where it’s better if the child goes to the mother’s side?

KM: Yes. There are some reasons. If my daughter, there is someone who has taken her. And in Sesotho culture...and they should be in agreement with the parents to show that their children have gotten married. And if there is no marriage, it is as if she was just living with him only. And she will come back at her home.

NL: What are the things that need to be shown to show that there is a marriage?

KM: The agreement of the marriage.

NL: Like what?

KM: If *likhomo* are there, if that person has paid *likhomo* to show that he is married.

NL: Meaning, the child can go to the mother's side only if the *likhomo* is not paid?

KM: Yes.

In this case, he used the lack of bridewealth as a strategy to make a claim about kinship, which allowed him to care for his grandsons.

'M'e Malefu cares for her daughter's two young girls. Unlike Ntate Kapo, she took her in-laws to court in order to ensure her right to the children, even though the paternal grandparents showed no interest in having them:

EB: And, how long ago did their mother pass away?

ML: This is the second year.

EB: And was she married?

ML: *Ach*, yes, but she was stolen, then after they were not able to pay *likhomo*, so she was not married.

NL: Not married how?

ML: Because they did not pay *likhomo*. And when she was sick, they were not taking care of her until she came back home. And after that, I was the one caring for her. And they didn't come at all. I took her to the hospital until she died. Even when she died, they didn't come for the funeral. And after that, we went to ask for the children. The children were at the house where she was married. And we went there and asked for them because their father died before the mother. And we went to the court and we told those people that we want our children because the parents of their father did not pay *likhomo*. And they gave us the children. And we came with them here.

EB: Did the paternal grandmother also want to take the children?

ML: No, they didn't say anything. They were told when my daughter died, but they didn't come. And my husband called them to the court because he didn't see them coming. And my husband at the court showed that he wanted the children because the parents on the father's side didn't like his daughter. And they didn't pay *likhomo* and he didn't think they would take good care of her children.

NL: Meaning, when you got to court, they didn't show that they wanted the children too?

ML: Ah ah. Even the letter that was given by the chief [from the father's side] when they were told about the death of my child, and the chief from that village on the father's side said [in the letter] the grandparents don't have a problem if we take the children.

EB: Why did you have to go to court if the other family didn't even want them in the first place?

ML: We went to the court because we wanted things to be certified. Not to agree only. We wanted something which certified that we have taken the children.

'M'e Malefu repeated many times that bridewealth was not paid – this was her legal claim to the children. Yet, she also emphasized a lack of care on the part of the paternal family as the primary motivation for taking the children. They did not take good care of her daughter, and she feared they would not take good care of the children. If the family had exhibited the ability to take good care of the children, perhaps 'M'e Malefu would have ignored the failure to pay bridewealth.

The Ntho family was also caring for their grandchildren because the paternal grandparents did not care for their daughter during her illness. Ntate Kanelo said, "The parents on the father's side were not taking care of the mother. And that's why we took her baby and the brothers and the sisters are also living here. They were not taking care at all." However, they felt deeply insecure about the lack of formality in their arrangement:

KN: When we die, what is going to happen? Because we don't have a boy¹⁰⁹.
What is going to happen to our houses? I don't know.

MN: We are not the same¹¹⁰.

KN: It's what I think.

MN: Me, I just think what if *Ntate-moholo* and I, we can both die, who is going to take care of these children of my daughter? Because we are the ones taking care of them. Because, on the father's side, they seem not to take care of them. And I'm always praying to God to help me so that I can live for a long time and they should be old enough to do things for themselves.

EB: So, if they are old enough when you pass away, can they work your fields and take care of your houses?

MN/KN: Yes.

EB: So, that is what you hope for?

MN: Yes, I pray that to God.

KN: Yes, 'M'e.

EB: I hope so too.

KN/MN: Yes, 'M'e.

¹⁰⁹ To inherit their property.

¹¹⁰ 'M'e Maliehi is saying here that she and her husband, Ntate Kanelo, differ in what they worry about.

Even though the Ntho's had negotiated the right to care for their daughter's children, and the father's family had shown no interest in them, years of care would not be enough to ensure that the children belonged to them. Ntate Kanelo worried, "Because we are the parents of their mother we have to take care of them. When they grow up and if they want to go to that family [father's side] they will go because they are still using their surname." When the Ntho's daughter married her husband, he paid four cows, a partial bridewealth payment. Although incomplete, this partial payment created insecurity for the Ntho family. Bridewealth payment – or the lack thereof - is one of the strongest factors used for negotiating locality among orphans. However, the motivation for making such a claim is rooted in the desire to care for the children, not to settle the accounts regarding any bridewealth payment.

The emphasis on bridewealth payments in negotiating caregiver rights is notable in that in practice bridewealth exchange is a fading tradition among Basotho, yet it remains important as a cultural ideal. All of the elderly caregivers had received some bridewealth at the time of their marriages, whereas only a handful of the young parents had received any. If a girl is not married, the father and his family are not expected to partake in raising the child, and the family does not even acknowledge the name of the father. When processing client intakes for MCS, it was normal procedure to collect information about the father. However, if the mother was unmarried, the common response was that the father was unknown. In Lesotho there are "maintenance" laws that require men to support their legitimate and illegitimate children, however, these laws

have major structural and cultural weaknesses that make such laws difficult to enforce, especially in rural communities (Armstrong 1992).¹¹¹

Bridewealth, as a negotiating tool, has mixed implications for gender equality and the role of women in Lesotho, and its fading prevalence is evidence of both compliance and resistance. Bridewealth recognizes women's value in terms of production and reproduction, but it can also create pressure for women to stay in an abusive marriage. It also threatens a woman's security as a mother because, if enforced, it would prevent her from leaving an abusive marriage without abandoning her children (Eldredge 1993). Although bridewealth payment is in decline, it still carries weight as a cultural ideal when caregivers are negotiating for the rights to foster orphans. This argument is only used when it works in favor of the family that is making claims for the child; in cases where it is not a viable negotiating tool, or it is irrelevant, it is ignored. For example, two grandmothers were caring for their daughters' children even though bridewealth had been paid, at least in part. In contrast, another grandmother was caring for her paternal grandchildren even though bridewealth had not been paid. In these cases, quality of care, which is closely linked to willingness to provide care, was the deciding factor in finding a home for the children.

Not all caregiving arrangements are negotiated based on the presence or absence of bridewealth. The negotiation of care for Lebo and his siblings is interesting in that even though 'M'e Masello was initially not interested in caring for the children, she was

¹¹¹ Lesotho's maintenance laws require women to demonstrate that the father failed to provide for the child. The laws do not cover cases where paternal support is irregular, and does not require the support of fathers where the mother is capable of supporting them on her own. These laws also do not recognize potential contributions of extended kin (Armstrong 1992).

still deemed the best person by the paternal family and therefore the children were left with her. She explained how she came to care for the children in great detail:

After the death of [Lebo's] mother, when we were at the funeral, and the mother left him still young. And they said that I should take the child. And I said, how will I take the child yet I'm sick. And the thieves have taken all my animals. And at least here, he will have milk to eat, and I refused to take him. And you know that the thieves have stolen all my animals, and this child is yours not mine. And after I buried the mother, three days passed, the daughters-in-law of that 'M'e [the paternal grandmother] and Lebo's father they came and brought this baby saying their mother said this child is supposed to be here. She doesn't have energy to take care of him. The baby how? Yet, I said I don't need him. And they left him. He was very sick. He was very sick. He nearly died. He was just like that. And I told the chief that there are some people who have brought the child, and I could have called you [MCS] but I did not. And the chief said, 'they were not supposed to leave the child because the child is theirs'. And I said, 'oh the child is very sick. Let me take him to the doctor.' And we were admitted at the hospital for this many months [holding up fingers], three. And I asked for support at the babies house [meaning MCS] not knowing what I'm going to do to feed him because I didn't have anything. He grew up there. He was very sick, *kanete*. They helped me a lot at the baby's house there. And they were taking him to the privates [doctors] doing what and what and what, and they are working those doctors there. A lot, *kanete*. Yes.

'M'e Masello's situation provides an excellent example of the complexity of crisis fostering. She felt that she did not have the resources or physical capabilities to care for Lebo and his siblings, yet there was no one else willing to care for them. However, this does not indicate any lack of love or affection on her part. She was particularly close with Lebo before her death in 2011, and they were very affectionate with each other. After three years of caring for the children, she had a more positive view of her caregiving role:

MP: They are so helpful, *kanete*. They are so helpful. There is no one I'm related to in this village. And I could have died in the past because of having no food and from the cold. And these children are cooking for me and making a fire for me. And they give me food.

NL: What would you do if these children were not there?

MP: I could have died in the past. Past, past, past. *Kanete*.

However, just because she was deemed the best person to care for Lebo and his siblings, this does not mean that they are getting the care they need. Until recently, 'M'e Masello was physically and mentally able to provide for the children, especially Lebo whose HIV diagnosis was particularly complex. However, in the year preceding her death, 'M'e Masello had not been able to provide Lebo with the proper care, and because of it, his ARV adherence declined.

It is common for Basotho to send their children away until they are older, and then have them return to help with work in the house and fields. Now that Lebo's siblings were older (the eldest was 16) the paternal grandparents expressed interest in them. Although the older ones occasionally visited them, 'M'e Masello did not want them to leave her:

EB: Do Lebo's father's parents ever help you at all?

MP: They are still alive.

NL: Are they helping you?

MP: No. Not at all. Not at all. *Hao*. Not at all. Not at all. They don't do anything for all these children. The older ones once went there and they were very dirty, you could only see they were people when they were smiling and because of their eyes. They were black...like...black. You would not like to look at them.

Kanete.

EB: So do they still go there?

MP: There?

NL: Yes.

MP: Last week it was only one who went. The elder one. And now, now, they like to have them because they do work at their household. And they like them to go back. And they like them because now they have grown up to help.

EB: So are they going to try to take them back?

MP: No, they are just talking. Now you know them.

'M'e Masello thought the paternal grandparents did not care properly for the children.

However, her motivations were not purely altruistic – she also benefited from the children's assistance with chores. Household labor fulfills a practical need, but is also a way of creating social belonging and solidifying household membership. Like Ntate

Kapo, there was tension between 'M'e Masello's desire to have the children in her household, and anger towards the paternal family for not taking proper care of the children. This complex interplay helps explain why child fostering is sometimes aptly called child circulation (Leinaweaver 2005; Walmsley 2008) because it is an ongoing process of movement and negotiation. For example, when 'M'e Masello died, the negotiation process for the children's care began again. Matseli's paternal grandparents may decide that they want the children to return to their village, and the Ntho's will have to let them go, or negotiate to keep them, which might include the chiefs, or even the courts.

The animosity that can develop between families during negotiations regarding the locality of childcare can create problems for the children. Reamohetse was forced to go from caregiver to caregiver as her family argued about who was best suited to care for her. During the year I was there she lived at the MCS safe home. Meanwhile, her father and aunt, who live adjacent to each other, were fighting because the father had taken Reamohetse back to his home without discussing it with the aunt, then wanted the aunt to take her back after he realized that he was doing a poor job of caring for her. Ultimately, Reamohetse's father would have liked her to live with one of his sisters who lives in South Africa, and who is already caring for one of his daughters, but he was trying to get the appropriate papers for her when he was put in prison. When I last saw Reamohetse, she looked thin and unhappy, and cried whenever she was not being held by her aunt. Reamohetse's situation emphasizes both the advantage of having a stable caregiving situation, and the disadvantage of not having a healthy mother. Although a father can make important contributions to a household if the marriage is intact, a healthy mother is

an enormous advantage in Lesotho's current social climate, particularly in terms of health and access to education (Nyamukapa and Gregson 2005; Kang et al. 2008).

'M'e Nthabiseng has the perspective that comes from serving of hundreds of families. Her broad exposure gives her an excellent overview of shifting trends in the community. I asked her about the trends in caregiving:

EB: Do you see certain caregivers doing a better job?

NL: They are doing their best. I would say they are all doing their best. There's no better, as in, because each one will start very struggling, but I think generally, they are doing a better job in providing, based also on what the family situation is. I think in a family that has less kids, there's better care. With more kids, it's difficult. So, most of the families we work with if they have more kids in the family to take care of, and there is no income.

EB: Ok, but, in terms of orphans, not people who are with their mothers, but orphans. Do you find that kids are better off with a grandmother versus with an aunt or the mother's sister versus the father's sister, or something like that?

NL: You know what, I think also that's hard to answer. Because I think what my own judgment or conclusion would be if I had a good relationship with either my in-laws, or my own siblings, or my parents, my child is going to be better off with those people. Whoever I was in good terms with. So if you say mother-in-law and daughter-in-law, in most cases they really don't go along that much. So, if you really didn't like the mother of this kid, it's really hard to adjust in caring for this kid. That's what I've seen. So, I think it's hard to say. It depends on which side the baby, the mom was really better cared for. So, what happens is, if the kid stays with paternal parents because the father, the mother passed away, and they stay with paternal, so they like this kid because it's their son's kid. But, if this kid...the father is still alive but the mom passes away, they see it as her kid. So, it doesn't really get the best care, as, she should go to their mother's side.

Especially when they are still young, they should go to their mother's side. So, it's kind of like how the other relationship situation is. I think the better the situation, the better the care that the kid will get no matter how many other kids are in the family.

'M'e Nthabiseng's perspective corroborates much of the evidence articulated in this chapter. Family situations differ, so does the quality of care for children. Families with fewer children are able to better provide for the orphans in their care, which perhaps is why grandmothers are often ideal caregivers because they are not living with their own young children. Mothers are often not properly cared for by their mother-in-laws during

their illness, and therefore, there is a trend towards care by the maternal family. As many caregivers affirmed, the quality of care for the mother is a good indication of the quality of care, or willingness to care for the child.

Conclusion: The shifting gendered landscape

There is a long history of child fostering in Lesotho, and throughout sub-Saharan Africa (Madhavan 2004). Basotho children move easily between kin for various social and economic reasons, with an emphasis on nurturing strong bonds between grandparents and grandchildren in order to facilitate mutual assistance for both children and the elderly. However, the form and function of fostering in Lesotho is taking on new dimensions as HIV/AIDS limits family members' ability to care for children, and increases the responsibility of caregivers because of the special needs of HIV-infected and exposed children. In addition, pervasive poverty and structural inequalities make the additional costs of orphan care challenging for many families.

HIV/AIDS has undermined Basotho families' capability for kin-based foster care. More children are in need of care, yet there are fewer caregivers to provide it. In rural communities where institutionalized care is virtually non-existent, and government or NGO support is limited, kin-based care is the only option. In order to cope with these pressures, families are organizing themselves by focusing on matrilineal resources. Nonetheless, they are making sense of this model of care within the context of an idealized patrilineal system of child fostering. This is evident in the ways family members negotiate for the care of children. In particular, families attempt to demonstrate their right to the children, often focusing on the presence or absence of bridewealth, depending on which position they wish to take. At the same time, there is an overriding

emphasis on the quality of care that potential caregivers are able to provide.

The day-to-day role of women – particularly elderly women – in this system has not drastically changed: women still do the majority of the carework, despite a slowly emerging population of male caregivers. In fact, women are being called upon to rise to the challenge of caring for an increased number of children – including those with greater health problems – yet with fewer resources. What has changed, however, is the role a woman’s natal family plays in supporting her. In this time of crisis, families are pooling their resources with their daughters instead of their sons. In conformity with the conceptualization of “official kin”, the rules of child fostering are rigid and fixed. In practice, however, fostering practices are flexible and allow for a wide range of household configurations. Caregivers who are trying to legitimate their right to care for a child emphasize its rigidity because it allows them to point to the ways in which the other family is subverting these rules. Matrilocal caregivers are therefore able to negotiate for the care of children while maintaining the dominant patrilineal ideology of care. In doing so, caregivers have been able to represent “practical kin” as if it were “official kin,” thus legitimating matrilocal care within the patrilineal system. In this way, women are simultaneously reinforcing the patriarchal structure of the Basotho family, and resisting it in order to accomplish one of their most important social roles: that of the caregiver.

HIV’s impact on caregiving is also significant in that it provides insight into community responses to demographic changes as a result of a health crisis. Basotho have demonstrated flexibility and adaptability in the face of a crisis in caregiving that, in practice, would seem to undermine the legitimacy of the patrilineal system. One of the primary social constructs that has emerged as particularly flexible are cultural notions

about gender and its role in care. Basotho have capitalized on this flexibility and malleability in ways that both reinforce and subvert normalized notions about gender. Yet, Basotho have maintained a strong ideal of patrilineality despite a trend toward matrilineal care. They have done so by reconstructing their understanding of matrilineal care as legitimate within the patrilineal system under certain circumstances. This has allowed Basotho to maintain social cohesion and continuity, while privileging the work of the caregiver over the location of care.

CHAPTER SEVEN

CONCLUSION: HIV AND KINSHIP - CONTRIBUTIONS AND IMPLICATIONS FOR INTERVENTION

HIV as a kinship disease

HIV/AIDS is a biomedical illness, yet its impact on African communities goes far beyond individual patients' physical response. AIDS scholars have long noted the impact that kinship and culture have had on the epidemic in southern Africa. Problems such as inconsistent condom use, mother-to-child transmission and crisis fostering are shaped by Africans' cultural beliefs, stigma, and social organization. However, most studies only examine a small part of HIV/AIDS – often to understand the success or failure of an intervention – and how ideas about culture and sociality influence it. In this model, HIV/AIDS is the stable component of the equation, bolstered by its biomedical assertiveness, and culture is the external (and often irrational) influence that maps on to the biomedical facts of HIV/AIDS, hampering the efficacy of interventions. In this dissertation, I demonstrated, through an exploration of kinship and caregiving practices, that social relationships, political, economic and historical circumstances, and cultural ideas about illness, treatment and care do not merely attach onto known biomedical truths about HIV/AIDS, thus altering their outcomes. Instead, the intersections of HIV and kinship must be understood as existing in a dialectic that mutually reinforce each other, and that encompass all of these other social and structural factors. The structural, political economic and cultural context of rural Lesotho not only shaped the course that

HIV/AIDS took there, but the disease itself was transformed as it intersected with these contextual circumstances. HIV is a kinship disease because kinship and HIV simultaneously influence each other.

What makes HIV/AIDS unique in its impact on southern African communities is a confluence of factors. First, the astonishingly high rate of HIV/AIDS in countries like Lesotho means that its impact is felt in each household and in every rural corner of the landscape. With a local prevalence rate of 23.6 percent (UNAIDS 2010b), HIV is an integral part of everyday life. More than merely the high rates of illness, however, are the fundamental ways in which HIV intersects with ways of kin-making. It spreads through sexual intercourse and through the life-giving processes of birthing and feeding that are so fundamental to the cementing of social relationships. As a result, HIV-related stigma has spread faster than the disease itself and has been mediated by slow and inadequate political responses and inaccessible ARV treatment. This dissertation has employed a fully biocultural lens in order to examine the often contradictory meanings and practices surrounding kinship and caregiving for AIDS orphans.

Anthropology and social work are well suited to address many of the issues presented here. A biocultural study of AIDS has been of interest to anthropologists since the emergence of the disease. Likewise, the care and protection of children is a quintessential concern in social work research and practice, and is deeply embedded in social work's core mission. These two disciplines provide the necessary theoretical perspectives and practical orientations that allow this research to make fundamental contributions to anthropological theories of kinship and medical anthropology and to social work research, practice and approaches to intervention.

The broad theoretical framework that combines a theory of structural violence (Farmer 2003), local biologies (Lock and Kaufert 2001), and a person-in-environment perspective (Hare 2004), works to provide a holistic understanding of the social and political landscape that has shaped the HIV epidemic in southern Africa. The experiences of Basotho highlighted throughout this work emphasize how everyday negotiations and practices around illness, kinship and care intersect with broader structural factors such as access to treatment, migrant labor, and wider social movements. A narrow focus on either micro-level individual practice or broader socio-political structures alone would miss the important connections between these realms of investigation that this holistic perspective provides. Each of these theoretical perspectives goes beyond the behavior of individuals to encompass the broader social, cultural and structural factors that have shaped the disease.

A theory of local biologies fits well with the view of HIV as a kinship disease because it recognizes biology and culture as being in a co-productive relationship that results in an individual's unique experience of illness. Social work's person-in-environment perspective, like the theory of local biologies, recognizes the contextual, embedded nature of individuals in their environments (Buchbinder et al. 2004; Kondrat 2002), and is therefore well suited to investigations that take place outside of a researcher's own local context (Hare 2004). A cultural humility perspective helps to translate the person-in-environment approach into research and practice. This perspective helps the researcher to recognize the ways their own cultural lens shapes their worldview and the diversity of cultural roles and experiences that exist in any context (Ortega and Faller 2011). Ortega and Faller (2011) suggest that by using a cultural

humility perspective one can avoid the monolithic view of culture that can accentuate power differences. Although Ortega and Faller propose this model for social practitioners working with diverse clientele, a cultural humility approach also works for researchers working outside of their own cultural context. This perspective, which aligns well with the person-in-environment approach, helps to move beyond an explanatory model to one that is oriented towards intervention, social engagement and change.

While it is important to focus on the lived realities of individuals as members of families and communities and to understand HIV in its lived context, it is likewise important to look beyond everyday practices lest we forget the ways in which global economic and political forces – both contemporary and historical – have differently impacted populations. Goodman and Leatherman draw attention to the political economic structures that both influence and compromise human biologies and “threaten the social fabric” (1998:5) of communities. I would further this argument to say that the AIDS epidemic does not merely threaten the social fabric; it fundamentally changes it as part of its emergence and embeddedness in society. The person-in-environment approach already recognizes how social systems shape people’s experiences (Hare 2004). However, this research helps to move the person-in-environment theory forward by emphasizing how a person, as an integral part of an environment, also changes these social systems and structures. This dissertation has demonstrated how individuals’ and families’ experiences with HIV/AIDS has both been shaped by and helped to shape the social, political economic and demographic environment.

In recognition of the larger forces at play, Farmer (2004) moves beyond the “ethnographically visible” to investigate the historical and political economic structures

that make some populations, communities and individuals more likely than others to be vulnerable to health inequalities. The effects of diseases such as HIV disproportionately impact the world's poorest and most vulnerable people. He urges us to remember that we are part of the social order that creates and perpetuates these structural inequalities, and that history, materiality, and biology are all part of the structure that leads to global health inequalities (Farmer 2004).

This dissertation has kept these unequal structures at the forefront of the analysis by incorporating a broader historicized view of Lesotho's progression as an enclave within South Africa. Lesotho has been both the beneficiary and victim of an entrenched migrant labor economy, which has created structures that have led to the unequal distribution and access to lifesaving medical treatments. Yet, the micro-level lens that predominates this dissertation puts these structural inequalities and their impact on individuals and communities into sharper focus. This three-pronged theoretical framework that incorporates the structural, interpersonal and engaged aspects of HIV/AIDS is well suited to addressing the concerns presented in this work, in particular regarding orphans and caregiving. The following theoretical and empirical findings about kinship, care and social change stem from this broad theoretical framework in conjunction with the recognition of HIV as a kinship disease.

An exploration of Basotho caregivers' everyday practices revealed that idealized notions about kinship such as lineality and gender, although often presented in their inflexible idealized form, were far more flexible and adaptable to social change. Basotho used this flexibility in order to adapt to the pressures that emerged with the onset and proliferation of HIV/AIDS. The first – and most readily identifiable – trend was the

centrality of the house as a stable fixture in Basotho social and economic life, even as other aspects of relatedness were deemphasized. In its simplest form, the house is a place where people live and where fundamental acts of kin-making – birthing, caring, feeding, raising – take place. Anthropologists have long noted the house as more than merely a space where these acts of sociality unfold. Rather, it is a place where people “dwell” and the “dynamic” and “processual” nature of the house is key to producing and reproducing social relationships (Carsten and Hugh-Jones 1995). In this way, the house mimics the dialectic and mutually productive relationship between HIV and kinship. Neither HIV nor the house is merely a discrete entity that maps onto Basotho’s everyday experiences and understandings of kinship; instead, they are actors in the production of those experiences and meanings.

The house is a focal point of this dissertation because it is also a reflection of the social and political economic context in which people live. In a time of transition, where adults and children are moving between households because of employment, illness and caregiving, the social geography of the house provides a good indication of these movements. An analysis of household members over time provides a real portrayal of demographic changes taking place. These shifts are important for understanding the broader changes in social organization and in indicating the configurations of people that are sharing the space where kin ties are strengthened and shaped.

It is through an exploration of these movements that I first noticed a demographic shift toward matrilineal caregiving practices. Despite a continued emphasis on idealized notions of patrilineality, in practice there has been an increase orphan care by maternal relatives. The tensions between ideal and practice are fully realized when one explores

the negotiations caregivers use in asserting claims to care for orphaned children. Paradoxically, matrilocal caregivers often position themselves as strong believers and enforcers of idealized rules of patrilineality. By doing so they are able to legitimate their roles as caregivers by demonstrating how the paternal family failed to adhere to these same rules. One specific area where this phenomenon frequently occurred was with the fading institution of bridewealth. Even though bridewealth payments are in decline, maternal caregivers pointed to the ways in which the paternal family failed to make, in full or in part, their bridewealth payments in order to legitimate their caregiving relationships.

The increase in the number of AIDS orphans in Lesotho has necessitated a readjustment in care because of the shortage of healthy caregivers combined with an increase in the number of orphans. Lineality has thus emerged as a flexible cultural resource that has allowed families to find the best possible caregiver in terms of willingness, health, emotional attachment and economic means. This has resulted in an increase in maternal caregivers – particularly maternal grandmothers – as primary caregivers for AIDS orphans. Although strong idealized notions about lineality and kinship can be limiting, they can also be negotiated in ways that create both flexibility and legitimacy to support a variety of caregiving and household arrangements.

In light of this shift towards matrilocal care, and in the slow but visible increase in the number of male caregivers, gender has also emerged as a malleable cultural resource on which to draw in order to respond to the crisis in caregiving. Like matrilocal care, the presence of male caregivers is often understood and reframed in the context of the idealized strength of female care. Male caregivers providing poor care are often excused

because they are not women, whereas those providing good care are equated with women. These flexible gender constructs have contributed to a broader shift in the gendered role of care within an idealized patrilineal system and have protected some orphaned children from abandonment. Male caregivers also present a potential resource that could be harnessed to help lessen the strain on elderly and female caregivers.

Interventions for AIDS orphans and their caregivers

A social work perspective has, from the initial formulation of this research project, been instrumental in guiding both the choice of topic and the orientation towards a pervasive global social problem. This dissertation focuses mainly on Knowledge Development (KD), one of the stages of the Rothman and Thomas (1994a) model of intervention research. As I discussed in Chapter 1, KD research is defined as “empirical research to extend knowledge of human behavior relating to human service intervention” (Rothman and Thomas 1994a:3). It distinguishes itself from other social science research in that it is oriented towards finding solutions to problems that arise in human service fields.

There are numerous specific challenges that arose during this dissertation in terms of orphan care and the social and physical problems that stem from HIV/AIDS related illness and death. However, KD research is not intended to make recommendations for specific interventions (Rothman and Thomas 1994a). Instead, KD research contributes more broadly to the knowledge development used in intervention design. This ethnographic research has uncovered significant theoretical and empirical findings that can inform intervention strategies. In this section I will first describe the process by which KD research can be converted into intervention design and development. Then I

will outline two broad theoretical frameworks and three specific empirical findings from which those interested in the development and design of interventions for orphan care and HIV/AIDS in southern Africa can benefit.

According to Rothman and Thomas (1994a) KD is the first of three stages of intervention research for human services. The knowledge generated from KD research is useful in providing the foundation for intervention research, particularly in gathering relevant data about the social, contextual and environmental conditions in which a problem exists. The authors suggest that appropriate methods for KD research are similar to those used in social science research more generally. Although they do not list ethnography as one of the specific methods that is useful in gathering this knowledge, and although few social scientists, including social workers, use ethnography for this purpose, I demonstrate here how rich insight can be gained from this immersive approach, which is particularly useful for studying this type of socially embedded and sensitive problem.

This research also contributes to the long-standing debate that seeks to bridge the gap between research and practice that is of special interest to social workers whose work exists firmly in both realms (Herie and Martin 2002; Epstein 1996; Chavkin 1993; Hess and Mullen 1995). I contribute to this discussion by demonstrating how my research translates from Knowledge Development to Knowledge Utilization (KU) – the second stage of intervention research according to Rothman and Thomas (1994a). This stage is necessary in assessing the applicability of empirical data because, in practice, the direct influence of basic social science research on intervention or policy development has been limited (Weiss 1979). The KU stage includes the collection, appraisal and synthesis of

knowledge from KD research and attempts to assess its power, usefulness, and relevance for intervention research (Rothman and Thomas 1994a:18). In this section, I make recommendations for the KU stage of intervention research by suggesting ways that this work can be utilized to design interventions. Once this knowledge has been synthesized into a useful form during the KU stage, researchers may then develop innovative interventions in the third stage of intervention research – Design and Development (D&D). D&D research includes the following six sub-stages: problem analysis and project planning; information gathering and synthesis; design; early development and pilot tests; evaluation and advanced development; and dissemination (Rothman and Thomas 1994a:9).

Social work's person-in-environment approach is a useful framework for conceptualizing how KD research can be used in developing intervention recommendations because it recognizes the complexities that stem from all levels of the environment in which a person is embedded (Green and McDermott 2010; Weiss-Gal 2008). To this end, I return to social work's micro (individual), mezzo (family and community) and macro (policy and institutions) levels of research and practice. All three of these levels of research and practice need to be considered as potential targets for intervention and such interventions should be based on empirical evidence that is context specific (Corcoran 2008). The focus on all three levels of research and practice helps to further this dissertation's goal of addressing the ecological perspective of the person-in-environment. McDermott and Green explain that a person-in-environment perspective "provides a compelling understanding of the ways in which phenomena evolve into more and more complex, interacting and interdependent systems" (2010:2427). In converting

the theoretical and empirical findings that follow into intervention models, researchers should consider micro, macro, and mezzo-level processes for potential interventions in order to address individual, community, and structural challenges that stem from HIV/AIDS. It is my hope that this research will contribute to the design and development of interventions in the applied social sciences, while illuminating the larger role that ethnographic fieldwork should play in intervention research.

Theoretical findings for the design and development of interventions

The primary theoretical finding that should guide intervention research for AIDS orphans and caregivers, particularly in rural impoverished communities in southern Africa is the inseparability of HIV and kinship. As I have demonstrated, kinship does not merely impact people's decision making regarding HIV, but HIV and kinship are mutually produced and inextricable. HIV/AIDS interventions have increasingly responded to the specific local needs of communities through culturally competent research and the use of local populations for the design and implementation of interventions (Kidman et al. 2007; Foster et al. 1996; Higginbotham et al. 2001; Drew et al. 1998). However, this new way of framing the intersection of HIV and kinship will also help to further the goal of meeting the needs of local populations in culturally competent ways and improving the odds of intervention success. The empirical findings that stem from this theoretical orientation for intervention research are discussed below.

The intersections of HIV and kinship provide the overarching framework for the theoretical and empirical contributions of this dissertation. However, a second important theoretical framework, which stems from this overarching finding, highlights the malleability of cultural resources in responding to the challenges of HIV/AIDS. This is a

strengths-based approach, which identifies the strengths and resources of individuals and communities in dealing with adversity (Cohen 1999). For example, idealized and seemingly rigid notions about gender, lineality and appropriate models of care were far more flexibly employed in responding to the needs of AIDS orphans than it initially appeared. Such flexibility revealed itself, for example, in the increasing presence of male and maternal caregivers. Cultural malleability was an important adaptation to a crisis in caregiving that should be viewed as a community strength to be harnessed through the development of interventions.

Long-term ethnography was critical in uncovering these strengths because examples of these malleable cultural resources were originally framed by caregivers as “exceptional cases,” but in reality local cultural resources were far more adaptable than short-term investigation would have revealed. This important finding confirms the hazards of implanting a Western approach to social work research and practice in Africa not only because of its subordinating potential (Anucha 2008), but as this work demonstrates, because it may overlook important findings that an etic perspective alone is unlikely to uncover. These malleable resources, which are often discussed by Basotho using the language of dominant ideologies about kinship and culture, also reinforce the importance of community-based approaches to intervention that include the input of local organizations and people at every stage of the process (Kidman et al. 2007; Foster et al. 1996; Higginbotham et al. 2001; Drew et al. 1998). In moving forward, researchers should consider the ways that easily identifiable cultural practices or ideals might be masking local practice variations hiding potential strengths that could be utilized for successful interventions. This theoretical framework, which challenges static notions of

culture and credits individuals and communities for their adaptability to adverse situations, must be understood within the context of the mutual inseparability of HIV and kinship. It also reinforces the potential for making theoretical contributions that can be accomplished by understanding more fully how HIV – and illness more broadly – is embedded in its cultural context.

Empirical findings for the design and development of interventions

The recognition of HIV as a kinship disease and the flexibility of cultural resources provide the underlying framework for the following empirical findings. These three specific findings coincide with the Knowledge Utilization stage of intervention research. First, interventions for HIV/AIDS orphans need to include components of caregiver support in order to be effective. Caregivers often lack the knowledge, health and income to provide adequate support for the children in their care. This is exacerbated by the increase in the number of elderly caregivers whose physical and material means may not match their affection or desire to provide for the children in their care. Although most of the caregivers I spoke with were willing to provide love and care, these relationships are not exempt from cultural expectations and social pressure and these constraints must also be considered. Intervention approaches must also recognize the embedded nature of orphans in their fostering households and the difficulty of excluding other household members – particularly the primary caregiver – from the targeted intervention. This recommendation confirms numerous studies that recognize the added caregiver burden stemming from HIV/AIDS (Singh et al. 2011; Kimemia 2006; Kipp et al. 2006; Cook et al. 2003; Zimmer and Dayton 2005). Caregiver support should, likewise, respond to the increasing presence of male and maternal caregivers and the

important role they play in protecting orphans from illness and abandonment.

Researchers should also be aware of other potential models of care that were not examined in this research. Interventions that include caregiver support should seek the support of local groups in order to maximize community strengths.

The second empirical finding recognizes the strength of the household as a unit of analysis, evaluation and intervention. In the context of demographic changes stemming from both historical and proximal causes such as migrant labor, changes in marriage practices and HIV/AIDS, the household has emerged as a stable and important site where kinship and care are central. This research has demonstrated that practices that previously reinforced idealized notions of patrilineality such as patrilocal residence, care and bridewealth are in decline. Yet, the household remains an important locale where social relationships are nurtured and where care is primary. In fact, as other aspects of Basotho kinship are in flux, the house has emerged as arguably the most stable and important space where relatedness is constructed. The movement of people within and between households accurately represents household composition and reflects real and important caregiving relationships. Unlike other externally defined social units such as the “family,” the household is a useful cite of intervention because it is a salient and locally-defined social unit. Hunter (2010) also recognizes the salience of the household as a unit of analysis and its reflection on broader economic and social forces at play. He says, an investigation of South African households helps to “capture the fluid, interconnected geographies of reciprocity and attachment that exist as people make a living in different ways and places” (Hunter 2010:13). Interventions focused on the household have the ability to target resources to a group of people that are mutually

dependent for care and support. It is also a space where researchers can accurately assess any demographic changes occurring at a broader level. This micro-level view of household life and its implications for broader social movements was once again facilitated by cultivating close relationships with caregivers so that I was able to gain access to private spaces and observe everyday practices.

Finally, biomedical or biocultural interventions for HIV/AIDS should incorporate the underlying theoretical framework of HIV as a kinship disease. This research has demonstrated that all areas of intervention for HIV/AIDS including AIDS education, prevention (including PMTCT), testing, treatment, stigma, condom use and ART adherence are strongly mediated by Basotho's assessment of the social implications of their responses. Therefore, intervention research should seek to understand the ways in which proposed biomedical and biocultural interventions implicate or threaten social relationships. Intervention design and development in this area needs to move beyond a model where culture is seen to interfere with biomedical responses to HIV to one where the two are viewed as mutually produced and inextricable. This is consistent with a person-in-environment perspective. Only then can the importance of Basotho's social relationships be viewed as a strength rather than a barrier in interventions.

The value of ethnography in social science research

The contextual and rich nature of the theoretical and empirical findings of this work was facilitated by long-term ethnographic engagement in the community. This methodological approach produces a unique kind of relationship building, insider cultural knowledge and facilitates the observation of people in a variety of social contexts over time. The isolated use of ethnographic methods such as semi-structured interviews or

participant observation alone can produce decontextualized knowledge (Briggs 1986). Instead, the ethnographic fieldwork presented here involved a variety of approaches including participant observation, semi-structured interviews, extensive field notes (Bernard 2006) and long-term immersion in a community. This work contributes both to context-specific knowledge about this population as well as a broader understanding of the unique insights that ethnographic research can provide at the initial stages of knowledge development for intervention research.

There are several excellent examples of ethnographic research in social work, particularly when used to study marginalized populations (McClelland and Sands 2002; Iversen and Armstrong 2006; Hall 2003; Floersch 2002). However, ethnography is not widely used, even by qualitative social workers, and has not been the focus of knowledge development research for intervention (Gilgun 2010; Fortune 1994). As I demonstrate in this work and elsewhere (Block 2012), ethnographic research can make important contributions to KD intervention research. Specifically, I show how an ethnographic approach has the benefit of long-term engagement, the ability to form deep relationships with research participants, and the unique insights, such as the malleability of cultural resources, that are made possible by this level of cultural immersion (Block 2012).

Ethnographic research is not highly rewarded in social work either as basic social science or intervention research. However, the value that an ethnographic approach added to the study of this marginalized population indicates that perhaps it should be. Current qualitative and quantitative research trends in social work and applied social sciences are useful and important. However, academic structures in departments outside of anthropology, and to some extent sociology, need to allocate time, resources and

academic rewards such as tenure and publications to ethnographic researchers in order to facilitate this kind of important work for diverse and hard-to-reach populations. This is particularly true for programs in social work, where research interests are predominated by marginalized populations in need of services and intervention. This approach will not only enhance cultural competence in social work, but contribute to reducing the research-practice gap through close understanding of social problems in context. Facilitating ethnographic research in social sciences outside of anthropology is critical for the development of deeply contextual and genuine knowledge

Implications for future research

This research provides a strong foundation for future investigation of the impact of HIV on rural, impoverished communities. Despite significant improvements in access to treatment and stigma reduction, southern Africans will be dealing with the implications of this disease for decades. Also, the biomedical and social aspects of HIV/AIDS are constantly in flux. The disease itself is changing, as are available treatments. In particular, there is a need for exploration into several health and demographic changes that are on the immediate horizon: the widespread need for second line antiretroviral medications, and the passing of a generation of mostly HIV-negative elderly caregivers. A major limitation of this research is that a longitudinal study is needed to examine the social and physical implications of these broader shifts.¹¹² These changes will necessitate close investigation as they alter the African landscape in terms of health and orphan care. There are three areas in particular that would benefit from investigation through the lens

¹¹² Other methodological limitations, in particular, those focusing on the role of the ethnographer and the challenges and benefits associated with my close relationship with MCS are discussed in Chapter 1.

of the deep connections that exist between the biomedical and cultural aspects of HIV/AIDS.

Future research needs to consider the widespread need for second line antiretroviral medications that is looming on the near horizon. I was not able to observe this transition during my fieldwork period, as few people were in need of second line drugs during that time. However, as Basotho are on ART for longer, the need for second line ARVs will become increasingly urgent. According to the WHO (2011), only 2.5 percent of Africans on ARVs were taking second line drugs as of 2009. Fortunately, the majority of Africans currently on ART remain successfully on first line antiretroviral drugs since second line drugs are less readily available and cost five to ten times more than first line medications (UNAIDS 2009). However, treatment failures, which are caused by even short-term interruptions in treatment and the length of time on a single treatment are inevitable (UNAIDS 2009). Most low-income countries cannot afford the higher cost of improved first line treatment or second line treatment (Zaidi 2011). In addition, healthcare providers in Africa are not yet equipped or trained to properly diagnose treatment failure. In my clinic observations, I encountered many patients whose health was not improving— some with good adherence and some with poor adherence — and I never once saw local healthcare providers consider the possibility of treatment failure. Yet, as Saphonn et al (2011) note, there is little value in improving healthcare providers' ability for early diagnosis of treatment failure until new treatments become available. Studies investigating the potential problems that arise from the lack of available treatments have primarily emerged from those who are interested in biomedical outcomes. However, there is a critical need for investigation of the social impacts of

these transitions. Like all areas of HIV, the structural inequalities that make access to optimal treatment difficult for certain populations have social consequences for individuals and families and will impact social organization, health and orphan care. A biocultural investigation of this shift in treatment patterns from its earliest stages could provide insight into the potential ways that interventions can manage both predictable and unexpected social responses to the upcoming treatment crisis.

There is also a grave need to investigate the demographic shifts and the local responses and adaptations caused by the death of a generation of mostly HIV-negative elderly caregivers. I saw the beginning of this transition, but again, the length of study limited me in my ability to observe this problem over time. As I have demonstrated, elderly caregivers are in great demand in responding to the needs of AIDS orphans. However, as grandmothers like 'M'e Masello continue to die over the next decade, communities will be forced to respond to an intensification of the current caregiving crisis. Fortunately, those infected with HIV are living longer because of widely available treatment. However, little research has investigated the medical needs that are common to elderly HIV patients in resource-poor environments and this need will intensify as HIV-infected adults' lives are extended (Negin et al. 2011; Negin and Cumming 2010; Mills et al. 2011). As the current generation of HIV-infected adults age, elderly caregivers will be fewer in number and those infected with HIV will have the additional burden of dealing with the combined health challenges of HIV and the chronic illnesses that are common among the elderly. Future research needs to shift the analytical lens to focus more narrowly on the experiences of elderly caregivers, and the ways in which caregiver burden intensifies as these demographic changes take place.

Finally, those interested in intervention strategies should compare community-based organizations serving AIDS orphans in southern African migrant communities with high HIV-prevalence rates such as Lesotho, Botswana, and Swaziland to explore how biocultural issues are addressed at the local level and to make recommendations for best practice. Although the focus of this research was on caregivers and their experiences, I spent a good deal of time, especially during the initial stages of my fieldwork, with MCS and its staff observing the provision of outreach and safe home services.¹¹³ MCS provides an excellent model for both the benefits and the pitfalls of a locally run, community-based organization. Although I witnessed on many occasions the positive influence that MCS had in the community, the organization is not immune from some of the criticisms aimed at humanitarian aid that draws attention to the unintended economic and social consequences of development efforts (Farmer 2003; Ferguson 1990; Nguyen 2005; Dahl 2009; Wilson and Brown 2009; Heron 2007).

MCS, like other CBOs, creates divisions within the community precisely because of the necessary exclusivity of its services, the personal and political factors that influence choices about service provision and the limitations and restrictions placed on external funding. Future comparative research projects should focus on the ways in which local populations are divided and often stigmatized because of the assistance of CBOs, the unequal and exclusionary provision of services and the ways that people present and identify themselves to make claims about their eligibility for services. They should also investigate the ways in which local givers and receivers of aid attempt to

¹¹³ A thorough evaluation of the strengths and weaknesses of MCS is beyond the scope of this investigation. However, I intend to submit articles evaluating this CBO based on data collected for this dissertation as well as move this research forward with a comparative project on CBOs and orphan care.

subvert these negative consequences and highlight the success CBOs have had in providing locally appropriate, effective services for orphans and their caregivers.

Beyond Lesotho and AIDS: Broader applicability of this research

The focus of this dissertation has been on the everyday experiences of Basotho women and men in their particular social and geographical context. The many rich and vivid accounts of the successes and trials of AIDS orphans and their caregivers give color and context to the intersection of HIV and kinship in this particular place and time. However, the findings presented in this dissertation reach beyond the boundaries of Mokhotlong, and even Lesotho, to provide insights into other areas of theory, research, and practice. According to Lincoln and Guba (1985), qualitative research should have some transferability – the results should be generalizable to other contexts and settings. Although the ethnographic evidence presented in this dissertation is intended to give the reader a close and intimate understanding of the local context, the theoretical and empirical findings presented in this work have both localized and broader transferability. I will outline the broad areas of transferability of this work with reference to the major findings presented here.

The findings stemming from this work are most obviously transferable to other local and regional contexts. Studies coming from other areas of southern Africa note many of the same broad concerns regarding the social implications of HIV, the impact of migrant labor on communities and the importance of kinship and sociality in responding to AIDS interventions. In particular, those interested in rural southern African communities with high HIV rates and large orphan populations will benefit from the major theoretical and empirical findings of this research. Researchers should consider

the ways that HIV and kinship impact all levels of practice including household dynamics, caregiving relationships, treatment seeking behaviors and encounters with healthcare providers. They should also return sexuality to the investigation of family relations, and not relegate sexuality to something that is abstracted from other kinds of relations. Researchers need to shift their analytical framework for thinking about how culture impacts patient and caregiver behavior to acknowledge the complete interconnectedness of Africans' physical and social concerns. Acknowledging a deeper level of embeddedness at all levels will lead to a genuine understanding of people's beliefs and behaviors surrounding HIV. This can be accomplished by exploring new ways of investigating familial relations. The intimate and micro-level view of everyday practices in family life could be replicated in multiple contexts on numerous subject matters. This principle can also be extended beyond issues of care to guide basic social science research and intervention research. Intervention approaches that view HIV as an external factor that needs intervention are merely skimming the surface of the problem. Instead, research and intervention approaches need to recognize the intersections of social, political and economic life and view HIV in context as part of a whole integrated system.

In a regional context, this research also illuminates the potential areas where idealized notions about kinship and care might be masking and legitimating real coping strategies that are deployed in everyday practice. It also explores the balance between flexibility and adaptability and structural and social constraints that create tension throughout this work. Strict idealized notions about gender, lineality and caregiving should be questioned to reveal coping strategies that differ from originally stated norms,

while recognizing various constraints. Research should consider the ways that people justify behavior that does not fit with the stated norms in order to increase their flexibility in response to the HIV/AIDS pandemic. These will play out differently across cultures and geopolitical contexts, but the basic underlying principle should warn researchers that idealized notions about kinship and care are likely to mask actual practice in responding to the needs of AIDS patients, orphans and caregivers. Although further research in specific local contexts will be necessary, my research provides information that will be of assistance in designing research questions, research methodologies and intervention strategies for similar populations in other communities. Researchers undertaking such work should consider the intersections of HIV and kinship and the challenges of orphan care that are likely to impact local responses. Fruitful comparative studies could be borne out of investigation of the intersections of HIV and kinship in southern Africa with other geographical areas such as Asia, and other populations such as the course of the epidemic among GLBT populations in North America and elsewhere. This would shed light on those locally specific epidemics, and also help to build on the theory of HIV as a kinship disease in interesting and unexpected ways.

The transferability of the major theoretical contributions of this work also extends beyond southern Africa and HIV to lend insights into a number of important areas of research. This dissertation highlights the ways that everyday strategies of individuals and communities play a part in broader demographic and social change. In this case, my work illuminates where culture, illness and care intersect to explain how individual and community-level strategies during a health crisis have led to a demographic shift towards matrilineal orphan care. However, those interested in demographic changes precipitated

by major social disruption could benefit from an examination of everyday practices and negotiations as well. For example, this approach, which connects population processes and everyday practice would be useful in examining people's responses to conflict, forced migration or natural disasters. This research also highlights the tensions and contradictions that have arisen in negotiating the biocultural landscape and the importance of investigating both real and idealized cultural norms. The negotiations that take place between real and idealized notions of kinship and gender in particular would be useful in examining any number of contexts, especially those that highlight individual and community-level strengths in dealing with adversity, poverty, structural inequalities and marginalization. Anthropologists and demographers can both gain insights from these broader contributions to theories of social change because they illuminate the ways that micro-level everyday practice can impact larger demographic trends.

Most importantly, although this work explores the intersection of HIV and kinship by engaging deeply with biocultural realities of this particular disease in this particular context, it provides broad insight into the role that social relationships play in determining health outcomes in marginalized communities. Social scientists interested in the impact of pervasive health problems of any kind can learn from the deeply biocultural phenomenon examined here. I provide a framework for rethinking the ways that a biocultural approach to illness can impact health, care and social organization. There are many areas and illnesses where the idea of a kinship disease could apply and comparisons between HIV and other pervasive and widespread health problems might lead to interesting and profound contributions to medical anthropology and kinship theory more broadly.

I have examined Lesotho's AIDS orphan problem and the challenges caregivers face in the hope of discovering some insights into Basotho's coping mechanisms and to shed light on the impact the pandemic has had on their families and communities. I originally undertook this project with vague notions about the impacts that sociality and kinship have on health and care. However, as my investigation advanced, the deep intersections of HIV and kinship became ever more visible. It is my hope that this work helps others to understand these profound connections and to approach AIDS research in southern Africa and beyond with a renewed understanding of the benefits of a fully biocultural approach to global health inequalities. It is also my sincere hope that the children and caregivers that fill these pages will benefit from this renewed understanding of their social context and the ever-improving biomedical treatments to which they have been historically denied.

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