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UGANDAN WOMEN'S HEALTH BELIEFS, SOCIAL NETWORKS AND TUBERCULOSIS TREATMENT SEEKING

by

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Submitted in partial fulfillment of the requirements
For the degree of Doctor of Philosophy

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DEDICATION

This dissertation is dedicated to my husband, John Schumacher.
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experiences truly made this study possible. The treatment seeking challenges facing female TB patients in Uganda are immense. I hope this work increases awareness of women’s treatment seeking efforts and eventually reduces the amount of sacrifice that is needed from both patients and their families for treatment success.
Ugandan Women's Health Beliefs, Social Networks and Tuberculosis Treatment Seeking

Abstract

by

Sarah Ellen Chard

This research examined female Ugandan TB patients' treatment seeking, health beliefs, and social networks. The study had 5 specific aims:

1) Describe participants' TB health beliefs and explanatory models, particularly regarding TB's transmission, treatment, and relationship with HIV;

2) Identify the patterns of care of female Baganda TB patients;

3) Determine whether there are differences in the social network structure and social support exchanges of urban vs. rural patients;

4) Identify the role(s) of social network members throughout the treatment-seeking process; and

5) Determine whether TB patients are stigmatized because of their active TB infection and/or the disease's association with HIV.

Eighty-nine participants were recruited using a convenience sample from Kampala's Mulago Hospital TB clinic (N=64) and from Kawolo Hospital and Mukono Health Centre in Mukono (N=25). Participants completed interviews that elicited their explanatory models, treatment seeking patterns, and social network data.

Participants tended to view their illness as a set of symptoms, rather than as a systemic bacterial infection. Participants were often symptomatic for months before seeking TB clinic treatment. During this time, patients attempted to relieve their symptoms using local herbs, over-the-counter medications, and prescriptions from private clinics, but they were rarely diagnosed or treated for TB. Patients' treatment choices
were based upon their health beliefs and treatment costs. Only after exhausting other
treatment options did patients visit the government TB clinic.

Although the literature describes TB as a stigmatizing disease, patients were
firmly embedded in social networks that provided support throughout their illness.
Indeed, few subjects could manage the process and costs of biomedical TB treatment
without the support of network members. Networks also offered nonmaterial support,
e.g., serving as confidants about participants' illness concerns. There were few
differences in the type/amount of support provided by urban vs. rural networks.

Both urban and rural networks included relatives and friends. Urban networks
tended to be larger than rural networks due to the identification of more extended family
members. Urban networks, however, did not include significantly greater numbers of
non-relatives than rural networks. These findings contrast with anthropology's
conceptualization of urban networks as more association-based than rural networks.
Chapter 1: Introduction

This study explores the dynamics of women’s tuberculosis (TB) treatment seeking among female TB patients in Uganda. In particular it focuses on women’s TB health beliefs and the role of their social networks. This research builds on earlier anthropological literature that has established the important but varied role of social networks in Uganda (e.g., Gutkind, 1965; Epstein, 1961). It also expands on previous treatment-seeking research which suggests treatment seeking is (a) a multi-staged process (Suchman, 1965; Chrisman, 1977), (b) often guided by interpersonal relationships (e.g., Janzen, 1978; 1987; McKinlay, 1981) and (c) involves the weighing of beliefs, costs, and benefits (e.g., Sargent, 1982). Further driving this research is the serious TB epidemic in Uganda, which is fueled in part by the country’s on-going HIV epidemic, and the importance of deciphering how patients’ explanatory models link HIV and TB illnesses and treatment decisions. Finally, this study addresses the need for investigations of the complex social, cultural, and economic variables influencing women’s health, beyond the traditional discourses on maternal and child health (MacCormack, 1988).

Research objectives

This project examines the TB treatment seeking of Baganda women and the role of social networks and social support exchanges in treatment seeking and self care. The specific objectives of this study are to:

1) Describe participants’ TB health beliefs and explanatory models, particularly regarding TB’s transmission, treatment, and relationship with HIV, in order to understand the impact of such beliefs on the treatment-seeking process;

2) Identify the patterns of care and process of treatment seeking of female Baganda TB patients;
3) Determine whether there are differences in the social network structure and social support exchanges of urban vs. rural patients;

4) Identify the role(s) of social network members throughout the treatment-seeking process and in supporting the participant through her illness; and

5) Determine whether TB patients are isolated and stigmatized because of their active TB infection and/or the disease’s association with HIV.

To meet these objectives, this study interviewed outpatients from three government TB clinics using a series of semi-structured and close-ended instruments. A primary goal of this study was to examine variation in both the structure and function of urban vs. rural networks. Therefore, one sample was drawn from Kampala’s Mulago Hospital TB clinic and the other sample was taken from two health clinics in Mukono, a largely rural neighboring district. Participant-observation and informal key informant data were collected to supplement the formal interviews with patients.

Study Significance

The study’s findings contribute to anthropology’s understanding of the TB treatment-seeking process among women with limited socioeconomic resources. This study increases knowledge of both the structure and function of present-day urban and rural social networks and determines with greater specificity the roles of social network members across the numerous stages of treatment seeking. In addition, this research provides information on the function of social networks in the face of a stigmatized illness (i.e., TB) and extends understanding of the local health beliefs surrounding the relationship between HIV and TB.

Complementing the anthropological significance, this study contributes to a better understanding in the public health community of the factors that delay or promote
biomedical treatment seeking. Although biomedical adherence is not a primary focus of this research, this study reveals some of the less commonly described variables influencing patient adherence and biomedical treatment satisfaction.

Limitations

This study has three major limitations. First, participants were recruited from the patient populations of government TB clinics. These recruitment populations likely resulted in a sample that is predisposed to using biomedicine and/or has not been overwhelmed by the biomedical treatment-seeking process. Participants seeking treatment solely from traditional healers or herbalists, without biomedicine, are not represented. Despite this limitation, this sample does reveal the extent to which patients who do seek biomedical treatment also attempt other treatments, either simultaneously or prior to attending the TB clinic.

It should also be noted that the use of government clinics for recruitment resulted in the exclusion of individuals who exclusively attended private clinics. The sample does contain participants who previously sought private treatment but can no longer afford the expense. This bias limits the study’s generalizability to all female TB patients. However, few patients can afford to consult private practitioners over the long term. Thus, the government clinic population is likely to be relatively representative of the population as a whole.

The second limitation of this study is that although Mukono district is a largely agricultural district and 88% of the population is classified as “rural” dwelling (Rwabwoogo, 1997), portions of the area of recruitment are relatively accessible to Kampala. Because of this direct access to Kampala and the city’s ever-increasing
suburbs, TB patients in Mukono district may have more treatment-seeking choices than patients in more distant and isolated districts. However, the cost and energy involved in seeking treatment in Kampala, or from private clinics in the suburbs, prevents the majority of Mukono TB patients from obtaining long-term assistance there.

Third, it should be noted that the small sample sizes require that statistical findings be interpreted cautiously. Nonetheless, this study provides important, in-depth qualitative data that suggest directions for further research using a larger sample.

Chapter organization

The rest of this dissertation is presented in nine chapters. Chapter 2 provides an overview of the Baganda and the cultural, political, and economic context of the study. Chapter 3 reviews the literature on treatment seeking in general and TB treatment-seeking in particular. Chapter 4 examines the theories regarding social networks and social support, highlighting the ways in which social support can be both supportive and counterproductive. It also reviews the literature on the impact of urbanization processes on social networks. The project's methodology is presented in chapter 5. Participants' demographics are described in chapter 6. Chapter 7 contains the findings regarding participants' health beliefs, while chapter 8 explores the findings on participants' TB treatment seeking, and chapter 9 describes the structure and function of participants' social networks and social support. Finally, chapter 10 discusses the results and the study's conclusions.
Chapter 2: The Baganda, TB, and the Ugandan context

Before beginning a discussion of women's TB treatment seeking, it is important to understand the historical, political, and social contexts that have shaped both social relationships and treatment seeking resources in Uganda. Located on the northern shore of Lake Victoria in Eastern Africa, Uganda has experienced many tragedies over the last 30 years, including economically and politically destructive dictatorships, on-going civil war, and over the last fifteen years, the HIV/AIDS epidemic. These events have influenced the population's health status, their economic resources, and the public health infrastructure. In addition, as a former colonial territory, Uganda must address the multiple problems associated with colonial and post-colonial urbanization. This chapter explores the historical and current anthropological literature that has examined these issues. In particular, it discusses Baganda culture, highlighting traditional political and social relationships and the role of women. It then examines Uganda’s post-colonial economic, political, and social characteristics. Finally, it explores the country’s health care systems and its current TB and HIV epidemics.

The Baganda

It is hypothesized that the Baganda\(^1\) are descendants of iron age Bantu peoples who migrated slowly from West Africa across Central and Eastern Africa. There is archeological evidence of their presence on the northern shores of Lake Victoria from around 400 AD (Iliffe, 1995). Historians suggest that the kingdom of Buganda was established by the fifteenth or sixteenth century (Shillington, 1995; for a complete

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\(^1\) To clarify terminology, the term “Baganda” refers to the entire ethnic group, while a “Muganda” is a single individual. The Baganda kingdom was “Buganda.” The traditional language of the Baganda is Luganda. The term “Kiganda” is used when referring to Baganda culture (Kilbride and Kilbride, 1990).
discussion of the origins of Buganda, see Mafeje, 1998). Indeed, by the 19th century, the kingdom was one of the most powerful in the region. With the Kabaka, or King, as the ultimate ruler, political and economic power was centralized through a clan system and, later, hierarchical patron-client relationships (Mafeje, 1998). The relatively prosperous kingdom was supported through the taxation of subjects and tributes from neighboring kingdoms, such as Busoga (Larimore, 1958; Shillington, 1995). As a result of this tributary relationship and their common Bantu heritage, many of these surrounding groups, including the Basoga, developed similar cultural characteristics to the Baganda (Fallers, 1965; Parkin, 1969).

In part because Buganda was a highly organized society, centrally located, and the Kabaka engaged in separate treaties with the English, the Buganda regions known as Kampala and Entebbe became important economic and political centers. Buganda was ultimately joined with its neighbors to form the British protectorate, Uganda. Not only were Baganda given prominent roles in the country's administration, but the asymmetrical development of southern Uganda over the rest of the country offered the Baganda increased business opportunities and prosperity (Shillington, 1995).

In 1962, Uganda received its independence from the United Kingdom. The Baganda's powerful political and economic position within the country continued with independence. For example, the major planning discussions regarding the transfer of power upon independence were held with Baganda representatives, with limited input from other ethnic or religious-based groups. Furthermore, the country's major political party, the Democratic Party, was established by eight Muganda and consisted predominantly of Baganda (Lamwaka, 1998).
These uneven power relationships helped ignite ethnic-based tensions, which were ultimately exploited by a corrupt political elite (Brett, 1995). Just four years after independence, for instance, the country's first prime minister, Milton Obote, sought to increase his personal power and limit the power of the Baganda by removing Uganda's President, Edward Mutesa II, who was also the Buganda Kabaka. Mutesa fled Uganda after being attacked by the army later that year. In 1967, after assuming all executive powers and suspending the country's constitution, Obote officially dissolved Buganda and the other traditional Ugandan kingdoms (Kalyegira, 1997).

Throughout the first decades of independence many of the country's political struggles were presented as ethnic issues. Contrasting the relative wealth of the southern Buganda region with the much poorer northern districts not only helped Obote maintain power, but also led to his overthrow by another non-Muganda, Idi Amin, in 1971 (Brett, 1995; Mazrui, 1978).

Today, Uganda is a multiparty democracy, led by the President, Yoweri Museveni (see below). Although being a Muganda is not necessary in order to engage in politics or business in Kampala, discussions on the role of the Baganda and the need to reduce "tribalism" are quite common (e.g., Omuzirango, 1999; "Whose Independence Is It," 1998).

As a final note on the colonial and early post-colonial period in Uganda, similar to other cultures with colonial histories, over the years, the Baganda have incorporated many non-indigenous customs and beliefs into their culture. As a result, such customs are now viewed as "Baganda." For example, most Baganda express affiliation with a western religion, frequently Catholicism, Protestant Christianity, or Islam (Fallers, 1961),
so that these religions have become a central component of individual identity. Similarly, after its introduction by Sir Albert Cook in 1897, biomedicine also proved popular (Daniel, 1998), and there is evidence that biomedical concepts have been transformed into local, culturally-constructed, healing ideology (e.g., Birungi, 1998).

Baganda social organization

Baganda society is patrilineal and patriarchal. Strong social obligations exist between family members and across generations. As will be described in chapter 4, both traditionally and today, the extended family plays a pivotal role in the care and education of children, and the overall provision of food, shelter, and health care. It is expected that prosperous individuals in particular will assist less fortunate family members (Kilbride and Kilbride, 1990; Obbo, 1986, 1987).

There are many types or expressions of marriage among the Baganda. These range from formal church or “ring” weddings and receptions, to bridewealth-type exchanges, to common-law live-in arrangements. Traditionally, marriage was exogamous, with individuals marrying outside their clan. Engagements were negotiated through gifts to the bride’s family (Philips, 1971). This ritual still occurs, but many of the traditional items, such as papaya, whose seeds were used for washing, have been replaced with modern items, like soap. Until Christian missionaries and colonial administrators began to forbid the practice, polygamy was also accepted, though not necessarily common (Kilbride and Kilbride, 1990).

Interestingly, the idea that men “need” more than one woman continues. Kilbride and Kilbride (1990), in particular, argue that the formal practice of polygamy has been transformed into a system wherein men may maintain simultaneous social, economic,
and/or sexual relationships with both wives and girlfriends. For women whose economic opportunities may be limited, such relationships can be an important financial resource (see also McGrath, Ankrah, Schumann, Nkumba, and Lubega, 1993).

**Role of women in Buganda society**

Two of the most well known studies of Baganda and East African women in general are Obbo’s (1980) *African Women: Their Struggle for Economic Independence* and Kilbride and Kilbride’s (1990) *Changing family life in East Africa*. These authors suggest that prior to colonialism, Buganda was patriarchal and gender-biased. A woman’s overall social status before marriage was predominantly dependent on the status of her father, while her status after marriage was based on her husband (Obbo, 1986). Women could acquire social status through their beauty, verbal skills and children, but there remained limits to their power within their household (Kilbride and Kilbride, 1990). Ultimately, Kilbride and Kilbride (1990) suggest,

...the position of women in traditional Kiganda society did have its unfavorable aspects. Co-wives were often competitive with each other, and a barren woman possessed an unenviable status. In particular, a barren woman was not a contributing member of her household’s economic enhancement because she had no children who would be a source of labor and a potential means of material gratification... (p. 157)

Although Ugandan women’s rights under the law have increased in the post-colonial era, in practice their freedom is not well protected by both the legal system and social custom. As Uganda’s Ministry of Finance, Planning, and Economic Development [MOF] (1998) reports,

Article 33 of the Constitution of the Republic of Uganda offers women equal rights and dignity with men...However, equality under the law is constrained by a number of factors such as women’s inadequate knowledge of the law, women’s financial inability to meet costs [sic] of legal redress, conflict between modern
law and cultural rules and practices, and ineffective law enforcement mechanisms and procedures. (p. 240)

In addition, although women constitute 80% of the agricultural labor force, they still have limited decision-making power within their home and the country as a whole (MOF, 1998). While an increasing number of local and national women’s associations seek to combat social, economic, and political inequalities in order to increase women’s access to and control over resources, their success has varied and change has been incremental (Tripp, 2000).

Kilbride and Kilbride’s (1990) earlier argument that “urbanization, monetization, and Christian values combined to render the traditional polygynous household dysfunctional and in general to lower the status of women” (p. 158) remains true for the majority of women. Kilbride and Kilbride (1990) also note that women’s increased “delocalization” from the mainstream economy has had a detrimental impact on both women and their children. Their research indicates that limited economic opportunities have forced many urban women to serve as barmaids who are expected to develop emotional and/or sexual relationships with male clients. These largely economic, non-monogamous relationships not only put both partners at risk of HIV infection, but also any additional spouses or partners, particularly other wives.

In addition, there is evidence from across East Africa suggesting that urban women have had to be extremely creative as traders and small merchants in order to earn a living in a society which is weighted towards men and men’s rights (e.g., Musisi, 1995; Robertson, 1995). Such independent income can be critical for both a woman and her children’s survival; furthermore, for an urban married woman, whether she has independent economic resources may determine her willingness to stay with a husband or
partner who is suspected of having high-risk sexual affairs. Thus, while there is some
evidence that women now engage in a range of professions (Tripp, 2000), the primary
jobs available for uneducated women are in the informal economy, while educated
women are largely directed towards low-level white collar jobs, teaching, or nursing

A woman’s role in a rural or more traditional household often is no better than the
position of an urban woman. In traditional households, women’s body language must
indicate their subservience: women are expected to kneel in the presence of men and
remain silent during conversations (Kilbride and Kilbride, 1990; Obbo, 1980). Earlier
research in neighboring Kenya also suggests that rural women may have much higher
psychological stress and anxiety levels (Weisner and Abbott, 1977). Furthermore, with
the development of western “modern” institutions, these women are often responsible for
“preserving” traditional culture. Thus, women who refuse to maintain cultural traditions
are not just betraying their family, but Baganda society. Fully independent women are
often called “wild” or “uncontrollable.” When a “misbehaving” woman falls victim to ill
fortune, her fate is often viewed as justified (Obbo, 1980; see also Ulin, 1992).

Traditional, especially rural, life also frequently involves strenuous agricultural
labor, limited control over monetary earnings or household decisions, and few protections
from domestic abuse (Obbo, 1980). While women report moving to the city to escape
this role and gain independence, once in the city, as mentioned above, women must enter
a monetary economy which tends to favor men (Kilbride and Kilbride, 1990). Ultimately,
whereas urban women may have more personal freedom and control over their income
than traditional, rural women, urban women are very vulnerable to poverty, exploitation, and abuse.

One final point regarding the position of women in Uganda, which should be made explicit, is that gender issues and social class are closely tied (Obbo, 1986; see also House-Midamba, 1990). While Kilbride and Kilbride's (1990) ethnography reveals the conflict existing between elite vs. non elite women, Obbo (1986) argues that women with higher socioeconomic statuses may exploit their lower-class female relatives who are willing to serve as maids in exchange for room and board. Elite women, i.e., relatively wealthy and/or educated females, also tend to have more economic opportunities, which may result in an independence that is not available to poor women (Obbo, 1986).

Thus, the position of women in Ugandan society is complex. Although city life may bring increased freedom and economic opportunities for many women, those without an education are at higher risk of impoverishment (Appleton, 1996; World Bank, 1996). In addition, continued expectations about women's availability to men put women at risk of HIV infection in both rural and urban communities (Obbo, 1995). While romantic relationships may be a source of extra income for a single woman, she and any other partners in the same sexual network may pay a tremendous price. Thus in Uganda, as elsewhere, the "modernization" of the political and economic system has not necessarily led to gender equality or equity.²

Uganda's post-colonial political history

To briefly review Uganda's post-colonial political history, immediately after independence, Milton Obote led the parliamentary government as Prime Minister. From

² For a general discussion on women's "underdevelopment" with modernization, see Bossen (1975).
1966 until 1971, Obote attempted to increase his political power by suspending the constitution, nullifying the powers of the president, and threatening his political opponents and dissenters (Kalyegira, 1997). Assisting in these power schemes was the military commander, Idi Amin, who ultimately overthrew Obote in a 1971 military coup.

Amin’s atrocities during his nine year dictatorship are well documented (see e.g., Gwyn, 1977; Kyemba, 1977; Mamdami, 1984; Southall, 1980), and will only be summarized here. It is estimated that Amin was responsible for the murder of 500,000 to 800,000 people. His erratic and self-serving government policies led to high rates of unemployment, the virtual collapse of the formal economy, and the destruction of the health infrastructure (Scheyer and Dunlop, 1985; Williams, 1985). These interrelated catastrophes were in part the result of Amin’s decision to expel all residents of Asian descent\(^3\), his refusal to pay foreign debts, the alienation of neighboring countries, and the large-scale embezzlement of government funds (Bigsten and Kayizzi-Mugerwa, 1999).

Even while retreating from rebel fighters and Tanzanian soldiers, Amin’s forces continued to rob the country:

> Many factories were sabotaged, stocks of currency stolen from banks, tens of thousands of rifles and vast supplies of ammunition taken from the armouries, everything left removed from the shops, and all the vehicles they could lay their hands on were driven out of the country. Uganda was left not merely bankrupt, but literally bare of much of its infrastructure and physical plant. (Southall, 1980, p. 645)

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\(^3\) Asians formed the majority of the middle-class, operating shops and businesses throughout the country. When they left, they took not only capital but also business skills and contacts. For example, Asians largely controlled the pharmaceutical industry and after their expulsion, only six pharmacies remained open across the entire country (Williams, 1985; see also Bigsten and Kayizzi-Mugerwa, 1999).
After Tanzania’s 1979 invasion of Uganda, there was an attempt to restore political democracy. The election of Milton Obote, however, was not without suspicion and resulted in continued corruption and terror (Berkeley, 1994; Kalyegira, 1997). A brief military coup ultimately removed Obote from power for a second time.

The current government was established in 1986 when Yoweri Museveni, the leader of the five-year guerrilla movement against Obote, was named president. Museveni was reelected in both 1996 and 2001, and he has been both lauded by the west for his progressive economic policies, and criticized for his lack of support of multi-party politics and the country’s involvement in the war in the Congo (e.g., Berkeley, 1994; Morais, 1997). Currently, Uganda is politically stable, although a number of rebel groups conduct periodic bombings, raids and ambushes against the Ugandan government and the Ugandan people. The most well known of these is the Lord’s Resistance Army, which is responsible for the abduction of hundreds of children and the murder of countless innocent residents in northern Uganda (Blair, 1998).

As this summary of Uganda’s political history demonstrates, the country has experienced tremendous upheaval over the last forty years. This largely prosperous, fertile country was reduced to a depth of poverty that is taking years to overcome. Progress is hampered by continuing conflicts with neighbors and internal rebel groups that are further draining Uganda’s resources. As a result, the nation’s economy and social services have not witnessed the advances that were originally anticipated at independence.
Socioeconomics

Currently, Uganda is one of the poorest nations in Africa (World Bank, 1993). The country is highly dependent on external aid for the provision of social services, while the annual per capital income is estimated at $220 (World Bank, 1996). While the World Bank (1996) classifies 61% of the population as "poor," households that fall above the poverty line often are only minimally better off than those beneath the line. Indeed, the separation between poor and non-poor is so precarious that the sickness or death of a family's major wage earner can quickly lead to the impoverishment of a previously well-off family (Barnett and Blaikie, 1992). Although its economy has begun to improve since the election of the current government, the depth of Uganda's poverty is extreme; it will take years for the economy to return to the productivity levels of the 1970s (World Bank, 1993).

Uganda's primary income is from agricultural exports, particularly coffee, tea, and cotton (Statistics Department and Macro International [Statistics Department], 1996). Agricultural production is the major employer or means of survival for the population, with 90% of the population involved in either subsistence farming or "agro-industry" (Statistics Department, 1996). Because much of the country is either tropical or savannah grassland and supports farming and/or herding, Uganda is able to produce enough food on average to feed its population.

4 The southern, central, and western regions of Uganda have a tropical climate and experience biannual rains. The eastern and northeastern regions of the country tend to experience one rainfall per year, which results in climates that are savanna and semi-desert, respectively (Statistics Department, 1996).

5 Although self-sufficient overall in terms of food, Uganda still experiences high rates of wasting and stunting. Wasting is primarily found in children under two, and tends to disappear with age. Stunting, however, remains a problem, with 44% of children in the lowest economic quartile and 37% in the highest economic quartile having low heights with respect to age (World Bank, 1996).
Looking at women's employment in particular, 39% of women are officially unemployed, while 67% of those reporting employment are self-employed. Rural and urban women are equally likely to be employed full-time; however, rural women are more likely to work for relatives or to be self-employed. Women in the greater Kampala area also are more likely to earn cash for their labor than women elsewhere. Thus, while many women contribute to the formal economic sector, the majority are self-employed or work for relatives, which often does not result in a monetary wage. Women ultimately have fewer economic opportunities than men, especially for cash, skilled-labor, and white-collar jobs (Statistics Department, 1996).

One other socio-economic impact of the tumultuous 1970s and 80s is that much of the current adult population has minimal education. Specifically, 43% of adults in the bottom economic expenditure quartile and 18% in the top quartile never attended school. The data on women indicate that 38% of women in Uganda have no school experience, 43% have some primary school training, and 19% have completed primary school (World Bank, 1993).

The number of children currently receiving a formal education has increased, as 70% of school age children are now officially enrolled in primary school (World Bank, 1996). These numbers are misleading, however, as it is likely that many will leave school before completing their primary education. For example, one study of the students starting primary school in 1986 found that 75% of females and 64% of males stopped attending before reaching the seventh level. It is also notable that while an equal

These trends suggest that protein deficiency is a major problem among children, which is due to a number of causes, including illness, weaning practices, increases in women's work load and resulting decreases in breastfeeding and child care. Food scarcity is a problem primarily among the poor (Statistics Department, 1996).
number of girls and boys enter primary school, girls are more likely to leave. The drop out rate for secondary school is also high, with 47% of children entering secondary school not completing their degree (World Bank, 1996). By some estimates, though, only seven percent of girls in Uganda even enroll in secondary school (World Bank, 1993).

Thus, there is some improvement in the number of children presently in school, but education rates are not likely to increase dramatically for the country’s children without the introduction of an universal primary education system. Although Kampala City Council and other organizations are developing free school programs and scholarships, the cost of sending a child to school currently ranges from 15,000 Ush. per quarter (roughly $15) for a non-prestigious day primary school to hundreds of thousands of Ugandan shillings per year for more prestigious schools. A long-term investment in the education of multiple children is simply beyond the means of most families, and young girls’ education in particular suffers as a result.

These overall low rates of formal education have many implications in terms of the economic development and health of Uganda’s population. Education levels are one of the most important factors for both national and individual economic growth. Indeed, adult literacy accounts for roughly 46% of the regional differences in the country’s poverty index (World Bank, 1996). Uganda’s high illiteracy may also compromise the country’s economic growth in the coming years, as much of the workforce is unable to access written agriculture and small business advice and training (World Bank, 1996).

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6 A secondary school degree is roughly the equivalent of a high school diploma in the U.S.
Thus, Uganda’s low literacy rate has many implications for individual economic
development and the country’s overall personnel resources.

The country’s education rates also may indirectly and directly influence health
statuses in the region. Data from across the world suggest that education indirectly
impacts health by increasing child survival, decreasing fertility, and increasing women’s
household decision-making power (World Bank, 1996). A more direct relationship
between health and education is that illiterate individuals are unable to read public
service signs or pamphlets targeting infectious illnesses, including messages regarding
dangerous symptoms, appropriate actions, or the availability of free biomedical
treatments. This is especially troubling in terms of the poor who are the least likely to
have reading skills but are at the greatest risk for contracting TB and other infectious
diseases. While currently there are no studies quantifying the impact of literacy on
treatment seeking and treatment adherence in Uganda, the high illiteracy rate must be
considered in the design of public health programs. Ultimately, an increase in literacy
and formal schooling is critical in order to improve the financial and physical well-being
of Uganda’s population.

Health Care system

Uganda’s health care system is a plural health care system, consisting of both
traditional and western biomedical practitioners. Although the traditional health care
sector predates the introduction of western biomedicine, the two healing systems have
coexisted for over 100 years. Both are incorporated into local explanatory models of
illness and healing (Namboze, 1983). The following sections discuss the Baganda’s
traditional healing system and then examine the country’s western biomedical system.
Traditionally medicine in Uganda

Traditional African medicine employs both curative and preventive measures to address social, psychological, and/or biological disorders. The World Health Organization (1976) defines traditional medicine as:

The totality of all knowledge and practices, whether explicable or not, used in diagnosing, preventing or eliminating a physical, mental or social disequilibrium and which rely exclusively on past experience and observation handed down from generation to generation, verbally or in writing. (p. 2)

Practitioners may be lay or professional, i.e., “using” traditional medicine may refer to the lay use of “non prescription” traditional herbs, or it may involve consulting a traditional healer, who may order religious rituals, prescribe medicine, or conduct surgery. Many local herbs are attributed with therapeutic properties, some of which are understood by the general public, others of which require assembly by a traditional healer (Kokwaro, 1993). Beyond these generalizations, however, there is much variation in the local healing customs among different ethnic groups. This discussion of the Baganda traditional healing system should not be viewed as discussion of African traditional medicine as a whole.

To discuss traditional healers first, a traditional healer is commonly defined as:

A person who is recognized by the community in which he lives as competent to provide health care by using vegetable, animal and mineral substances and certain other methods based on the social, cultural and religious background as well as on the knowledge, attitudes, and beliefs that are prevalent in the community regarding physical, mental and social well-being and the causation of disease and disability. (WHO 1976, p. 2)
Historically among the Baganda, each clan had a relationship with specific traditional healers, and the healers were among the most feared of the religious class (Roscoe, 1911/1965). Traditional healers had a number of roles, serving as diviners, exorcists, and curative and preventive healers. Their techniques involved cupping, preparing fetishes or amulets to ward of harm, and/or divining the cause of a sickness. As Roscoe (1911/1965) described,

They diagnosed illness, prescribed for the sick, and understood how to deal with the sickness caused by ghosts; they were surgeons...their skill in exorcising ghosts from haunted houses, or from people who were possessed by them, was fully acknowledged by all...they compounded drugs, made the objects which worked magic (kulogo) on people, and sold them to those who wanted them either for personal use, or to bewitch them. (pp. 278-279)

While Roscoe tended to classify all traditional healers together, other researchers suggest that traditional healers in East Africa should be divided into two groups, those who specialize in divination and those who are herbalists. An individual might consult an herbalist to deal with symptoms and then a diviner to uncover the cause of the disorder (Ankrah, 1994). In either case, it is clear that the traditional Baganda healing system has developed complex medico-religious rituals and identified medicinal herbs to address the health care needs of the population.

Along with having a multidimensional healing system, the Baganda traditionally have many complicated health beliefs that address illness etiology, contagion, and disease transmission. Although not necessarily expressed in terms of microbial pathogens, there are many traditional beliefs regarding the spread of disease. For example, Roscoe (1911/1965) found that phthisis, or TB, was believed to be caused by an ancestor's ghost who died of the disease. Unless there was proper atonement, the afflicted descendant...
would also die of the illness. Furthermore, Roscoe (1911/1965) reported “the expectorations [sic] from such a person were greatly dreaded as being a channel for the ghost’s malign influence over any one who came into contact therewith” (pp. 100-101).

Baganda traditional medicine flourished until the arrival of Europeans. Both Christian missionaries and the British Protectorate discouraged the practice of traditional medicine and medico-religious beliefs. The effectiveness of these campaigns against traditional medicine, however, was limited. Ulin (1980) noted that while there was general public acceptance of western biomedicine, Ugandans differentiated between sicknesses that were appropriate for western doctors and those which required a traditional healer. In addition, the urban focus of biomedical infrastructure development limited the health care options of rural residents. For many, traditional healers were and are the only nearby health care provider (Ulin, 1980; Ankrah, 1994).

Over the decades since independence, the Ugandan government has continued to limit their official support of healers. Nonetheless traditional healers have maintained a presence in Baganda culture and can be found in both urban and rural markets. Patients may seek these healers for illness, to improve their life situation, or for protection (e.g., Nsambu, 1998; Whyte, 1997). The HIV/AIDS epidemic, in particular, has prompted many individuals to consult traditional healers for an explanation and cure (Ankrah, 1994; Buregyeya, 1998; Mugaju, 1999). Elsewhere in Africa, traditional healers, themselves, have also promoted various “cures” for HIV and TB (e.g., Block, 2001; McKinley, 1996). Religious “faith healers” likewise are growing in popularity throughout the region due to HIV/AIDS (e.g., Fisher, 2001; Mugaju, 1999). Thus, both

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7 As described in chapter 3, this separation of biomedical and traditional illnesses has been found in many nonwestern countries (e.g., Lozoff, Kamath, and Feldman, 1975; Schwartz, 1969).
professional traditional practitioners and Christian-based healers are active in Uganda’s health care system.

It should also be noted that ironically, some western health care planners have promoted training traditional health care providers to serve as low level biomedical personnel. Not only did many of the primary health care initiatives (PHC) of the 1980s view traditional healers as a resource for identifying individuals in need of further medical assistance, but in Uganda, for example, doctors may work with local healers to treat patients together (e.g., Buregyeya, 1998; for a recent example from South Africa see also Block, 2001) and programs exist to train local women as birth attendants (Mugeere, 1998). In this way, it is believed that traditional healers may serve as critical local level PHC workers (Ulin, 1980). Despite these efforts, however, many tensions remain between the traditional and biomedical health care sectors and the two disciplines are far from integrated professionally (Mugaju, 1999).

Along with the treatments of traditional healers, the lay use of medicinal herbs has also been an important feature of Uganda’s traditional healing system and there is considerable lay knowledge on the purpose of various plants. Medicinal plants are usually collected by male family members who then prepare them for the afflicted individual (Ankrah, 1994). Zeller (1971), Kokwaro (1993), and Hirt and M’Pia (1995) have compiled full descriptions of the traditional medicinal herbs found in East Africa and their many uses. Zeller (1971), in particular, developed a Baganda “pharmacopoeia appendix” detailing the medicinal plants of the Baganda. These authors have suggested that there are herbal treatments for countless ailments, including headache, venereal disease, pneumonia and tuberculosis. More recently, Neema (1999) noted that women
also may use medicinal herbs during pregnancy and delivery. Finally, along with studying locally defined herbal remedies and their uses, there is an increasing amount of research on the pharmacological properties of individual plants (see e.g., Anokbonggo, 1974; Ogwal-Okeng, 1989; Willcox, 1999; World Health Organization, 1996, 1999b).

The Biomedical health care system

The Baganda use traditional healers and herbs for both curative and preventive purposes. In contrast, biomedical practitioners have focused primarily on developing curative health care services. This trend dates back to the arrival of the first English physician, Sir Albert Cook, who established the country’s first hospital in 1897 (Daniel, 1998).

During the colonial period, Uganda’s biomedical health care system developed as a network of government-run, local level health care units that served as referral centers to the government’s major hospitals. Under a centralized administration, urban bureaucrats determined both the activities and funding of rural health units (Okello, Lubanga, Guwatudde, and Sebina-Zziwa, 1998). While it is estimated that some form of biomedical health care was within ten kilometers of the majority of the population during the initial years of independence (Dodge and Wiebe, 1985), higher level, curative hospital care was found mainly in urban areas and was not evenly distributed within the country (Macrae, Zwi, and Gilson, 1996). Indeed, Mulago hospital, the country’s primary referral hospital, was built in Kampala in the 1960s as an independence gift from the English. Mulago also served as the country’s only medical training facility for many years.
Thus, although the colonial government and early independence political leaders can be credited with establishing a biomedical health care system, including advanced hospital care and a training program for future Ugandan doctors, the health care system was inequitably distributed (Macrae et al., 1996). The successive dictatorships of Obote and Amin further amplified the system's troubles as money for health care was cut, clinics and hospitals physically deteriorated, and the number of doctors in the country diminished by half (Mugaju, 1999; Scheyer and Dunlop, 1985; Williams, 1985). The current Ugandan government has been left with the job of revitalizing a poorly planned and ill-staffed health care system (Macrae et al., 1996).

In absolute numbers, the country currently has 1,505 governmental and non-governmental (NGO) health units, which range from minimal referral health posts and dispensaries to maternity units and hospitals. There are 55 government-run and 43 non-profit or private hospitals. In terms of medical personnel, the country has one doctor for every 20,228 individuals. When including midwives and various health staff, there is one trained medical person for every 8,311 Ugandans (Hutchinson, 1999).

Through multiple vertical programs with the World Bank, United Nations, and other NGOs, the goal of Museveni's government has been to establish a multidimensional, accessible primary health care system, largely based on the colonial framework. The effectiveness of this approach to reviving the country's biomedical health care system, however, is unclear. As Macrae et al. (1996) note, the government was possibly motivated by political, rather than health, goals in their decision to rebuild rather than reform Uganda's health care system:
these interventions served important psychological and political functions, but they failed to provide the foundation for the development of a sustainable and equitable health system...the political imperative was to achieve a return to normalcy, symbolized by the restoration of the physical fabric of health facilities, rather than a radical departure from the pre-conflict health system.  

( pp. 1105-1106)

Ultimately, the policy decision to restore Uganda’s pre-existing health care infrastructure has not resolved the country’s unequal distribution of medical services.

In addition, several new concerns have been raised regarding the government’s health care programs. First, as noted above, Macrae et al. (1996) question whether a multi-level referral program is sustainable given the country’s still developing economy. Second, despite frequent calls for a more effective, decentralized administration (Oberender and Diesfeld, 1983; Okello et al., 1998), the Ministry of Health still determines funding allocations and controls the distribution of drugs. It is only recently that Health Ministers have shifted the responsibility for program management to individual districts while developing a policy-making and technical support role for central administrators (Hutchinson, 1999).

Third, the effectiveness of the biomedical health care system is hampered by the lack of attention to developing positive practitioner-patient relationships. Whether because of overwork, oversight, or lack of training, poor patterns of care are reported in some biomedical health care facilities. For example, Birungi’s (1998) key informants report:

"There is normally a long queue and the nurse...takes no more than one minute before she calls out for the next patient"

"It is as though she was sewing cloth, you never get to talk or even look into her eyes"  (p. 1458)
These comments echo the earlier work of Minde and Kalyesubual (1985) who found the personnel in two Kampala clinics were disinterested in patients and spent insufficient time on each case. They attribute this indifference to lack of professional training and inadequate financial compensation. One impact of this impersonal treatment is that it undermines the establishment of trust between patients and providers (Birungi, 1998). Therefore, government policy and training programs need to emphasize the importance of the practitioner-patient relationship as a form of professionalism, along with ensuring that staff are not so overburdened and underpaid that they become completely alienated from their goal of helping patients.

A fourth concern regarding Uganda’s biomedical health care system is the many reports of medical practitioners demanding “tips” (or fees) from patients for otherwise free services (Barton and Bagenda, 1993; E. Kironde, 1985; Muhanga and Okello, 1998). Such corruption further undermines poor patients’ access to services and community members’ trust in practitioners.

Finally, in Uganda as elsewhere, there is a common view that government health units and hospitals are unreliable and of a lower quality than non-governmental or other private facilities. Ill individuals may avoid seeking care or they will pay for private care rather than seek free or almost free government services (Hutchinson, 1999; Kironde, 1985; see also Akin and Hutchinson, 1999; Lonnroth, Tran, Thuong, Quy, and Diwan, 2001).

To summarize, then, the effectiveness of Uganda’s biomedical health care system has been limited by inequities in its original design, and current problems with centralized planning, corruption, and staff compensation and training. As a result, many
patients are dissatisfied with the care received at government health clinics, view
government practitioners as rude and/or dishonest, and ultimately, many prefer to pay for
services at private clinics if they have the funds.

**Biomedical tuberculosis treatment**

The Ugandan Ministry of Health established a specific program, the National
Tuberculosis and Leprosy Control Programme (NTLP), in 1990 to manage the country's
TB and leprosy epidemics. Built on the pre-existing leprosy control infrastructure, the
NTLP has experienced many of the problems with resources and staff morale that typify
Uganda's health care system as a whole.

To describe the NTLP's structure, the NTLP characterizes itself as a "semi-
vertical" organization. A "Central Unit" in Kampala plans and directs the country's TB
control activities (Ministry of Health, 1997). For TB control planning and program
supervision, the country is split into nine zones, which are further divided into 39
districts. NTLP supervisors are stationed in each zone and district. While the zonal
supervisors oversee the activities across their districts, the district supervisors are
responsible for ensuring that local health units (hospitals, clinics, and dispensaries)
address their communities' TB treatment needs (Ministry of Health, 1997). Thus, TB
care is provided through community hospitals or dispensaries, rather than independent,
NTLP clinics. Local or regional supervisors serve as the critical link between the Health
Ministry's central planning office and local level government health care providers.
The NTLP’s treatment protocol generally follows guidelines set by the World Health Organization. The recommended treatment for smear positive patients is two months of streptomycin, rifampicin, isoniazid, and pyrazinamide and then six months of thioacetazone and isoniazid. Smear negative cases receive two months of streptomycin, thioacetazone, and isoniazid and then six months of thioacetazone and isoniazid. The streptomycin is administered as a daily injection. Defaul ters, relapses, and chronic cases take two months of streptomycin, rifampicin, isoniazid, pyrazinamide, ethambutol, and five months of rifampicin and isoniazid (National Tuberculosis and Leprosy Control Program [NTLP], 1992).

The majority of patients are treated as outpatients who must return to the clinic for their medications daily, weekly, or monthly, depending on the treatment and the practice of the individual clinic. The Ugandan health care system lacks the capacity to hospitalize the country’s TB patients, even for the initial two months of treatment. In fact, the NTLP argues that, “hospitalization itself has little or no effect on the outcome of the treatment: if the patient takes the drugs mentioned….he will do equally well whether treated in or out of the hospital” (NTLP, 1992, p. 18). In-patient care is reserved for those who are direly ill, experiencing extreme drug reactions, or who are at high risk of not returning regularly for their medications.

Despite the NTLP’s strategy of integrating vertical and horizontal approaches to TB control, the organization has encountered numerous difficulties that have limited its effectiveness. First, the NTLP has had a number of staffing problems. Not only does the

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8 A smear positive patient has TB bacilli in his/her sputum. The microscopic examination of the sputum is the primary test to determine if a patient has an active TB infection. A smear negative patient does not have the bacilli in his/her sputum, but the patient may be quite ill. In this case, an x-ray or sputum culture may reveal the presence of the bacteria (World Health Organization, 1997).
Central Unit and primary laboratory require more staff in order to manage the epidemic, but there is also concern that the district and/or zonal supervisors are not ensuring that local health care facilities understand the importance of TB control and the need for following national treatment protocols. Second, while there is an effort to increase the number of health centers that have the resources to diagnose TB, there is an insufficient supply of microscopic equipment to meet the needs of the entire country (NTLP, 1992; see also “Assessment of Infectious Disease Surveillance,” 2000). NTLP’s third difficulty is maintaining a steady drug supply (Saunderson, 1995). This issue, however, appears to be resolved through assistance from international aid organizations (Dr. A. Okwera, personal communication).

A fourth problem with Uganda’s TB control efforts is that while clinics keep patient registries and a few may attempt home visits, follow-up can be problematic (Saunderson, 1995). In addition, if patients relocate, there are few checks to ensure that they continue their medication. Furthermore, as described above, health care services are not evenly distributed across the country. Patients in remote regions may not have easy access to treatment because of the NTLP’s reliance on the existing health care system. Thus, there are serious infrastructure issues which limit both clinics’ ability to track patients across the country and patients’ access to TB care. Although the country is currently piloting a few directly observed treatment programs that involve the constant monitoring of patients’ adherence, these programs are still preliminary and are not widely available.

Finally, for both rural and urban residents, as will be discussed in chapter three, transportation and time costs for treatment-seeking can be high. Although the TB drugs
themselves are free, these additional costs are largely born by the patient. Indeed, up to 70% of the total cost for TB treatment-seeking is paid by patients, many of whom have very limited incomes (Saunderson, 1995).

Despite these staffing and resource problems, the NTLP has gradually increased both the number of cases identified and the country's case cure rate (Ministry of Health, 1997). For example, between 1992 and 1996, the case detection rate increased from 68 to 77 patients per 100,000. The cure rate increased from 21% in 1994 to 37% in 1995 (Ministry of Health, 1997).

Thus, Uganda's NTLP has attempted to integrate vertical and horizontal program organization in order to decentralize TB care and increase the number of TB treatment providers. While these efforts have led to some success in curing TB, the epidemic continues, and problems with treatment access, sufficient diagnostic facilities, and consistent standards of care remain.

Causes of morbidity and mortality in Uganda

The average life expectancy in Uganda is 41 years at birth (UNAIDS/WHO 1998). The infant mortality rate is 122 per 1,000 (World Bank, 1996), while the under five mortality rate is 203 per 1,000 (World Bank, 1996). As in many developing countries, infectious diseases are responsible for much of Uganda's morbidity and mortality. It should be noted, however, that up-to-date, reliable population based statistics on causes of death are largely unavailable because of reporting difficulties. Not only is there widespread underreporting due to incomplete or improper diagnoses, but many ill individuals never visit a clinic or hospital, while those who do often prefer to be discharged in order to be cared for or die in their home village.
The data that do exist indicate that AIDS, TB, and malaria are the leading causes of death for Ugandan adults (World Bank, 1993). To briefly describe the HIV epidemic, Uganda was among the first countries in Africa to recognize HIV/AIDS, and it has experienced some of the heaviest caseloads in the world. Although there are signs that Uganda's HIV prevalence is declining (e.g., Kamali et al., 2000; Kilian et al., 1999), it is estimated that 820,000 Ugandan adults and children are currently HIV-positive (UNAIDS, 2000). There were 110,000 AIDS deaths in 1999, and 1,700,000 children have lost at least one parent since the start of the epidemic (UNAIDS, 2000).

Underreporting is so extensive, however, that it has been suggested that there are between five and seven times more infections in the country than are currently reported (Bevan and Ssewaya, 1995). Additional epidemiological studies have found prevalence rates ranging from 9.7% (Kengeya-Kayondo et al., 1999) to 16.7% in rural southwest Uganda (Sewenkambo et al., 2000). In urban antenatal clinics, 13.8% of women are HIV-positive (UNAIDS, 2000).

This HIV/AIDS epidemic has been devastating to both the national economy and individual families. For example, it is estimated that by 2010, Uganda will experience an .8% loss of growth per year in the gross domestic product due to the AIDS epidemic (UNAIDS, 2000). On the local level, the majority of families have lost at least one member to HIV/AIDS. The sickness and death of a primary wage earner can have a rippling effect on a household's well being, e.g., reducing the amount of money available for purchasing food and school fees, and decreasing the manpower hours spent gardening by the ill person and his or her caregiver, which in turn reduces the season's harvest (Barnett and Blaikie, 1992). Death frequently leaves children as orphans in need of
extended family support. It is suggested that such illnesses can start a cycle of malnutrition and impoverishment that increases the vulnerability of future generations to HIV infection (Barnett and Blaikie, 1992).

Although this is not a study of HIV/AIDS per se, HIV/AIDS is highly relevant because the HIV epidemic is in large part responsible for the current rise of TB in Uganda and elsewhere (World Health Organization, 1999a). HIV reduces the effectiveness of the immune system and many AIDS patients who previously have been exposed to TB will develop active infections. Alternatively, upon new exposure to TB, the immune systems of HIV-positive individuals may be unable to prevent the development of disease (Samuelson and von Lichtenberg, 1994). Thus, with much of the population commonly exposed to Mycobacterium tuberculosis, the spread of HIV serves as a synergistic force for a TB epidemic. Indeed, TB may be the most common AIDS-related illness (Farmer, 1997), and it was estimated that by the year 2000, HIV will have led to 750,000 new TB cases worldwide ("TB: the leading infectious killer of adults," 1999).

Tuberculosis worldwide and in Uganda

Before beginning a discussion of the TB epidemic’s infection rates and causes, it is important to have basic understanding of the disease itself, especially the routes of transmission, major symptoms and progression. There are two primary types of bacteria which cause TB: Mycobacterium tuberculosis var. hominis and Mycobacterium tuberculosis var. bovinus (Jenkins, 1994).

Generally, M. bovis or "bovine TB" is transmitted from infected animals to humans through the consumption of unpasteurized milk products (Grange, 1994). In
contrast, *M. tuberculosis* is typically transmitted directly between humans as bacteria droplets become airborne through the coughing, sneezing, talking, or singing, of an infectious individual (Enarson and Rouillon, 1994). Because the bacteria quickly dissipate in the air and are destroyed by sunlight, it is believed that prolonged contact with an infectious individual, particularly in a poorly ventilated environment, is required for transmission to occur (Enarson and Rouillon, 1994). Recent studies, however, suggest that not only are close, especially domestic contacts, at risk of infection, but also broader social networks whose primary interactions occur in public places (e.g., Klovdahl et al., 2001).

Once infection occurs, 95% of human immune systems prevent the development of disease (Samuelson and Von Lichtenberg, 1994; see also Grange, 1994). Although a compromised immune system or infection with a virulent disease strain may lead to immediate secondary or disseminated disease, the majority of TB cases are “post-primary” infections which develop through later activation of an initial infection or through re-infection (Samuelson and von Lichtenberg, 1994). Thus, a distinction is generally made between individuals with passive or controlled infections, and those with active or infectious tuberculosis disease.

Although pulmonary TB is most common, the disease can attack any organ, including the stomach, central nervous system, the reproductive tract, as well as skin and bones (Sheffield, 1994). This study focuses on pulmonary TB because of its prevalence in the Ugandan TB epidemic.

The symptoms of an active infection vary considerably. As Ormerod (1994) notes,
the symptoms of respiratory tuberculosis may be non-specific and constitutional or specific and respiratory. General symptoms include tiredness, a feeling of malaise, or anorexia. Weight loss occurs as disease progresses, and may be accompanied by sweating associated with fever, particularly at night. (pp. 77-78)

Ormerod (1994) also suggests that a cough, which may be accompanied by mucous with or without blood stains, is one of the most common systems, but chest pain, whether dull or highly localized, is uncommon. As the disease and lung damage increases, patients may experience breathlessness. Thus, “the development of symptoms is usually insidious over a period of weeks to months, but a presentation with a relatively short history of cough, fever and dyspnoea simulating pneumonia is recognized” (Ormerod, 1994, p. 77).

Without treatment, 30-40% of active TB patients will die within one year of the development of symptoms, while 50-70% will die within five to seven years (Rieder, 1999). The pharmacology of TB drugs is reported in Winstanley (1994) and will not be reviewed here. It is important to note, however, that TB can mutate quickly, therefore, effective treatment often requires the simultaneous use of two or three drugs. While HIV-positive patients can be treated for TB fairly effectively (e.g., Whalen et al., 2000), they may experience increased side effects to certain medications (Okwera et al., 1997), as well as different disease manifestations and progressions (Ormerod, 1994; see also Humphries, Lam, and Teoh, 1994; John Johnson et al., 1997; Whalen et al., 2000).

**Worldwide infections**

Both the incidence and prevalence of TB have increased in Uganda and worldwide over the last 20 years. TB is now the world’s leading infectious cause of death ("TB: the leading infectious killer of adults…," 1999). One-half of 20-40 year olds in developing countries are infected with tuberculosis (Bermejo et al., 1992). The
worldwide figures for women alone are also staggering, as 900 million females are infected with the bacteria. In 1997, seven million new female TB cases were reported and three million women died of the disease (TB: the leading infectious killer of adults…,” 1999).

Uganda’s epidemic

To provide a brief history of the disease in Uganda, tuberculosis has been documented in the region for over 100 years. It was originally recorded among the Baganda in 1878 by a traveling medical student, Robert Felkin (Daniel, 1998). Sir Albert Cook, who established the first hospital in Uganda, further documented the disease among his patients. A recent review of Cook’s records found there was a low and fairly constant prevalence of tuberculosis among patients admitted to Mengo hospital at the end of the nineteenth and beginning of the twentieth centuries…how prevalent it was [throughout the country] cannot be judged, but its incidence was probably relatively stable (Daniel, 1998, p. 786).

Daniel’s findings suggest that TB was probably first introduced through historic North-South trade routes along the Nile and/or (re)introduced through early Arab traders and European explorers. TB was well-established in Uganda by the twentieth century.

Currently, there are an estimated 300 TB cases per 100,000 persons in Uganda (Kalyegira, 1997). The NTLP reports that there were 27,196 known TB cases across the country in 1996 (Ministry of Health, 1997). Furthermore, up to 50% of Ugandan adults have inactive TB infections (Wendo, 1998). These numbers have tremendous public health implications both in terms of the loss of life and productivity (Saunderson, 1995). They are also alarming because it is estimated that every person with active TB can infect ten to twenty additional people per year (Neergaard, 1997).
Explanations for the TB epidemic

There are a number of factors that have contributed to this current TB epidemic. The disease's increased prevalence is in part due to the simultaneous HIV epidemic and larger structural problems, such as the collapse of the health infrastructure in the 1970s, which reduced the availability of TB medications and BCG vaccines. In addition, civil conflict that has limited rebuilding of Uganda's health care system is also cited as a factor behind the disease's continued spread (NTLP, 1992; Okot-Nwang et al., 1993).

Furthermore, many of the same poverty-related variables that are cited as factors behind the HIV/AIDS epidemic, such as marginal nutritional statuses, compromised immune systems and overwork, also contribute to TB vulnerability. Indeed, the findings of Poss (1998) regarding Mexican migrants in the U.S. could apply equally to the situation in Uganda. She writes:

To understand why tuberculosis is so prevalent among migrant workers and other impoverished groups, it is imperative to consider the larger social context in which they live and work. Macro-level factors such as extreme poverty, the need to travel great distances to find work, overcrowded living and working conditions, inadequate nutrition, racism and an unresponsive health care system all contribute to the tuberculosis epidemic...

(Poss, 1998, pp. 201-202)

Farmer (1997) likewise notes the role of economic, structural factors in the prevalence of TB, suggesting they particularly contribute to the development of multi-drug resistant TB. He argues that political-economic "structural violence" and cultural beliefs are not "of equal significance in all settings" as determinants of TB susceptibility (Farmer, 1997, p. 352). As will be discussed in chapter 3, Farmer suggests that it is primarily the
political-economic context that influences patients' disease statuses and their access to appropriate treatment.

Indeed, the relationship between economics and tuberculosis has been repeatedly documented in Africa, using both historic data (e.g., Packard, 1989) and present-day populations (for review see Jaramillo, 1999). These studies have found that socioeconomic variables determine TB's distribution, whether the disease is properly diagnosed, and the availability of medication (e.g., Cornwall, 1997; Needham, Godfrey-Fausett, and Foster 1998). Thus, there are powerful historic and current data suggesting that TB needs to be viewed and addressed as a social and economic illness. The impact of the political economic context on treatment seeking is discussed in the following chapter.

*Women's global tuberculosis rates and Ugandan women's overall health*

Regarding women's health specifically, it should be noted that women's health likewise must be examined as the product of the social and economic context (Packard et al., 1989; Raikes 1989). As discussed above, Baganda women frequently have a subordinate economic and social position to men. This marginalized status often translates into heavy workloads, minimal control of economic resources and fertility, and less overall access to education (MacCormack, 1988; Raikes, 1989). Together these factors increase women's risk of suffering from malnutrition, disability, illness, and physical violence, while simultaneously reducing the time available for seeking biomedical health care (Hutchinson, 1999; Raikes, 1989).

Worldwide, TB is the leading cause of death for women of reproductive age ("TB: the leading infectious killer of adults...," 1999). Although research from Uganda
suggests that tuberculosis infects men and women at similar rates (Eriki et al., 1991),
globally, reproductive-aged women are more likely to develop active infections than men
of the same age ("TB: The leading infectious killer of adults...," 1999). It is suspected
that women have an increased vulnerability to TB during pregnancy and due to their
more marginal working conditions, nutritional statuses, and overall health (Farmer,
1997).

To review Ugandan women’s overall health statistics, in terms of reproductive
health, the total fertility rate averages 6.8 births per female, with 65.9% of these births
considered at “high risk” for maternal or child injury or death (Hutchinson, 1999). Very
few women receive prenatal care and the maternal mortality rate is estimated at 506 per
100,000 (Statistics Department, 1996).

Data from elsewhere in East Africa reveal that women previously have suffered
from high levels of psychological and physical stress, including increased rates of
wasting, stunting, and chronic pain (Ferguson, 1986; Weisner and Abbott, 1977).
Women’s marginal “biophysical environment” is also cited as contributing to women’s
overall poorer health (Kettel, 1996).9

These data suggest that Ugandan women are vulnerable to multiple health
problems, but they have limited resources with which to obtain adequate medical
treatment. As Neema (1999) writes,

9 For a complete discussion of African women’s health issues, see Turshen (1991). Likewise, in her
introduction to a Social Science and Medicine issue on women’s health in developing countries, Puentes-
Markides (1996) examines the problems with current approaches to women’s health policy.
A woman's risk of being ill or dying is highly contingent on her socioeconomic status, her family and the community in which she lives. It also revolves around her educational attainment, employment and reproduction... Rural women are more vulnerable to disease than men partly because the former have less access to health services and they do not have adequate health care resources to seek treatment from rural health providers. (p. 98)

Although she is referring to rural women, Neema’s comments are undoubtedly true for poor urban women as well. Thus, women’s illness in general must be viewed within a social and economic context. This context influences both their disease vulnerability and their ability to seek treatment.

Summary

To summarize, since independence, Uganda and the Baganda have experienced many political and social transformations. Successive, corrupt dictatorships from the 1960s through the 1980s led to the complete collapse of the country’s economy and health infrastructure. This destruction, combined with the recent HIV-epidemic, have resulted in a crippling TB epidemic. Women in particular are vulnerable to TB, both because of their high rates of HIV, and their lower access to health care. While the current government has attempted to increase women’s economic and social rights, women’s struggle for equity, if not equality, continues. Thus, one question that arises from this discussion, is how do female TB patients who may have limited socioeconomic resources cope with the extended demands of biomedical TB treatment seeking. The factors influencing patients’ treatment seeking are discussed next.
Chapter 3: Anthropological Literature on Treatment Seeking

How individuals and societies define and seek treatment for illness has been a core interest of medical anthropologists for decades. The resulting wealth of research on treatment seeking and health care utilization, which began with theories on local health beliefs and the cross-cultural acceptance of biomedicine (e.g., Schwartz, 1969), now includes complex models seeking to predict treatment decisions (e.g., Young and Garro, 1994; Mathews and Hill, 1990). Anthropologists have also expanded investigations of the influence of social and political-economic variables on treatment choice. Despite these many discussions on the social, cultural, and political determinants of treatment-seeking, TB health care utilization research has largely neglected to consider the process or stages of TB treatment seeking until recently. Instead, researchers have focused primarily on the individual factors influencing TB patients' adherence to biomedical treatment regimens.

This chapter reviews the major debates and models of health care utilization in general and the literature on TB treatment seeking specifically. First it examines how the factors influencing treatment seeking are conceptualized, including the relative importance of health beliefs and “cultural congruence” in determining treatment choice vs. the social and economic costs of treatment. Second, the discussion explores the cross-cultural data on TB health beliefs in particular and the barriers to TB treatment. Third, the literature on the “stages” of treatment seeking and “patterns of resort” is examined. This is followed by a discussion of the approaches used to study or measure treatment seeking, including ethnographic and variable-set models.
Health beliefs vs. the costs of treatment seeking

Many of the first treatment-seeking studies by anthropologists explored the acceptance and use of western biomedicine in non-western settings. The primary motivation for much of this research was the apparent ambivalence towards the introduction of biomedicine in many locations. As Foster (1977) indicated in his critique of initial efforts to increase the availability of western biomedicine in developing countries, “early workers in international health programs saw their task in simplistic, easily definable terms: transplant the American models, and health goals will be achieved” (p. 528). It was believed that local individuals would increasingly use biomedicine because of its apparent efficacy, and eventually biomedicine would completely replace traditional health care systems.

In studying the use of biomedicine, however, anthropologists found that treatment choice often was strongly influenced by local beliefs. In this literature, a health belief is frequently defined as a “proposition accepted as true about the causes, symptoms, and remedies related to wellness and sickness” (Chrisman, 1977; Goodenough, 1963). Many researchers found that the perceived etiology of an illness impacted whether a cure was sought from biomedical or traditional practitioners (e.g., Colson, 1971; Lozoff et al., 1975; Schwartz, 1969; Wolff, 1965). It was theorized that treatment “will be accepted or rejected depending on its agreement (congruence, consonance) or disagreement (incongruity, dissonance) with the traditionally established [illness] classifications and their associated behaviors” (Kunstadter 1975, p. 376-377). Biomedicine was also perceived as being too powerful for some individuals (e.g., children) or failing to address
the underlying cause or meaning of an illness (e.g., Kleinman, 1980; Nichter, 1980; Steen and Mazonde, 1999).

Kleinman (1980) expanded the concept of local health beliefs with his suggestion that individuals create “explanatory models” for each illness episode. These models are based in part on patients’ personal beliefs and experiences, as well as cultural norms and beliefs (Garro, 1988; Rubel and Hass, 1990). According to Kleinman, explanatory models “offer explanations of sickness and treatment to guide choices among available therapies and therapists and to cast personal and social meaning on the experience of sickness” (1980:105). In other words, patients’ explanatory models provide insight into an illness’

1. etiology; 2. time and mode of onset of symptoms; 3. pathophysiology; 4. course of sickness (including both degree of severity and type of sick role…); and 5. treatment. (Kleinman, 1980, p. 105)

Good’s (1977) similar concept of “semantic illness networks” also highlights how illness explanations and decisions incorporate the local cultural context. Along with demonstrating the impact of cultural and individual beliefs on illness construction and treatment choice, explanatory model theory suggests that health beliefs may influence the success of treatment. Both patients and health care practitioners develop explanatory models for an illness episode; the degree of agreement between a patient’s and a practitioner’s model can influence the success of a clinical encounter (Kleinman, 1980; see also A. Young, 1982). Supporting these findings, Dressler (1980) also found that treatment adherence is dependent upon agreement of beliefs.
Critiques of cultural congruence theory: costs, barriers, and access to health care

Despite the range of evidence that culturally derived health beliefs influence treatment choices, the argument for the necessity of a “cultural congruence” between illness etiology and a chosen therapy has been widely critiqued. Kunstadter (1975), for example, suggested that this theory assumes that “people are ‘rational’ in attempting to make their behavior conform to a single consistent set of general cultural rules…” (p. 376). In reality, people do not “ordinarily intellectualize their behavior in the sense of making everything consistent…” (p. 377). Foster (1977) likewise noted that it is simplistic to view biomedical and traditional healing systems as “dichotomous” and “adversarial” (p. 528) – people tend to be pragmatic rather than ideological in their treatment seeking decisions (see also Leslie, 1980). Nichter’s (1980) experience in India also suggested that medical belief systems are not coherent and comprehensive as assumed. He found that participants did not understand the intrinsic theories of Ayurvedic medicine but nonetheless adopted Ayurvedic practices.

The notion that western biomedicine represents a foreign healing system in nonwestern societies must also be questioned as currently many adults have grown up with biomedicine as part of their health care system. This is particularly true in Uganda, where the first hospital was established in the 19th century (Daniel, 1998), and Makerere University has trained hundreds of Ugandan doctors and nurses. Western technologies, e.g., needles and injections, have been incorporated into local belief systems. As Birungi (1998) found in Uganda, “currently there has been an appropriation of expert knowledge to lay persons…injectables, syringes and needles are now well positioned among lay persons” (p. 1458). Thus the argument that biomedicine represents an external and
opposing system to traditional medicine is not necessarily true, although individuals within a society may have individual preferences and beliefs concerning biomedical and traditional practitioners.

Perhaps the most compelling arguments against the singular importance of cultural congruence, however, is the evidence that political and economic factors may play a role in treatment choice. As Foster (1977) noted:

...I am increasingly convinced that economic and social costs are more important in determining the use or nonuse of scientific medicine than is the belief-conflict between traditional and modern medicine. (p. 529)

Oths (1994) also suggested that treatment choices are often an issue of economics with her findings that individuals and families with limited resources must prioritize their health needs and choose the healer who “maximized their satisfaction.” Similarly, in Uganda, whether participants had cash to pay for treatment was one of the primary determinants of where participants sought treatment for an illness, whereas the relative wealth of households was associated with whether treatment of any kind was received (Barton and Bagenda, 1993). If not outright eliminating patients’ ability to seek treatment, health care costs may at least lead to delays in treatment seeking (e.g., Miguel, Tallo, Manderson, and Lansang, 1999).

As discussed below, anthropologists examining health care choices have also found that barriers such as access to treatment, including the distance and ease of travel to a clinic, may influence treatment decisions (e.g., Young and Garro, 1982; see also Barton and Bagenda, 1993). These barriers may also be social in nature. For example, poor interaction or communication between health care providers and patients as a result of
differences in social status or cultural background can negatively impact patients’ attitudes and adherence (WHO, 1995).

This debate regarding the role of health beliefs versus extrinsic factors in determining health care utilization is more than a rhetorical debate, as it has implications for improving community health and use of health care services. Indeed, citing Bonfil-Batalla (1970), Morsy (1980) suggested

attributing causal priority to conceptual inconsistency in explaining problems of health care relegates such asymmetrical power relations which are the basic cause of problems of public health, to a position of secondary importance. (p. 96)

Thus, in this view, whether patients use biomedical clinics is not an issue of differing beliefs, but due to the inequitable distribution of both biomedical resources and barriers to care.

**TB Health Beliefs vs. treatment barriers**

The discussion of the relative role of health beliefs vs. the social and economic costs of treatment is a central debate within the TB literature specifically. To explain, the literature on TB patients’ health beliefs and explanatory models reveals that there are a range of traditional beliefs regarding the disease, and there is some evidence that these beliefs may influence treatment choices and adherence (for a review see Poss, 1998). In particular, evidence of local health beliefs regarding coughs and TB’s etiology have been described by Nichter (1994) in the Philippines, Barnhoorn and Adriaanse (1992) in India, and Ndeti (1972) in Kenya, among others. Eighty-five percent of Ndeti’s participants, for example, believed in the power of traditional healers; and those who thought their illness was caused by witchcraft often sought help from a traditional healer – either in conjunction with or instead of seeking help at a clinic.
More recently, in Botswana, Steen and Mazonde (1999) found that although the number of patients describing TB as a traditional illness has decreased over the last seven years, whether patients view their illness as "Tswana" or "European" influences the treatment sought. In addition, they report that patients often have only rudimentary understanding of TB’s characteristics as a biomedical disease.

In Uganda, the literature suggests there are at least six different types of coughs, each with its own symptoms and etiology (Sebudde and Nakku, 1994). These range from "ekfuba ekya bulijjo" (an ordinary cough) which is passed by dust or direct contract, to "olufuba" (wheezing) which is common in older children during the rainy season, to the highly infectious "akuraakirro" (whooping cough) and "akafuba" (tuberculosis). A focus group of mothers revealed that TB is frequently confused with other types of coughs and viewed as requiring biomedical practitioners to diagnose. One mother reported “Akafuba is something difficult. Unless you doctors who have special machines tell us, it is really very difficult to understand” (Sebudde and Nakku, 1994, p. 24). Most focus group participants did not know the cause of TB, but believed it to be quite serious, with symptoms including a chronic, dry cough, loss of weight, and dehydration. These mothers also noted that to treat acute respiratory infections in children, they would try local herb mixtures before consulting the professional health care sector.

Similar to the results from Botswana, patients in Uganda often have limited understanding of biomedicine’s characterization of TB. One study of Kampala TB patients, for example, found that 90% did not know the cause of their illness (Odongo-Aginya, 1985). Seven percent indicated that it was caused by witchcraft and only 3% reported "germs." Likewise regarding TB prevention, Ndeti (1972) found that up to
20% of his sample in Kenya did not know “how can you protect your family from tuberculosis” (p. 401). He also suggested that “the confusion that exists between tuberculosis and other diseases known by the patients to attack the same area of human body is alarming” (p. 403). Thus, this literature suggests that TB patients’ explanatory models may include both biomedical and traditional beliefs. However, even patients who identify that they have the western illness “TB” may not understand the etiology or treatment of the disease, or the implications in terms of transmission.

Within this literature, however, the extent to which HIV/AIDS and TB have become linked, and whether an association further influences treatment seeking is not clear. In general, Sumartojo (1995) noted, “research has not yet clarified the influence of HIV on health care seeking behaviour among tuberculosis patients. Such research is particularly needed in developing countries with high burdens of tuberculosis and HIV” (p. 10). These studies are critical in order to determine the extent to which co-morbidity influences patients’ treatment-seeking decisions or the attitudes and investment of social network members. There is some evidence from Uganda that TB infection is increasingly associated with HIV/AIDS, and that patients may be socially isolated because of their illnesses (Saunderson, 1995).

**Barriers to TB treatment**

At the same time that TB health beliefs clearly influence treatment choices, the literature suggests that the economic and social costs of biomedical TB care can be substantial. As noted in chapter 2, Farmer (1997, see also 1992) in particular, strongly argues that barriers to health care services, as well as poverty itself, are major contributors to the TB epidemic and the growth of multi-drug resistant TB.
To describe some of the economic costs or barriers to treatment seeking, as mentioned earlier, many countries, including Uganda, provide TB medication for free and are attempting to decentralize TB treatment facilities in order to increase the population's access to care. Nonetheless, other treatment expenses, including the costs of related health care services (sputum tests, x-rays) and transportation to the clinic, may be prohibitively expensive. Furthermore, TB treatment seeking often requires six to eight months of regular visits to the clinic, which means these costs are repeatedly incurred. Indeed, in Kampala, even when receiving free medication, patients may bear up to 70% of the total cost of treatment (Saunderson, 1995). Similar studies in Zambia found that patients may spend up to 127% of their mean monthly income in the process of simply finding a diagnosis prior to seeking treatment (Needham et al., 1998). Not surprisingly, then, treatment costs have been found to influence patients' ability to seek or maintain extended biomedical TB treatment (Ndeti, 1972; Needham et al., 1998; Van der Werf, Dade and Van der Mark, 1990; Wamai, 1993).

These arguments regarding the economics of the TB epidemic, however, have not gone unchallenged. First, regarding poverty as the "cause" of the epidemic, a case-controlled study comparing the socioeconomic characteristics of TB patients and non-TB patients in a "high-incidence" South African population found no differences in demographic variables, general living conditions, ownership of luxury items and weekly consumption of four proteins. These findings indicated a lack of evidence on the linkage between individual socioeconomic factors and risk of TB...

(Schoeman, Westaway, and Neethling, 1991, p. 438)
This study suggests that the relationship between economics and TB is complicated, and that it is difficult to determine the specific economic factors that influence susceptibility among seemingly equally vulnerable individuals. It should be noted, however, that this study does little to negate or explain the overwhelming epidemiological data that TB is more prevalent in impoverished and marginalized populations, and that such populations are less likely to have access to appropriate treatment.

A second challenge to discussions on the structural roots of the TB epidemic comes in direct response to Farmer’s (1997) article. While agreeing that there is much evidence of the relationship between political and economic well-being and the incidence of TB, Barnhoorn and Van Der Geest (1997) question the usefulness of such arguments:

> What disturbs us in Farmer’s article is the likelihood that terms such as ‘structural violence’ may lead to inertia...The key question here is: do we begin with trying to change larger society’s unjust structures or do we start at the individual level, with the victims of that society’s system? (p. 1597)

They suggest that instead of such grandiose directives, anthropologists can promote critical changes when working locally by determining the factors that influence both the “demand” for TB treatment, e.g., individual characteristics and health beliefs, and its “supply,” e.g., the availability of drugs and outreach programs, and the characteristics of health care workers. Barnhorn and Van Der Geest’s comments highlight the need to understand the context in which TB treatment is (or isn’t) offered or sought.

Thus, while political and economic structural issues are important variables when examining both the distribution and treatment of TB, the local setting must also be considered. Furthermore, while Farmer (1997) charges that anthropologists overestimate the ability of TB patients to adhere to recommended treatments, it should not be
suggested that patients make no decisions within their context of limited choices. Rather, a key question becomes how do patients cope within this marginalized political-economic context and what can be done locally to maximize their choices in the face of continuing macro-level restraints.

A final point regarding potential barriers to treatment is that there are a range of social costs that may have a lasting impact on TB patients and their families. As Cornwall (1997) succinctly describes,

there is a social cost to accepting a diagnosis of tuberculosis: a disease with social stigma sufficient to preclude marriage of family members; a disease known to be often fatal; and the daily humiliation of reporting to often rude and inconsiderate staff. (p. 661)

In sum, it is clear that health care access, financial costs, and social barriers to treatment all may influence treatment decisions. At the same time, there remains strong evidence that individual and cultural belief systems impact illness conceptualizations and ideas about appropriate treatment. Ultimately, it is difficult to untangle the relative roles of health beliefs and political and economic access. Of particular interest here are two issues that are missing in much of this debate. The first is whether health beliefs and political-economic context influence each other, e.g., whether health beliefs, particularly ideas of contagion, influence participants’ economic resources by limiting their social network contact. Second, few researchers have examined how patients, in the face of such barriers and costs, do manage the long-term treatment-seeking that biomedical TB care demands.
Patterns of resort and stages of treatment seeking

Along with examining the factors motivating health care decisions, how to accurately conceptualize the act of treatment-seeking itself has also been a major focus of the health care utilization literature. As mentioned above, early studies on health care utilization viewed biomedicine and traditional medicine as dichotomous health care systems, and believed that patients directed cure efforts toward only one type of care (Foster, 1977). Further research, however, revealed that treatment-seeking is more complex. As Schwartz (1969) described, treatment choices “may be ordered in hierarchies of resort, where sequences of one, or usually more alternatives may be resorted to as the illness passes from one phase to another when cure is not forthcoming” (p. 205).

Kleinman (1980) suggested that there are three general patterns of resort: simultaneous, hierarchical-exclusive, and hierarchical-mixed. Simultaneous resort refers to patients who seek treatment from multiple health sectors at the same time, e.g., popular treatments, traditional medicine, and biomedical practitioners. With hierarchical-exclusive resort, patients may progress from self-treating with local remedies to contacting consecutively either biomedical or traditional professional healers, i.e., alternating between healers to obtain a cure. Hierarchical-mixed involves a similar progression from self to professional treatment, however, multiple types of professional healers may be consulted simultaneously. Patients’ patterns of resort often depend on the acuteness of symptoms and patients’ ability to find a cure. Hierarchical mixed patterns are found most frequently with chronic illness cases (Kleinman, 1980). Similar descriptions of patients’ patterns of resort are found in Nichter (1978) and Hamnett and
Connell (1981). Thus, examining patients’ health care utilization in terms of patterns of resort helps to uncover the at times lengthy and cumbersome paths involved with finding a diagnosis, treatment, and cure. Research that focuses strictly on patients’ use of either biomedicine or traditional therapies does not fully capture the extent of patients’ dynamic treatment-seeking efforts.

Along with understanding the numerous healing systems and lay or professional practitioners that may be consulted in treatment-seeking, it is also important to examine the range of activities or the process involved with the search for treatment. One model that captures treatment seeking’s multiple dimensions is Chrisman’s stages model. Building on the earlier work of Suchman (1965b), Chrisman (1977) suggested that the health care utilization process consists of stages through which patients may pass as they become ill and seek a cure. These stages include the identification of symptoms, illness related shifts in role behavior, lay consultation and referral, treatment action, and treatment adherence. For any given illness episode, stages may be skipped or occur simultaneously. Throughout the process, however, symptoms are evaluated and decisions regarding future action are made. Chrisman’s model successfully integrates the treatment-seeking concepts of symptom labeling, explanatory models, and the sick role (e.g., Alexander, 1981; Parsons, 1975; Segall, 1976) along with multiple health care sectors.

Chrisman’s stages theory is useful because it presents a clear model for exploring how treatment-seeking occurs as a process over time, rather than viewing health care utilization as a single event. A longitudinal perspective is especially crucial for chronic illnesses which are likely to demand repeat medical encounters, regardless of the
patient’s adherence to medical recommendations (Alexander 1981). As noted in the previous chapter, TB, in particular, may require six to twelve months of biomedical treatment. This is in addition to the time patients may have spent on non-TB treatments for their initial cough. Failure to examine the numerous levels and actions that constitute patient health-seeking can result in a limited and distorted view of patients’ treatment-seeking.

*Patterns of TB treatment seeking*

Within the TB literature specifically, treatment-seeking has not been thoroughly examined as a process. Although the illness is chronic and multiple practitioners may be approached for treatment (e.g., Nichter, 1994), there is a tendency for TB researchers to focus on a single help seeking outcome, i.e., patient adherence to therapy recommendations (e.g., Chaulet, 1987; Cuneo and Snider, 1989; Klein and Naizby, 1995; Nuwaha 1997, 1999). Rarely is there consideration of the prior stages of the treatment-seeking process that might influence a patient’s future adherence and healing. Due to these tendencies, there is a need for more comprehensive examinations of the entire health-seeking process of TB patients, including symptom recognition, social network support, and influences on decisions to continue or change TB therapy (Rubel and Garro 1992).

Odongo-Aginya’s (1985) unpublished data, however, revealed that patients’ treatment seeking patterns in Uganda are consistent with the literature described above. Ugandan patients may consult several traditional or private, biomedical health care practitioners before they are referred to a district hospital with the capability of

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1 For a complete critique of the compliance literature, see Trostle (1988) and Donovan and Blake (1992).
biomedically diagnosing TB. This treatment seeking effort may be delayed considerably
as the patient raises funds to travel to the region’s hospital. Once at the hospital, the
patient is given a sputum test and told to return in two weeks for the results. The patient
again must raise transportation money for this second visit. Upon returning to the
hospital, at times months after the onset of symptoms, the patient may begin TB
treatment. Little is known, however, about which symptoms alarm patients into seeking
treatment or the interaction with their social network members during this process of
health care decision making.

Social networks and treatment seeking

Yet another focus of interest in the treatment seeking literature is the role played
by social networks throughout the treatment seeking process. Indeed, beginning with
Friedson (1960, 1970), there is much literature indicating that social networks can play a
critical role in treatment seeking.

To briefly review this body of research, Friedson (1960, 1970) developed the
concept of the “lay referral system,” which Chrisman (1977) adapted into his model as
the “lay consultation and referral stage.” During this stage, sick individuals may
approach kin and friends in gradually wider social networks in the search for a diagnosis,
cure, and/or referral to a practitioner. According to Friedson (1960, 1970), the number of
network members approached influences the time lapsed before a doctor is consulted. In
addition, the degree of congruence between an individual’s and/or their network’s
diagnosis and a practitioner’s recommendations will influence acceptance and
implementation of the practitioner’s treatment. Suchman (1965a) further argued that
networks may influence whether a practitioner is even consulted. He suggested that individuals in “parochial” networks, which are oriented to popular medicine, are less likely to approach a professional health care practitioner than “cosmopolitan” or scientifically based networks. While the reliability of Suchman’s theory has been questioned and sub-culture variation may influence health care choices (Geertsen, Klauber, Rindflesh, Kane, and Gray, 1975), social networks clearly influence treatment seeking decisions.

More recently, Janzen (1978, 1987) found that social networks serve as the primary treatment decision-makers for ill individuals among the Azande. Janzen suggested that the “therapy management group,” consisting of a patient’s kin, has the responsibility of determining treatment. Unlike Friedson’s model, however, Janzen argued that the therapy management group never releases care to a physician and there is no status differential between the network and the practitioner. Treatments are decided and utilized based upon debate and power relationships within the therapy management group. Janzen’s approach of studying the social network influences on treatment-decisions helps to reveal the non-medical, social and political negotiations which influence treatment-seeking.

Other researchers examining the role of social networks include McKinley (1980), Coreil (1983), Dressler (1986), and Berkman (1980). Together, this literature demonstrates that social networks influence all aspects of the therapeutic process – from the existence of ill health and the identification of symptoms, to decisions about health seeking, the managing of the social and economic costs of health care utilization, treatment adherence, and recovery. In addition, while the exact role of social network
members may vary by network or individual, and social networks may have a negative or positive impact on treatment-seeking (e.g., Dressler 1986), it is clear that across cultures, social networks are frequently involved in at least a few, if not all, stages of the treatment-seeking process.

Social networks, TB treatment seeking, and stigma

The role that social network members play in the TB treatment seeking process has not been well studied. As with other illnesses, extended family members may play a role in ensuring that patients obtain appropriate TB treatment (e.g., Liefooghe, Michiels, Habib, Moran and De Muynck, 1995). However, there are also reports of TB patients and their families hiding the illness, being shunned, and/or having difficulty marrying because of the diagnosis and illness (Menegoni, 1996; Metcalf, Bradshaw and Stindt, 1990; Nichter, 1994; Odongo-Aginya, 1985; Rubel and Garro, 1992).

The extent of TB's stigma is difficult to determine as the data – even within similar populations – are not consistent. For example in Uganda, Wamai (1993) found that 74% of her participants from Kampala’s Mulago hospital reported talking freely about their illness, compared to Odongo-Aginya’s (1985) earlier finding that over 81% of participants reported that friends and relatives were “avoiding and fearing” them because of their diagnosis. Elsewhere in Africa, studies report either little or no evidence of a social stigma associated with TB (e.g., Steen and Mazonde, 1999; Van der Werf et al., 1990). Thus, the evidence is ambiguous regarding whether TB patients hide their illness or whether they are shunned by those who know their diagnosis. While the data above might suggest that the stigma is decreasing, a growing concern is that TB’s association with HIV, another feared illness, might lead to increases in patient ostracism.
Further research is needed to confirm whether an association between the two diseases impacts attitudes towards individual TB patients.

**Measuring treatment seeking: ethnography, decision models, and variable models**

Social scientists have used three primary approaches to study treatment seeking. The first method, "ethnographic decision-making" gathers qualitative information to explain the treatment seeking process (e.g., Janzen, 1978, 1987; Sargent, 1982, 1989). The second approach is to create formal decision-making models that seek to predict patients' treatment choices (e.g., J. Young, 1981; for a discussion of decision tree modeling in general, see Gladwin, 1989). The third uses etically defined sets of variables to examine treatment behavior (e.g., Rosenstock, 1966).

To examine the ethnographic approach first, Janzen and later Sargent used ethnographic research methods to contextualize decision-making within a wider social framework. Janzen's (1978) analysis centered on the influence of power dynamics within the therapy management group. Sargent's (1982) research found that birthing decisions in Benin were made by weighing the social and economic costs and benefits of various delivery options. A woman's wants, goals, and values influenced whether she sought to deliver a baby with a midwife at a government clinic or at home. "Modern" wives of civil servants tended to view government clinics as the appropriate setting for delivery, while more traditional women who preferred local birthing practices and feared the potential for witchcraft were more likely to deliver at home. Sargent (1989) also suggested that control of decisions shifts with cultural context, e.g., depending on whether one lives in the city or countryside and one's social status or social aspirations.
Thus, through qualitative descriptions and analysis, Sargent's and Janzen's research revealed that health care utilization decisions are not simply based upon the desire to become well or have a successful delivery. Rather, they also may be influenced by patients' social and economic context and the social or cultural implications of a treatment decision (see also Whyte, 1997).

An ethnographic decision-making approach obtains detailed information on patients' treatment decisions and the process of decision-making. It is criticized, however, because of its reliance upon participant-observation and the observation opportunities of the researcher (Young and Garro 1982). In addition, to obtain a depth of information, ethnographic samples tend to be small and researchers may focus on unusual rather than normative cases (J. Young 1981).

In part to overcome these criticisms of the ethnographic approach, other researchers have begun to develop formal decision tree models. The work of James Young in Pichataro, Mexico is among the best examples of this type of research in the treatment seeking literature. Young drew from cognitive psychology theories which suggest that a community's members share sets of rules that guide behavior in situations that frequently and repeatedly occur (J. Young, 1981). Young believed that by uncovering these rules, it may be possible to predict behavior. With a rigorous methodology that involved both building an emic model and validating it on separate data, Young suggested that four factors influence decision-making: 1) the gravity of the illness, 2) knowledge of a home remedy, 3) faith in treatment, and 4) availability of

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2 Additional examples of the ethnographic study of treatment seeking and health care can be found in Jacobson-Widding and Westerlund's (1989) volume on African healing systems. As Whyte (1989) discusses, the ethnographic study of misfortune and healing can also be traced back to the early works of Evans-Pritchard (1937) and later, Turner (1968).
resources. While the probability of a treatment's success helped determine treatment preferences, the cost of treatment was a consistent consideration. When tested, Young's model accurately predicted 91% of participants' treatment choices. As mentioned above, Young and Garro (1982) later found that differential access to biomedical treatment, rather than differences in health beliefs, also explained variation in treatment choice. Thus, much of Young and Garro's work stressed that both geographical and financial access are critical determinants of patient's health care seeking decisions.

Other examples of decision tree models include the work of Auerbach (1982) and Mathews and Hill (1990). The strength of this approach is that it allows the researcher to trace individuals through the health care utilization process and determine why they do or don't use specific treatment options, e.g., whether it is due to health beliefs or economic factors. It also allows for the analysis of a large number of cases and is more easily comparable than ethnographic approaches (see also Gladwin, 1989).

Despite these strengths, formal decision making models have a number of weaknesses. First, compared to the ethnographic approach of Janzen (1978) and Sargent (1982), for example, formal decision-making models lack a rich contextualization. Although they may establish a set of "rules" which predict treatment outcomes, most are unable to demonstrate how decision factors interact, or how costs and benefits are weighed. Second, as Harris (1974) argued, it is difficult to establish firm ideational rules. When situations change, rules may become invalid. He suggested that behavior is as likely to determine thought as frequently as thoughts determine behavior. Third, Mathews and Hill (1990) found that the explanatory power of decision-making models decreases in heterogeneous populations. Analyzing their West Indian and Hispanic
participants' explanatory models revealed that treatment choices were based on attitudes and access to clinics as well as idiosyncratic decisions. While Mathews and Hill advocated exploring both patients' explanatory models and their decision models in order to understand treatment choices, they also noted the weakness of decision models, particularly for chronic conditions:

Chronic conditions with oscillating symptomatic and asymptomatic episodes may be handled very differently by different people. In part, the individual's explanatory model of illness will determine how specific episodes of a single condition will be conceptualized and treated. Yet the models for the few, widely shared chronic conditions in the community were fairly standard across informants and the range of treatment options believed to be effective was limited...On the other hand, completely idiosyncratic choices based on personal experiences and interpretations that differ from those of the majority will never be predictable. (Mathews and Hill, 1990, p. 167)

While predicting behavior, particularly patients' treatment decisions, may have important theoretical and practical implications for anthropology and public health, this study did not seek to develop a decision model for women's TB treatment-seeking. Along with the difficulty with using decision-models to study chronic illness, there remains a need for more detailed examinations of the context and process of TB treatment-seeking. As noted, previous TB research has focused almost exclusively on identifying the key variables surrounding the final stage of treatment seeking, i.e., patient adherence. Once the context of the TB treatment-seeking process is more fully understood, a large-scale study to construct a decision-model could be quite valuable.

The third and final approach to the study of treatment-seeking has involved using etically defined variable-set models. Focused on explaining illness behavior, these models have been extensively reviewed elsewhere (see e.g., Gochman, 1988; Kasl and Cobb, 1966; Loue, 1999; McKinlay, 1972; Wolinsky, 1980) and will only be examined
briefly. Two of the most influential models from the study of illness behavior are the Health Belief Model (Rosenstock, 1966) and the Health Services Utilization Model (Andersen, 1995).

To begin with the Health Belief model, although Rosenstock (1966) developed his theory to examine the use of preventive behaviors, it has since been used to study a range of health seeking actions (for reviews see Janz and Becker, 1984; Quah, 1986). This model suggests that three variables influence treatment decisions: 1) an individual’s “perceived susceptibility” to a condition; 2) the “perceived seriousness” of the condition; and 3) the “perceived benefits of taking action and barriers to taking action” (Rosenstock, 1966). As Quah (1985) explains:

in order for an individual to take action (either to prevent or to cure a given disease), this person would have to (1) perceive the disease as having ‘at least moderate severity’; (2) perceive him/herself personally susceptible, vulnerable or already affected by that disease; (3) believe that there are specific benefits in taking the given action, i.e., the disease will be effectively prevented or cured; and (4) the individual would have to perceive no major “barriers” – e.g., cost, convenience, pain, embarrassment – impeding his taking that action. (p. 351)

This sociological model of illness behavior reflects many of the concepts found in the anthropological study of health care utilization, e.g., the importance of patients’ beliefs or understandings of their illness and the costs/barriers to treatment-seeking. Subsequent research with the model suggests that the variable “perceived barriers” has the greatest explanatory power while perceived severity is frequently associated with sick role behaviors but not preventive-health seeking behaviors (see Janz and Becker, 1984).

Similar to the Health Belief Model, the Health Services Utilization model suggests that a complex set of demographic, predisposing, enabling, and need variables determine health care use (Andersen and Aday, 1978; Andersen and Newman, 1973; see
Andersen, 1995 for an expanded model). This is a useful model for exploring health care utilization because it can be tested on large samples.

Despite its theoretical appeal and frequent use, however, the Health Services Utilization model has limited explanatory power – the primary variable associated with health care utilization is need (Wolinsky 1978). This model also does not provide insight into the context of health care seeking (Mechanic 1979). As Mechanic (1979) summarized,

The benefits of the large-scale surveys include the size and representativeness of the samples studied, the range of variables included, and the ability to introduce statistical controls to identify spurious findings. In contrast, the traditional studies provide a richer view of perceptions and reactions and a better conception of social process... (p. 394)

Thus, the Health Belief and Health Services Utilization Models represent important conceptualizations of illness behavior that use ethically defined variables. While the issues they examine, e.g., patients' illness perceptions and activities, are similar to the issues discussed within anthropology, the models generally do not increase understanding of the process of treatment seeking.

Summary

The literature on the treatment-seeking process suggests that multiple factors may influence patients’ health care utilization. Along with local health beliefs and explanatory models, patients’ and their social networks’ geographic, economic and social access to health care services, their overarching social goals and attitudes, and previous experiences all may influence the choice of care. To truly understand the treatment-seeking process, it is critical to examine the range of factors impacting patients’ decisions.
Clearly, treatment seeking occurs in a social and political context that cannot be reduced to an issue of cultural congruence. Individuals with easier access to biomedicine tend to use its services more than those for whom biomedicine is expensive or inconvenient. At the same time, patients' health beliefs may impact the entire treatment seeking process – from the initial identification of an illness and the decision to seek care, to the adherence to treatment recommendations and/or the consultation of additional health care practitioners.

The literature on TB treatment seeking specifically mirrors the broader literature on health care utilization. For example, there are many local health beliefs regarding TB, which have been found to influence treatment choice, but biomedical TB treatment can be prohibitively expensive, despite free or subsidized drug programs. Ultimately, within the TB literature, a largely unanswered question remains: Once a decision to seek biomedicine is made, how do patients, especially those with limited income and resources, manage the many months of treatment that TB requires? In particular, the importance of social network members in coping with the demands of tablet consumption and weekly or monthly clinic visits has not been fully explored. Whether social networks play a role in daily or overall treatment seeking is a critical issue given the concern that the growing association between HIV and TB may intensify the shunning and ostracism of TB patients.
Chapter 4: Social networks, social support, and urbanization

The study of social relationships, social networks, and social support is a vast literature with contributions from anthropology, social anthropology, sociology, and psychology. In part because of this multidisciplinary foundation, the methodologies that are used to explore the nature of social relationships are quite varied. They range from the development of standardized instruments and scales to formally characterize the dimensions of social networks, to ethnographic studies of social roles and the cultural context of social exchange. Each approach has advanced understanding of the impact of family and friends on individual health and well being. Social network researchers have also theorized how larger social changes, particularly urbanization processes, may influence the development and operation of social networks. This chapter examines how social networks and social support are conceptualized and operationalized. It also discusses the evidence regarding the impact of social relationships on health, disease, and illness management. Finally, this chapter examines the debate over differences in the structure and function of social networks in urban vs. non-urban environments.

Conceptualizations of social networks and social support

One of the most frequently cited definitions of a social network is Mitchell’s (1969) suggestion that social networks are “a specific set of linkages among a defined set of persons, with the additional property that the characteristics of these linkages as a whole may be used to interpret the social behavior of the persons involved” (p. 2). Dressler (1996) similarly suggested that social networks are “the concrete relationships among a defined set of individuals” (p. 261). A social network’s “structure” should be
distinguished from its "function" (Tracy and Whittaker, 1990). Whereas one of a social network's functions may be the exchange of social support, a social network's structural characteristics include the number of people in the network (network size), the relationship of the individuals (composition), their geographical proximity, and the quality/intensity of the relationship (e.g., degree of closeness or criticism) (O'Reilly, 1988; Tracy and Whittaker, 1990).

Beyond this basic definition, researchers conceptualize and operationalize social networks many different ways. One of the primary distinctions in the study of social networks is whether the focus is on whole networks, i.e., the social connections between an entire group of people, or examining an ego-centered network, i.e. the social ties of a single individual (Jeffrey Johnson, 1994). While both types of studies have advanced understanding of social relationships, the focus here is on ego-centered networks and their impact on illness management and treatment decision-making.

The literature specifically on ego-centered networks further distinguishes three primary types of social networks. The first perspective views social networks as an individual's "intimate, confiding relationships" (Thoits, 1984). These "significant other" networks are typically measured using questions like, "who are your best friends" (Milardo, 1983). This conceptualization and operationalization is problematic, however, because it may exclude those with whom an individual has negative support exchanges and

(a) selectively omits members of other important network sectors,
(b) yields invalid response with little interindivdual consistency...and
(c) places excessive demands on respondents to produce socially desirable responses (Milardo 1983, p. 2-3)
Indeed, the work of Schweizer (1988) in Java highlights how members of a social network may be drawn from separate kinship, business, and religious relationships. These important associates may not be identified through questions regarding a participant’s close ties. Furthermore, Hammer (1983) suggests that individuals have both “core” and “extended” social networks. Focusing on just the emotionally close core does not reveal the resources upon which an individual may be able to draw during times of crisis or to replace close core members.

A second conceptualization of networks is to view them as interactive. Such studies allow researchers to examine all interactions between an individual and others either prospectively or retrospectively. The advantage of this view is that it provides a measure of an individual’s social activity during a given time period. However, it does not necessarily measure the quality of the relationship or interaction, and it tends to create very broad networks. Anyone with whom a participant has contact becomes a network member, regardless of the participant’s views on their inclusion. The accuracy of participant recall in such studies has also been questioned (Milardo, 1983; see also Killworth and Bernard, 1976).

A third and final conceptualization of social networks defines them as exchange networks. According to this view, networks may include affective relationships from which participants perceive a high level of support, regardless of the amount or frequency of contact, and those who may not be as close, but with whom there is much interaction or exchanges (Milardo, 1983; 1988). Other authors specify that a subset of an individual’s social network is the “social support system” which is primarily responsible
for exchanging social support (Dressler, 1996). Citing Whittaker and Garbarino (1983),
Tracy and Whittaker (1990) further noted that, as will be discussed below,

A social support network refers to a set of relationships that provide nurturance
and reinforcement for coping with life on a daily basis...though not all networks
are socially supportive, nor do they always reinforce positive social behaviors.
(p. 462)

This definition of social networks as exchange networks does not have the same
theoretical and operational weaknesses as the first two approaches. From a theoretical
perspective, the concept of exchange networks recognizes that a participant’s important
social network members may extend beyond those who are emotionally close. At the
same time, a participant may not consider all of the individuals with whom he or she has
contact as part of his or her network. In addition, the concept of exchange networks
generally is operationalized to allow participants to define their own networks.
Participants may choose to include people who are emotionally or geographically distant,
as well as those who are close.

Social support itself is defined as “the perceived availability of help or assistance
from other persons during times of felt need” (Dressler, 1996, p. 260; see also Dressler,
1991). Social support is usually conceptualized as consisting of three dimensions:
emotional, social/informational, and material support (e.g., Philips and Fischer, 1981).
Material support may also be referred to as instrumental, concrete, or tangible support
(Brown, 1986; O’Reilly, 1988). It should be emphasized that this definition of social
support refers to individuals’ perceptions of support, rather than the actual support
received. Perceived support tends to show a greater relationship to outcome variables
than actual support measures (Pierce et al., 1996). Generally, an individual’s assessment
of his or her social support is dependent upon:
(a) the perception of actual exchanges or punishments, (b) the belief that material or symbolic rewards would be available should the need develop, or (c) the subjective feeling that one is more or less supported by network members (Milardo, 1983, p. 6-7)

In these conceptualizations of social networks and social support, it should be cautioned that both individual characteristics and cultural context influence the perception of social networks and social support. Sarason, Sarason, and Shearin (1986), for example, found that individual social skills or mental statuses may influence social network size and access to social support (see also Dean, Holst, Kreiner, Schoenborn, and Wilson, 1994). Individual or subgroup characteristics may also impact the beneficial impact of support (Riley and Eckenrode, 1986). At the same time, Jacobson (1987) suggested that culture:

...influences the perception of what constitutes support, who should provide it, to whom, and under what circumstances. Moreover, networks are composites of social relationships, the characteristics of which are shaped in part by cultural beliefs, values, and norms. (p. 49)

In other words, perceptions of the existence of social networks and social support and judgments about their adequacy and appropriateness are highly dependent upon cultural context (see also Dressler, 1994).

Thus, researchers have defined social networks and social support many different ways. In order to understand the impact of social networks on the treatment-seeking process in the Ugandan context, it is critical to view social networks as including both emotionally and physically close as well as distant individuals. Such a conceptualization allows members of Baganda women's potentially scattered rural-urban networks to be recognized. Likewise, social support is best viewed as multidimensional, consisting of tangible, emotional, and informational exchanges. This perspective helps reveal
participants' perceptions of a range of support types, rather than focusing on one type, e.g., tangible support, which may be scarce in Uganda’s political and economic context.

Measuring social networks and social support

Two major methodological approaches have been employed to measure social networks and social support. The first utilizes qualitative ethnographic research methods to uncover the dynamics of social relationships, especially in international settings. The second method has involved the development of standardized instruments and scales in order to characterize the dimensions of individuals’ social networks and social support exchanges and their relationship to stress and coping. Historically, anthropologists and social anthropologists have contributed to both traditions, but more recently, sociologists and psychologists have begun to develop the majority of the standardized social network and support instruments (Jeffrey Johnson, 1994).

Ethnographic study of social relationships

Among the first researchers to examine the importance of social relationships in society were anthropologists. Virtually all early ethnographies explored the construction of kinship and the organization of social relationships and exchanges (e.g., Evans-Pritchard, 1940; Kenyatta, 1965; Roscoe, 1911/1965). Likewise, numerous texts addressed the cross-cultural structure and role of kinship specifically (e.g., Fox, 1967; Schneider, 1968; Stack, 1974). Despite their contributions to the understanding of the formation of social ties, it should be noted that these works often are not associated with the study of social networks and social support. In part, this is because, as Jeffrey
Johnson (1994) noted, “...with only a few exceptions, network concepts, methods, and approaches were used little in the study of kinship” (p. 128).

As will be described below, this ethnographic research nonetheless has contributed to anthropologists’ understanding of the structure and functioning of social relationships, especially in East and Central Africa (Colson, 1958; Evans-Pritchard, 1940; Gutkind and Southall, 1957). Furthermore, many of these early studies, particularly those of social anthropologists like Gutkind (1969) and Epstein (1961), can be seen as direct precursors to today’s structured social network research (Jeffrey Johnson, 1994). Currently, anthropologists continue to pursue ethnographic research on the meaning and role of kin and non-kin relationships (e.g., Bell and Coleman, 1999; Carsten, 2000) and social support (e.g., Barnett and Blaikie, 1992; Kilbride and Kilbride, 1990; Weisner, 1997). Qualitative and contextual data are also being used in connection with formal, quantitative instruments in order to clearly define research questions and issues, to further discern meaning, and to provide more in-depth examples of social support exchanges (for review see Depner, Washington, and Ingersoll-Dayton, 1984; specific examples include Bian, 1999; Bollig, 1998; and Rao, 1998). There is a continuing call, however, for cross-cultural, ethnographic studies of the context and meaning of social support exchanges (Dilworth-Anderson and Marshall, 1996; Dunkel-Schetter, Sagrestano, Feldman, and Killingsworth, 1996; Jacobson, 1987).

Standardized social support measures

There are numerous examples of standardized instruments and variations on instruments (for reviews and critiques of these instruments see Kaplan, 1994; O’Reilly, 1988; Sarason and Sarason, 1994). It is not possible to review the entire body of research
here; however, some of the more major measures include the Multidimensional Scale of Perceived Social Support (Dahlem, Zimet, and Walker, 1991; Zimet, Dahlem, Zimet, and Farley, 1988), The Social Support Questionnaire (Sarason, Levine, Basham, and Sarason, 1983), and Philips and Fischer’s (1981) behavioral mapping technique. These instruments illustrate how the foci of social network and support measures can vary considerably.

To briefly describe how measurement techniques differ across instruments, one approach is to use general support questions to determine participants’ overall social support perceptions and satisfaction ratings. For example, the Multidimensional scale of Perceived Social Support asks participants to rate whether “there is a special person who is around when I am in need” or “I can count on my friends when things go wrong” (Dahlem, Zimet, and Walker, 1991). The Support Behaviors Inventory (SBI), which was designed for pregnant women, similarly inquires whether significant others and/or family, “helps get house and things ready for the baby” and “takes me seriously when I have concern” (Brown, 1986). The ratings obtained from the SBI can then be totaled to create an overall measure of support satisfaction.

A second measurement technique focuses on which individuals provide specific types of support. For example, the Social Support Questionnaire inquires, “whom can you really count on to listen to you when you need to talk?” and “Whom could really count on to help you out in a crisis situation?” (Sarason et al., 1983). Likewise, Philips and Fischer’s (1981) instrument asks participants, “who would care for their homes if they went out of town?” and “from whom they would or could borrow a large sum of money?” (p. 224). The advantage of inquiring who provides this support is that this list
can then be used to establish the structure of the participant’s social network. Participants can then describe the characteristics of each network member (e.g., how long they’ve known each other; where the member lives). As Philips and Fischer (1981) suggested, the support questions are more precise than questions like “whom do you feel closest to” and can focus on specific types and ranges of support (p. 223). These items uncover individuals who may help with specific types of difficulties or provide only one type of support.

One problem with this approach, however, is that by guiding participants to list individuals based on behavioral prompts, the instrument “eliminates potential network members who are bonded to respondents by affective ties exclusively” (Milardo, 1983, p. 6). In addition, as originally designed, Philips and Fischer’s (1981) technique is problematic because researchers may limit the number of persons for whom structural characteristics are obtained, e.g., the authors collect details on a subset of five network members. This constraint prevents accurate estimates of participants’ total network size and the network’s dimensions, especially the traits of “extended” vs. “core” network members (Hammer, 1983).

A third and final measure of social networks and social support involves creating a “map” of a participant’s social network by asking who is in the social network directly. Probes prompt participants to recall members from specific areas of life rather than from behavioral interaction. The advantage of this network mapping technique is that it allows participants to list an unlimited number of network members in each of seven life domains: household, other family, work/school, clubs/organizations/church, friends, neighbors, formal services. Participants are prompted to include people who are
important to them, and those “who made you feel good, people who made you feel bad, and others who just played a part in your life…” (Tracy and Whitaker, 1990, p. 465).

Similar to Philips and Fischer (1981), the resulting “map” can be used to obtain the network’s structure and the type and frequency of support exchanges, i.e., the social network “grid” (Tracy, 1990; Tracy and Abell, 1994; Tracy and Whittaker, 1990). For each network member, or as the authors recommend, for the first fifteen (if the participant has listed more than fifteen), information is collected on the individual’s “criticalness,” closeness, reciprocity, directionality, stability, amount of contact, and the frequency of emotional, informational, and concrete support exchanges (Tracy and Whittaker, 1990, p. 464). Thus, this method allows participants to include and describe network members who both give and receive support, as well as those who are perceived as important and emotionally close, but who may not exchange support frequently.

Ultimately, there are advantages and disadvantages to each of these social network and social support measurement techniques. Regardless of the approach, it is critical that network and support measures 1) clearly distinguish social network structure from its function (social support); 2) operationalize support as multidimensional; and 3) not assume that support is necessarily exchanged or that exchanges are always perceived as positive (O’Reilly, 1988). As with the theoretical construct of social networks and social support, the measurement technique utilized in large part depends upon the focus of the research question. Using a combination of techniques may help to overcome the weaknesses of the individual methods.
Relationship of social networks and social support to health and disease

The goal of much of this social network and social support research is to examine how networks function in society and the relationship between networks and/or support and health. This literature has also examined the role of social networks in facilitating treatment seeking. As will be discussed below, there is much evidence that social networks and social support exchanges can have a positive impact on individual well-being, but there may also be costs to social network involvement.

To briefly examine the evidence that perceptions of social support can have a positive impact on health, generally it is argued that social networks and/or social support serve as buffers or mediators in the "stress process" (Dressler, 1996). They either reduce the perception of stress or offer additional coping assistance in the face of a threat. Stress itself is conceptualized as a subjective or objective environmental phenomenon "which poses a threat to physical or psychological well-being" (Depner, Wethington, Ingersoll-Dayton, 1984, p. 38). Stressors may consist of daily hassles (e.g., job demands), or discrete life events (e.g., divorce or illness) (Pearlin, Lieberman, Menaghan, and Mullan, 1981). To highlight a few of the results of these studies, social network involvement and social support exchanges have been found to have a positive relationship with social network members' health statuses (McKinlay, 1980), resistance to the common cold (Cohen, Doyle, Skoner, Rabin, and Gwaltney, 1997), and illness recovery (Dean et al., 1994; Ell, 1984). Negative associations exist between levels of social support and hypertension (Dressler, 1982), depression (Dressler, 1985; Pearlin et al., 1981; Zimet et al., 1988), poor pregnancy outcome (Collins, Dunkel-Schetter, Lobel, and Scrimshaw, 1993; Nuckolls, Cassel, and Kaplan, 1972) and overall risk of morbidity and mortality.
(Berkman and Syme, 1979). For a review of the evidence on the connection between social networks and social support and health and well being, see Dressler (1996).

At the same time that the literature demonstrates both social network connections and social support have a positive health effect on a range of disease conditions, research also suggests that social networks can have a negative impact on health. Shin, Lehmann, and Wong (1984), for example, found that negative social interaction explains more variation in health outcomes than positive interaction. Network participation may require the reciprocation of high instrumental costs (Stack, 1974), may involve emotionally negative exchanges (Coohey, 1995), and generally increase the anxiety and irritation level of individual network members (Rogers, 1996). Thus, it cannot be assumed that the presence of social network or social support is necessarily beneficial.

Finally, as discussed in the previous chapter, social networks and social support may also have an indirect impact on health by influencing treatment-seeking and preventive health behaviors. Social networks have been found to serve as illness managers and treatment decision-making bodies (Janzen, 1978; Kleinman, 1980). Typically, social networks consisting of household and extended family members provide ill individuals with nursing care, child care, food, and money for transportation or medication (Barnett and Blaikie, 1992; Coreil, 1983; McKinlay, 1981). In terms of preventive health behaviors, for example, researchers have found that network support impacts infant feeding decisions (Bryant, 1982), and "indirect risk" preventive health behaviors, like exercise, seat belt use, and medical and dental check-ups (Langlie, 1977).

Thus, this literature suggests that treatment-seeking and preventive health behavior decisions often result from cognitive and social processes. Health care
utilization in particular is not an individual act, but rather involves "microhistorical social relationships" and "personal exchanges" (Janzen, 1978; 1987). Given this evidence that social networks often make important contributions to healing and treatment seeking, this study seeks to examine whether this role shifts in the context of a highly contagious and somewhat stigmatized disease like TB. An equally interesting issue is whether social networks and social support influence the physiological progression of TB and/or patients' symptoms or their experience of side effects. That question, however, is beyond the scope of this current study.

Social networks and support in Uganda

Researchers have been examining the role and impact of social networks and social support in East Africa and Uganda specifically for decades. These studies traditionally focused on the function of kinship and the extended family, although the rise of urban centers, as well as more recent appraisals of friendship, have led to additional consideration of the role of non-kin relationships (e.g., Aguilar, 1999; Epstein, 1961; Gutkind, 1969).

Radcliffe-Brown (1950) summarized both the importance of kinship and anthropologists' attitude towards the concept with his opening statement to African Systems of Kinship and Marriage, "For the understanding of any aspect of the social life of an African people – economic, political, or religious – it is essential to have a thorough knowledge of their system of kinship and marriage" (p. 1). According to many early anthropologists, consanguineal and affinal relationships ordered and/or determined social and political relations in a number of ethnic groups. For example, Middleton (1965) found that among the Lugbara, "genealogy explains and validates the social relations
between people of the present day” (p. 21). Among the Nuer, Evans-Pritchard (1970) likewise stated that kinship ties express all social relationships, and they are necessary in order to have any personal relationships. In Kampala, Southall (1961) described that for the Baganda, “kinship or tribal membership is still the most widely recognized bond. It is usually combined and reinforced by neighbourhood, profession, or occupation” (p. 226). Finally, in her assessment of anthropology’s emphasis on kinship, Aguilar (1999) cautioned that “kinship relations have been over stressed in the anthropology of Africa,” but she also explained that “…kinship relations have in many cases given clues to the analysis of societies, based on our participant observation, as African themselves have represented their lives through the idiom of kinship rather than friendship” (p. 169). Thus, the evidence is clear that in many regions, including among the Baganda, an individual’s social ties to others are often defined by and dependent upon kinship relationships.

Along with playing a critical role in determining social connection, being part of a kinship network carries many obligations, particularly the exchange of economic or material support. These obligatory relationships are particularly associated with extended family members. An extended family may be duo- or multi-local (Weisner, 1997) and contain multiple generations of the same lineage or affinal relations (Sudarkasa, 1982). To give a few examples of these family responsibilities, Aldous (1965) argued that in West Africa, the extended family is a “powerful cementing framework” that helps care for those who are old, sick, or destitute in regions where there is no government welfare system. Likewise, Comhaire (1965), found that extended family relationships are necessary for economic security, along with having religious and education roles. Much

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later, Kilbride and Kilbride (1990) found among the Abaluyia in Kenya that, "kin or extended family rights and duties are very salient" with the Abaluyia having a "cultural ideology of kin-based support groups" (p. 60).

Among the Baganda, the social expectation is that extended family members will provide assistance to their kin, whether in the form of food, education, money, shelter, or job referral (e.g., Obbo, 1986). Social networks are also critical for migrants, providing the newly arrived with emotional support, information concerning employment and housing, and connections with homelands (e.g., Epstein, 1961; Gutkind, 1965, 1966; Parkin, 1969; Southwold, 1952).

Successful family members in particular are viewed as having an obligation to assist their kin. As Obbo (1987) notes, "the assumption is that if one person climbs the socioeconomic ladder it is their responsibility to help others. These responsibilities are difficult to duck without getting a bad name..." (p. 268) (see also Cattell, 1997; Edwards, 1997). At the same time that expectations for extended family members continue, there is evidence that some members of the social elite resent the social demands placed upon them and view their extended family as a financial drain (Jacobson, 1973; Middleton, 1965; Shipton, 1989; Siegel, 1992). Failing to assist or provide for family members according to social norms, however, can lead not just to tension and social isolation, but also physical retaliation and murder (Ferguson, 1999). Thus, there are many expectations regarding support between family members, even among those who are distantly related, but this social obligation is not consistently met.

One particularly important role which social networks, especially extended families, are expected to fill is the care of the sick, the elderly, and the very young. Citing
the works of the Kilbride and Kilbride (1990; 1997) and Weisner (1997), Cattell (1997) noted,

most of the available evidence indicates that extended families, though overstretched and often with inadequate resources, continue to be the primary support system for vulnerable members, including children. (p. 158)

Extended families have provided critical support to victims of the HIV/AIDS epidemic, both caring for the ill and providing for their children (Ankrah, 1994; Barnett and Blaikie, 1992; McGrath et al., 1994; Wallman, 1996). Not only do family members provide the majority of outpatient and in-patient care, they must also cover the enormous costs of transportation to the hospital and medication1. The sheer volume of individuals infected and youths orphaned, however, have begun to overload these social networks (Hunter, 1990). Families do not have the funds to educate orphans, and many of these children are now living on the street (Masland and Nordland, 2000).

Barnett and Blaikie’s (1992) research in particular captured the multiple effects of HIV/AIDS on Ugandan families. They described a downward cycle that begins as one family member falls ill and household income and resources reduce because of medical and funeral expenses. The amount of time and money available for farming and educating children also decreases. This combination of factors, especially the limits on education, lowers the socio-economic potential of a household’s youths, and may place a new generation at risk of HIV infection. Barnett and Blaikie (1992) suggested that previously prosperous households may become unrecognizable, so sharp is the economic and personnel loss.

1 The majority of HIV/AIDS patients in Uganda do not have access to expensive antiretroviral medications, however, many of AIDS’ secondary infections can be treated. Access to AIDS drugs is expected to expand in the near future.
These models of the HIV/AIDS epidemic, however, do not examine how the social network influences the identification of illness and the stages of the treatment-seeking process. In addition, little research has examined how households and social networks specifically manage TB infections, which are yet another complication of the HIV/AIDS epidemic that require months of treatment.

The political and economic context of social support exchanges

The destructive impact of the HIV/AIDS epidemic on extended families and social support resources serves as an example of the way in which social networks and social support exchanges are influenced by a society’s greater political and economic context. As Pilisuk and Minkler (1985) noted:

Contrary to popular ideology, supportive networks do not operate in a vacuum...Family and community effectiveness in the provision of social support is heavily dependent upon the broader economic and social environment. Where this larger environment creates and tolerates war, poverty and injustice, social ties on the individual and community level cannot be expected to dramatically improve quality of life or later high morbidity and mortality rates. Indeed to overemphasize the singular influence of social ties on health and to ignore the broader context within which those social ties must operate, is to politically misuse the findings on the social support and health relationship. (p. 104)

Along with the HIV/AIDS epidemic, continuing poverty and civil war also limit the efficacy of social networks in East Africa. Weisner (1997) described,

Millions of Kenyan families and children today neither have their basic needs met nor possess a sense of basic predictability in life. Shared social support is not possible for them, but they hope for it. They continue to defend its possibility, if not predictability, in their lives. This is how the African family crisis is experienced. (p. 22-23)

Thus, in addition to the HIV/AIDS epidemic, on-going poverty is compromising traditional parenting practices (LeVine et al., 1996). Likewise, modernization processes and economic “delocalization” threaten the survival of women, children and the stability
and power of the family (Kilbride and Kilbride, 1990; see also Weisner, Bradley, and Kilbride, 1997).

Finally, economic power dynamics also influence exchanges within networks. For example, Dressler (1985) and Lane and Millar (1987) found that social network members provide greater support to those who have the highest social status in the network. Women's social status is frequently determined by control over economic resources (for a review, see MacCormack, 1988). As a result, in patrilineal societies, women who reside in traditional, patrilocal, extended family households tend to have little decision-making and economic power (Morsy, 1993; Warner, Lee, and Lee, 1986). In contrast, women who either maintain strong relationships with their natal kin (Hakansson, 1994) or do not enter traditional marriages tend to possess greater decision-making and economic control (Mandeville, 1975). In Uganda specifically, women in traditional marriages or rural locations often have a lower political-economic position within their households, while women who serve as the single household heads and/or reside in urban locations generally have become relatively independent with considerable decision-making power (Mandeville, 1975; Kilbride, 1979; Obbo, 1980; Rwabukwali, 1997). Thus, in many locations, having a valued "structural position" within a network (Lane and Millar, 1987) may assist an individual's ability to obtain support from their networks (Dressler, 1985; Liefooghe et al., 1995). Whether potential differences in network resource allocation influence women's long term treatment seeking abilities is unknown.
Urbanization and social networks in East Africa

In addition to rural-urban variation in the structural position of women within their networks, researchers have examined whether the entire structure of social networks changes in urban contexts. Over the decades, a number of contrasting theories have developed, with some authors suggesting that urbanization leads to an increase in impersonal, non-kin relationships. Others argue that kinship relations, especially the extended family, remain relevant in urban settings.

Before beginning a discussion of the debate surrounding urbanization, it is important to understand the migration processes, which in combination with natural population increases, led to the development of many African cities. In brief, researchers have identified two primary migration patterns in Eastern, Central, and Southern Africa. The first involves circular, often periodic or seasonal movement in which an individual moves to another location (e.g., a city, plantation, or mine) to earn money. The migrant, however, returns to his original homeland periodically, assisting with agricultural production and sharing his earnings with family members. The second migration pattern entails a permanent move to the city (Oucho and Gould, 1993; see also Hunt, 1989; Skinner, 1985). These authors suggested that Africa’s migration patterns stem in part from the institutionalization of colonial policies that encouraged single males to be non-permanent migrants, as well as from the economic and social desires of migrants to maintain connections (or disconnect) from their extended family. For women in particular, migration to cities may serve as a means for escaping poverty and/or oppressive family or marital relationships (Obbo, 1980; Pittin, 1984).
Despite many migrants’ hopes for economic opportunity, it should be noted that the increase in the number and size of urban areas in many African countries generally has not been accompanied by industrialization, as was the trend in Western Europe (Clarke, 1968; Okpala, 1987). Instead, many cities are “underdeveloped,” with major housing, sanitation, and employment crises (Gutkind, 1982; Kerri, 1977; Kironde, J., 1992; Okpala, 1987; Yach, Mathews and Buch, 1990). The urban poor are particularly vulnerable to high rates of infectious and chronic illnesses, as well as malnutrition (Harpham and Tanner, 1995). Children of migrants also tend to fall ill in greater proportions, having higher under-five mortality rates than nonmigrant children (Brockerhoff, 1990). Thus, though potentially holding more promise, life in East African cities for most migrants frequently proves just as or more challenging than rural subsistence.

In terms of social networks, early urban theorists suggested that the growth of cities has had a negative, transformative impact on the traditional, extended family (e.g., Wirth, 1938). Wirth (1938), for example, defined a city as “a relatively large, dense, and permanent settlement of socially heterogeneous individuals…” (p. 8), and he suggested that there is a “superficiality”, “anonymity”, and “transitory character” to urban relationships (p. 12). In his critique of this concept of the city, however, Gutkind (1963) argued that this theory mistakenly assumes that:

Social distance and impersonality of relationships…come about under conditions of rapid social change, particularly in the growth of urban communities which are not considered to be suitable places…for the development of new forms of social cohesion and solidarity. (p. 152)
Gutkind (1963) and Epstein (1961) further suggested that these early theories on urban vs. rural social relationships present urban society as dichotomized, with “atomistic” (Gutkind, 1963, p. 153) urban life on one side and highly-integrated, connected rural traditions on the other. More recent researchers in West Africa, although not embracing this extreme view of urbanization, suggested there may be a trend towards increased individualism and decreased involvement in extended families. They cautioned that further studies are needed to determine if such a shift is occurring and whether it impacts on coping resources (Watts, Brieger, and Yacoob, 1989).

In questioning these theories of urban social relationships, many anthropologists argued that a characterization of all urban relationships as impersonal and transitory is constructed largely from the Western European urbanization experience (Epstein, 1967). Furthermore, in his seminal work, *African Urban Family Life*, Gutkind (1963) warned that rural-urban differences in social organization should not be overemphasized. After examining age, type, and frequency of marriage unions, for example, he argued that rural and urban differences are not significant (see also, Lewis, 1976; Weisner, 1976). Instead, Gutkind (1963) suggested that most rural-urban comparative analyses do not take into account the dynamics of social change, the reciprocal relations and interdependence between town and country, and the flexibility and adaptability of African social systems and social organizations...There is much evidence that the African urban family, despite the stresses to which it has been subjected has not merely adapted itself more effectively than has often been suggested, but has maintained numerous rural characteristics. (pp. 204, 206)

Ross and Weisner (1977) likewise emphasized that depicting rural and urban societies as socially distinct ignores the complex social and economic ties connecting them. They argued that an informal “unbounded” network that is typically family-based connects city residents to those in the countryside. These networks directly influence the social and
economic resources available to individuals in both locations through multi-directional exchanges. The continuing importance of kinship is also evident in the use of kinship terminology in addressing non-relatives. As Epstein (1961) noted from his work in Central Africa,

...the modes of address and forms of behaviour appropriate between particular categories of kin are readily extended to unrelated persons, and close relations with neighbors and friends are frequently translated in this way into the idiom of kinship. (p. 99-100)

Thus, despite frequent geographical and temporal separation, kinship networks remain salient in Uganda and other regions of Africa. For many rural and urban residents, they are critical for economic survival, and their importance is further symbolized by the bestowing of kin names to non-kin.

Despite challenging assumptions regarding the demise of the extended family with the growth of cities, some anthropologists have suggested that there is a growth of non-kin social networks in urban settings. Networks in urban communities frequently combine consanguineal relationships with more general “ethnic,” neighborhood, or occupational associations (Gutkind, 1965, 1969.; Southall, 1961). Jacobsen (1973) further distinguished class bonds, with the socially elite tending to affiliate with each other, while non-elite ties form more along kinship or “ethnic” lines. Aguilar (1999) found that religious fellowship and the post-colonial education process also now serve as mechanisms for establishing friendship. Finally, working in Kampala’s slums, Wallman (1996) found that men and women have very different social spheres. Women’s social connections revolve around “microlevel” neighborhood acquaintances, while men do not identify as closely with their local community. Interestingly, Wallman (1996) also reported that a common expression is “a good neighbor is better than a relative.” Thus,
contrary to theories that the urban setting leads to isolated individuals, these studies suggest that "...urban society is as integrated as any other type of community, but that integration takes place around different variables...extended kinship is not necessarily incompatible with African urban society; nor does the mobility of Africans invariably weaken all traditional kin and group ties" (Gutkind, 1969, p. 392).

Because much of this research was conducted over 30 years ago, current patterns in network structure are not clear. If indeed, the trend is for urban participants to have more non-kin network members, as Wallman (1996) suggested, in addition to their extended family members, it is unknown whether such structural differences influence social network functioning, particularly the exchange of support in the context of an infectious illness. In addition, there is some evidence, as noted above, that networks are unable to cope with the care of multiple HIV/AIDS patients and their offspring, which has led to new suggestions of the "weakening" of extended family networks. Worsening economies in general can also lead kinship ties to be serious burdens rather than resources (Foeken and Tellegen, 1994). Finally, major social disruptions, like forced relocation, have been found to damage all types of social networks, and those who are relocated may have a difficult time establishing reciprocal relationships with their new neighbors (Sharp and Spiegel, 1985). Thus, it is important to recognize that kinship relationships are not "static" (Stichter, 1988), and further research is needed to determine the structure and function of networks in the face of the HIV/AIDS and TB epidemics and continuing economic hardship.

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Summary

To summarize, the role of social networks and social support has been the center of much anthropological research for decades. Although early scholars typically did not speak in terms of “networks,” their studies of kinship and social organization have led to greater understanding of the ways in which social context influences the development and operation of social network and social support systems. Anthropology continues to contribute to the field through both ethnographic studies and more structured surveys. Along with grappling with such issues as the impact of urbanization on social networks, researchers have begun to recognize the ways in which larger political-economic and illness contexts influence both the structure and resources of social networks. This research is particularly critical as the East African illness context is now complicated by the rise of a joined TB-HIV/AIDS epidemic.
Chapter 5: Methodology

To examine the dynamics of rural and urban Ugandan women’s TB treatment seeking, a cross-sectional study was designed and implemented in two Ugandan districts, Kampala and Mukono. The specific objectives of this study were to:

1) Describe participants’ TB health beliefs and explanatory models, particularly regarding TB’s transmission, treatment, and relationship with HIV, in order to understand the impact of such beliefs on the treatment-seeking process;

2) Identify the patterns of care and process of treatment seeking of female Baganda TB patients;

3) Determine whether there are differences in the social network structure and social support exchanges of urban vs. rural patients;

4) Identify the role(s) of social network members throughout the treatment-seeking process and in supporting the participant through her illness; and

5) Determine whether TB patients are isolated and stigmatized because of their active TB infection and/or the disease’s association with HIV.

Samples were drawn from the TB patient populations at Mulago hospital TB clinic in Kampala and Kawolo hospital and Mukono health center in Mukono. Permission to work at each of these sites was obtained from the Uganda National Council for Science and Technology, the National TB and Leprosy Control Program (NTLP), and the chief medical officers of the individual TB clinics.

Three survey instruments explored the study’s six dimensions: treatment seeking, health beliefs, social networks, network support, economic resources and treatment access. Participants completed the first instrument at the clinic, while the second, an extended instrument, was typically delivered a few days later at the participant’s home. A sub-sample of participants completed a third interview within a few weeks of the
second contact. Interviews were conducted either in English, Uganda’s national language, or Luganda, the language of the Baganda. Grace Nyakojo, a social science graduate of Makerere University, served as a research assistant. Data were collected from July 1998 to January 1999.

This chapter describes the project’s methodology, beginning with the study design, the sample criteria, and the recruitment process. It then examines the instrument development and data collection processes and the rationale for the research sites. Finally, it defines the study’s six major dimensions and the primary measurement techniques.

STUDY DESIGN

This study utilized a cross-sectional design to examine Ugandan women’s TB treatment-seeking, social networks, and health beliefs. Such a design allowed data to be collected on patients’ treatment seeking across three sites. A convenience method was used to draw the sample from the TB patient population at one urban and two rural clinics.

STUDY SAMPLE

Eligibility criteria

The sample had several inclusion criteria. Along with being female, participants had to 1) be over the age of eighteen; 2) consider themselves a Muganda or Musoga; 3) currently be treated for TB on an outpatient basis; and 4) Kampala residents had to have lived in the city for at least six months.
This supplemental criterion for Kampala patients was to ensure that women who had recently moved to Kampala for the sole purpose of TB treatment were not included. In designing the study, it was believed that participants would not move to a rural site for purposes of treatment, since such areas are not known for TB treatment. While people may move to their rural homeland if they need care from their family or if it appears they will not survive their illness, none of the participants interviewed in Mukono fall into either of these categories.

An additional inclusion criterion was that participants had to have pulmonary TB. It was not feasible, however, to establish definitively whether patients had active pulmonary TB. Many TB patients, especially in rural communities, may not be accurately diagnosed before beginning treatment. Thus, while all study participants were currently on TB treatment and most believed they had TB, there was no independent confirmation of their disease statuses.

Regarding whether patients had pulmonary TB vs. nonpulmonary TB, the majority of TB patients in Uganda have pulmonary TB, which may be accompanied by nonpulmonary TB (Dr. JL Johnson, Scientific Director, Uganda-Case Western Reserve University Research Collaboration, personal communication). Indeed, this association between pulmonary TB and extrapulmonary TB is not uncommon (see Humphries, Lam, and Teoh, 1994). Thus, it is likely that the majority of participants with active TB had pulmonary TB.

Finally, the original study criteria excluded non-Baganda women. While the focus on Baganda women remains, two Basoga, two Batooro, and one Munyankole were included in the sample. Because of difficulties in sample recruitment, the study was
opened officially to Basoga, who are culturally very similar to the Baganda (Fallers, 1965). Ultimately, however, few Basoga were eligible and enrolled. The Munyankole and Batoro women were unintentionally recruited during the first days of the study, but their presence does not impact the results significantly.

**Recruitment**

A convenience sampling method was used to establish a sample from the TB patient populations at each of the three clinic sites. The specific technique of identifying potential participants varied slightly across sites due to the number of patients at each clinic. At the Mulago TB clinic, where a large number of patients and relatives of patients attended each clinic day, the pharmacist assisted in identifying patients. On clinic mornings, the PI and Nyakojo arranged a series of stools a short distance from the pharmacist's window and the area where patients gathered to collect their medications. This position was close enough to the clinic to allow participants to hear if the pharmacist called their name for their prescription but far enough away that other patients could not hear participants' responses during the interview.

At the beginning of each recruitment session and when they were ready to interview another participant, Nyakojo or the PI would signal to the pharmacist. The pharmacist would then inquire to the next woman placing her registration card at his window whether she was the patient. If the answer was affirmative, the patient was asked to visit Nyakojo and the PI.

If the patient was willing to participate, the five screening/eligibility questions were read to the participant. If the patient was eligible, the fifteen-item initial questionnaire was administered. At the end of the questionnaire, Nyakojo or the PI
explained again that they would like to talk to the participant in more detail and inquired when there might be a good time to talk. The participant was asked where she preferred to meet, whether at her home, the clinic, or another location. If the participant wished to meet at the clinic or somewhere besides her home, she was told that the study would reimburse her transportation money at the meeting. The meeting location was recorded by the name of the location, the matatu stop, and the area’s major landmarks (e.g., shops, trees, and house descriptions). This was necessary due to the lack of formal street names and addresses throughout the districts. This process was repeated with each participant. Participants generally completed the consent form and interview while waiting for their prescription to be filled, i.e., within 20-30 minutes.

The recruitment procedures at Kawolo hospital were slightly different because fewer patients attended the clinic. The primary difference is that the PI and/or Nyakojo approached the women waiting at the TB clinic directly to determine whether they were patients and if they would be willing to talk. For female patients who were willing to participate, the process of administering the eligibility questions and initial questionnaire occurred as described above. The small patient volume allowed the project staff to approach the majority of women who visited the TB clinic on recruitment days.

At Mukono health center, there was a similar small volume of patients attending the TB clinic each week. This again allowed the project to present the study to most of the female patients who attended the clinic during the recruitment sessions. The center’s medical officer discretely assisted in the identification of TB patients. Patients were interviewed privately in the manner described above.
INSTRUMENT DEVELOPMENT

Data were collected using three instruments, which consisted of combinations of close-ended, semi-structured, and open-ended questions. The first instrument consisted of a five-item screening and 15-item initial questionnaire for use at the clinic; the second had 116 items for use at the participant’s home, and the third had 40 items as a final follow-up (see Appendices A, B, and C). The initial interview and 116-item second questionnaire were developed prior to the start of recruitment. The 40-item third interview was created mid-way through recruitment in Kampala. This final questionnaire was designed to investigate and/or clarify concepts uncovered by a preliminary analysis of the first two interviews. The instrument also served as a mechanism for examining or re-examining issues, such as participants’ evaluations of the recruitment clinics, once a level of rapport was established.

Although this research implemented the three instruments on separate occasions, it was not a longitudinal study. Data collection was divided between several visits and/or settings to minimize participant fatigue. In addition, because the second and third interviews were typically conducted at a participant’s house or in her neighborhood, the visit further increased the rapport between study staff and the participant. The home visits also minimized the influence of the project’s association with the clinic. Finally, another concern that influenced study design was that participants might not speak freely about their use of alternative treatments or their opinion of the hospital staff if interviewed at the clinic. Ultimately, however, interview location was not a major influence on participants’ openness.
Before implementation, each questionnaire was reviewed by American and Ugandan anthropologists on-site and in the U.S. Revisions were made based on their recommendations and the suggestions of Nyakojo. Nyakojo translated each instrument into Luganda, while working closely with the PI to ensure that the intent of each question was conveyed. An Ugandan not associated with the study who knew both Luganda and English then “backtranslated” the questionnaires from Luganda to English. This verified that the translation was intelligible to an individual unfamiliar with the project. The informed consent forms were translated and revised in the same manner. These tasks helped familiarize Nyakojo with the project’s key concepts and ensured that she understood the purpose of each question.

**Pretest**

The questionnaires were pretested on TB patients who were enrolled in the clinical studies of the Uganda-Case Western Reserve University Research Collaboration¹. This group was an appropriate pretest population because they are drawn from the same pool of Mulago TB patients as the current study. It was not possible to conduct pretests at the Mukono TB clinics.

For the pretest, participants were approached while they waited to see the physician at the CWRU clinic. The CWRU nurse assisted in identifying patients (as opposed to family members or other visitors) but did not reveal their names or other confidential information. Nyakojo explained to each pretest participant that the questionnaire was voluntary, anonymous, and would not influence the patient’s care or

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¹ These clinical studies were examining a range of issues on the transmission and treatment of TB, including a study of the efficacy of specific drug regimens in HIV-infected patients, a pilot immunology study, and a household transmission survey.
participation on the other CWRU studies. Most of the patients were quite willing to answer questions, as the activity provided an entertaining diversion during their wait. Because the questionnaires were lengthy, it was not possible to complete the entire series of questions on a single person. Each volunteer answered approximately thirty minutes worth of questions.

The pre-test served a number of functions. It proved an effective means of training and practice for Nyakojo. It also revealed questions that were duplicative or difficult to comprehend. These questions were either revised or deleted from the final questionnaire. In addition, the pre-test indicated that using cards and a pile-sort technique for the social network questions was not an effective means for eliciting participants' social networks. While volunteers could complete a pile sort after considerable discussion, they could complete a social network grid/map more effectively through probing and prompts from the interviewer. A pile-sort technique, as recommended by Tracy and Whitaker (1990), therefore, was not used during the actual interview process.

**INSTRUMENT SCHEDULE**

The screening/initial instrument was administered at the health clinic upon first meeting a participant. The 116-item instrument was administered shortly after the initial interview, at a time and place that was convenient to the participant. In a few cases, participants preferred to conduct the second interview on the same day as the initial instrument.

At the time of the second meeting, the participant was asked if an additional visit was acceptable and a tentative or if possible, exact, appointment was made for the third
Interview. The material in the third instrument was not time-sensitive, and therefore was not expected to be influenced by differences in the time of delivery.

DATA COLLECTION

Interviews were conducted in English or Luganda, depending on the preference of the participant. Nyakojo conducted the Luganda interviews using the Luganda instrument forms, but she recorded participants’ responses in English. This process of immediate translation allowed Nyakojo to clarify unclear responses with the participant, and reduced the amount of error introduced by delaying translation until the interview was completed. However, if a response was difficult to translate, she wrote the Luganda and then translated after consulting key informants.

During the beginning phase of data collection, the 116-item interview was tape-recorded because it contained a large number of semi-structured questions. The tapes allowed Nyakojo, and the PI for the English interviews, to verify that the written responses were complete and accurate. After Nyakojo and the investigator were accustomed to the long interview and writing all responses, the interviews were no longer recorded. Interviews that were not taped were reviewed after their completion. Any additional comments or clarifications that were recalled were noted on the interview in brackets.

HUMAN SUBJECTS/CONFIDENTIALITY

All participants completed an informed consent form that was both given to them and read in Luganda or English, depending on their preference. This consent form described the purpose of the study and explained that participants had the right to refuse
to participate or to stop participating at any time, without influencing their care at the clinic (see appendix D for consent form). Both the Institutional Review Board at Case Western Reserve University and Uganda’s National Council for Science and Technology approved the consent forms.

All participants were assured of confidentiality. Participants’ names and directions to their homes or workplaces were recorded on the last page of the initial interview. This information has since been removed from the interview. Participants were assigned an ID number after completion of the initial interview, which was the only identifier on the follow up interviews.

To assist in locating participants for the follow-up interviews, Nyakojo copied the participant’s first name and meeting directions into an ordinary daily appointment book. The book could be carried discreetly when locating patients in the field and contained no reference to the study. This ensured that non-study personnel would not be able to discern the planner’s contents.

All interviews were stored in a nondescript envelope in the bottom of a desk drawer in a locked office at the CWRU TB Research center until they were transferred each week to a locked cabinet in the PI’s home. Only CWRU data management staff had access to the CWRU office, while the PI held the single key to her home storage cabinet.

No participants were paid for their participation. All participants, however, were reimbursed for transportation costs, if any, that they incurred in meeting with the study staff. In addition, after both the second and third interviews, participants received a kilo of sugar or rice in appreciation for their time. Although a kilo is only a small token,
participants enjoyed the gifts, especially sugar, which many mentioned during the interviews as a desired, but unaffordable item.

RESEARCH SITES

The districts for the research project were selected based on a number of criteria. First, the study required recruiting participants from urban and rural districts, as assessed by population density of the area, primary economic activity (e.g., proportion agriculture), type of administration and access to basic services (Yach, Mathews, Buch, 1990). For this study, a rural district was defined as one in which there was a relatively low population density, the majority of residents were involved in agricultural production, and the area’s infrastructure was not fully developed.

Second, the districts needed at least one government outpatient TB treatment facility that was willing to house the project. Third, the study parameters necessitated working in districts where a large proportion of the population was Baganda. Fourth, districts needed an accessible public transportation system that would allow the P.I. and Nyakojo to reach the clinic and to follow participants.

Two districts, Kampala and Mukono, which neighbor each other in south central Uganda, were identified as fulfilling these requirements. The clinics within each district were selected based on the number of patients reported by the medical officer, and the accessibility of the clinic. The sections below present in greater detail the rationale for the specific research districts and clinics.
Kampala – Mulago hospital

Uganda’s capital city, Kampala, was the logical choice for the urban site. First, as described in chapter 4, the city has been the focus of many earlier discussions on the East African urbanization process. Because part of the study’s goal was to examine the structure and function of social networks today in relation to the previous literature on Kampala, it was important to conduct the study in the city. Second, Kampala is located in the heart of the traditional Buganda Kingdom, even incorporating the traditional palace and court of the Baganda Kabaka. As stated above, one criterion for the study is that participants must be Baganda. Although not all residents of Kampala are Baganda, the relatively high number of Baganda suggested that the project would be more likely to find participants that met the study criteria than in other locations.

Third, Kampala also has a high prevalence of TB. For example, there were 8,163 known cases in 1996 (Ministry of Health, 1997). The presence of such a large number of cases suggested not only the viability of the project, but a need, from a public health perspective, for understanding the social relations of TB patients.

Regarding the recruitment clinic specifically, Mulago hospital TB clinic is one of the largest TB treatment clinics in the country. The TB clinic is housed in one of the pre-independence wings of Mulago, commonly referred to as “Old Mulago.” This TB clinic previously served as the national referral hospital for TB, but the NTLP, as described in chapter 2, is attempting to decentralize TB treatment resources.

Currently, the TB clinic sees, on average, over 300 TB patients a week, including 100 new cases (Dr. H. Luzi, Mulago TB Clinic Physician, personal communication).
Although some of these patients do come from across the country to receive care at Mulago, the majority of the patients reside in the greater Kampala area.

Finally, Mulago hospital TB clinic was also selected because of the ongoing research collaboration between Case Western Reserve University (CWRU), the clinic, and Makerere University. The TB Research Unit of CWRU’s School of Medicine has been conducting research on TB and HIV at the hospital for over a decade. The investigator had previously assisted on two of these studies, which led to the development of the current project. Although the TB Research Unit did not formally sponsor the research presented here, members of the collaboration facilitated the investigator’s access to the TB clinic. Recruitment began at the Mulago TB clinic in July 1998. (For a full description of Kampala’s Mulago hospital see Appendix E).

Mukono- Kawolo hospital and Mukono health center

Kawolo hospital and Mukono health center in Mukono were chosen as the rural sites because 1) the area was traditionally part of Buganda kingdom and is therefore home to many Baganda; 2) the district is predominantly agricultural, with few major industries or large administrative infrastructures (see Appendix F for a description of the district); 3) officials at the clinics expressed great willingness to host the study; and 4) the two clinics were accessible to Kampala via a paved road and “matatus” or taxi-buses. It should be noted, however, that while Kampala was physically accessible for the PI and Nyakojo, the financial cost of such travel prevented many district residents from traveling to the city frequently. The use of two sites was necessary due to the smaller patient population in the district.
Recruitment began at the Kawolo hospital TB clinic in October, 1998. While the hospital serves a large number of TB patients overall, the recruitment process revealed that relatives often collect patients' medications each week. This reduced the number of potential study candidates since the study parameters required that participants themselves be approached for consent at the clinic. This obstacle to participant recruitment led to the establishment of a second Mukono district study site at the Mukono health clinic in November, 1998.

STUDY DIMENSIONS

This study's three survey instruments explored six primary concepts: 1) TB treatment-seeking, 2) social networks, 3) social support, 4) health beliefs, 5) participants' economic resources, and 6) treatment access. Measures for each dimension were developed through a review of the literature, discussions with key informants, and consultation with medical anthropologists in the U.S. and Africa.

Treatment-seeking

The first dimension, TB treatment-seeking, was conceptualized as including both biomedical and traditional remedies or healers, along with self-prescribed, "over the counter" medications or herbs. Of central interest were participants' patterns of resort, e.g., the types of providers or therapies used, frequency of use, and satisfaction with the treatment or remedy.

Participants' treatment seeking was assessed through two approaches. First, in order to elicit the "stages" of participants' treatment-seeking (Chrisman, 1977), semi-structured questions obtained participants' descriptions of their illness, including when it
began, their initial symptoms, the treatment for those symptoms, additional symptoms and treatments, and the social network members who were consulted or assisted in the care process.

Second, sets of semi-structured questions on treatment seeking explored the use of specific types of healers or treatments. For example, participants were asked about their use of herbal remedies, other “treatments at home,” traditional healers, visits to additional clinics or pharmacies, and the TB clinic that was the recruitment site.

To determine satisfaction with each type of treatment, participants were asked whether the treatment helped and if they were still using it. A separate series of questions focused specifically on participants’ assessment of their biomedical TB treatments. Participants described how frequently they took their drugs, whether they had “problems” (i.e., side effects) from the medications, if the problems influenced their use of the medicine, and their opinion on whether the drugs are working.

Participants also reported their satisfaction with the TB clinic staff and the TB hospital/clinic itself. These questions were placed on the final questionnaire, which was administered after rapport was established between the investigator and participants. This rapport helped to ensure that participants were comfortable answering questions about the clinic where they received much of their TB care.

Social Networks and Social Support

As discussed in chapter 4, this study conceptualizes social networks as “a specific set of linkages among a defined set of persons…” (Mitchell, 1969:2) that can be analyzed in terms of their structure and function. Social support is conceptualized as “the perceived availability of help or assistance from other persons during times of felt need.”
This aid may be tangible, emotional, or informational (Ritter, 1988). This study used a combination of approaches to measure participants’ social networks and social support. It should be noted that these measurements assessed participants’ perceptions of support both with respect to actual situations in their life (e.g., treatment seeking) and regarding hypothetical issues (e.g., information about jobs).

First, a small, initial measure involved a series of five close-ended questions (agree/disagree) on whether participants had told their partner, household, relatives, or neighbors about their illness. Along with constituting a basic measure of whether participants have concealed their illness, these questions were included in the initial questionnaire to determine whether participants with uninformed families or households were more likely to be lost to follow-up.

The more extensive method for measuring social networks and social support used an adaptation of Tracy and Whitaker’s (1990) social network “map” and “grid” system. As noted in chapter 4, this technique measures a participant’s social network, the network’s structural characteristics, and the support exchanged with network members. It was originally designed to determine the existence of network members in each of seven domains (household, other family, work/school, clubs/organizations/churches, friends, neighbors, and formal services) in order to create a social network map. Each network member listed on the map is then recorded on the social network grid and participants are asked structured questions regarding the types and frequency of support exchanged with each social network member (see appendix G for example of the grid). Tracy and Whittaker (1990) also recommend placing each network member’s name on
individual cards so that participants can use a pile sort technique to answer the questions on the frequency of support exchanged.

For this study, however, a separate network map was not created and the pile sort technique was not used after being found ineffective on pretest (see above). Instead, modified domain categories were used as probes to create the social network grid directly. With assistance from key informants, the original seven domains were adjusted to form nine culturally appropriate areas: 1) people in the household or compound; 2) other family members; 3) people from the neighborhood, RC1\(^2\), RC2, or the market; 4) people from participant’s place of birth (or home-village); 5) work or school; 6) church; 7) social clubs, associations, or meetings (e.g., wedding meetings\(^3\)); 8) the hospital, clinic, or other local healers; and 9) any other important people in the participant’s life over the past few months.

To begin this set of questions, as Tracy and Whittaker (1990) recommend, participants were directed to think about the people who had been important to them over the last few months, including people they saw, talked with, or exchanged letters with; people who made them feel good, bad, or just played a part in their life; people who had influence on their decisions, or people who lived far away but were still important. Without a specific probe, participants first were asked whom they would list as part of their social network. Next, the interviewer probed if anyone would be included from

\(^2\)“RCs” or “resistance councils” govern local communities in Uganda. Neighborhoods are divided into five RC areas, with RC1 representing one of the smallest local political divisions, while the RC2 level incorporates an RC1 into a slightly larger area. These culturally salient designations can be compared to the “wards” or “districts” that divide American communities.

\(^3\)According to key informants, weddings are major social events that may require considerable organizational and financial planning. Extended family members may begin meeting and planning many months before the event.
each of the domains. After completing the probes, the interviewer read or showed the list to the participant and asked if there were any names that should be added or deleted. No network members were ever deleted, but occasionally names were added. The resulting list formed the basis for the "grid" of people who were important to the participant.

Next, the grid was used to direct a series of questions on the exchange of concrete, emotional, and informational support. For each network member listed, the interviewer inquired if the exchange of support was hardly ever, sometimes, or almost always. If needed, the interviewer provided examples of each of the types of support, e.g., concrete support was described as "if you need help making a repair in your house, or assistance getting somewhere, or needed money for an emergency," while emotional support was characterized as someone "who comforts you if you were upset, is there for you in a stressful situation, listens to your problems."

In addition to the amount of support provided, several characteristics of the social network members were measured. For example, the interviewer asked how frequently each network member critiqued the participant, i.e., the network member hardly ever, sometimes, or almost always criticized the participant, her lifestyle, or her parenting. Participants also listed the direction that help tended to travel – whether the participant and network member help each other equally, the participant helps the network member more, or the network member primarily helps the participant. Finally, the participant indicated her level of emotional closeness to each network member, according to the categories of not very close, sort of close, and very close.

After describing the exchange of social support, participants provided a number of demographic details about each network member. The interviewer asked the participant
to indicate: the network member’s relationship (if a relative), his/her gender, age, education level (if known), how long they have known each other, how often they see one another, whether there was a change in the frequency of visits after the participant became ill, and whether he/she knows of the illness and has offered advice about treatment. A number of these questions (e.g., the illness related questions) do not appear on the original grid designed by Tracy and Whittaker, but were added to help answer this project's research questions.

This standardized grid is a very effective and efficient technique for gathering social network information (Tracy and Whittaker, 1990). Within a relatively short period of time (30 minutes), it is possible to collect systematic, detailed information on the structure and function of an individual’s social network, e.g., network size, domain size, perceived availability of emotional, concrete, and informational support, network “criticalness,” closeness, reciprocity, directionality, stability, and frequency of contact (Tracy and Whittaker, 1990, p. 464). It is also possible to compare the proportion of network members belonging to each domain across different networks. In addition, the grid is useful because it allows participants to list an unlimited number of friends or family members – first through their own recall and then with the help of probes. The technique is further notable for its range of probes that aid a participant’s recall and may limit the introduction of recall bias.

The second method for collecting social support and social network information utilized semi-structured questions that inquired about the exchange of tangible, emotional, and informational support in specific circumstances. This method is similar to the “scenario” method employed by Korbin, Coulton, Lindstrom-Ufuti, and Spilsbury.
(2000), and Philips' and Fischer's (1981) mapping technique. This involves describing situations or problems to a participant to determine whom she can go to for assistance and who would ask her for help. The descriptions utilized in this research were developed with the help of key informants in order to measure social support in treatment seeking and in daily living. Key informants consisted of local language instructors and members of the Joint Clinical Research Centre staff. These individuals were Baganda from various parts of Uganda.

For most of the questions, the interviewer recorded not just if the support was provided, but who provided the support, what was done, and whether the participant ever provided similar support to others. To briefly describe the different scenarios, the tangible support questions inquired into the care of the participant’s children while the participant visited the doctor; the payment of school fees; the exchange of food and financial resources; household help and caregiving to the participant during the participant’s illness; and the provision of assistance with obtaining prescribed medications or transportation to the doctor. The emotional support questions examined whether the participant ever spoke with others about either her own or their problems or worries in general, concerns about the children, worries about a significant other, or their concerns about their illness. The informational support questions inquired into the exchange of advice when making important decisions, job information, and information regarding doctors, other healers, or treatments. These semi-structured scenario questions helped to complete the picture of each participant’s support system by suggesting whom participants relied on most heavily and vice-versus and the specific context in which

---

4 As discussed earlier, there is no universal or free public school system in Uganda. The majority of parents must pay to send their children to both primary and secondary school.
support tends to be exchanged. They also measured who assists participants with daily living activities and treatment seeking, as well as the extent to which participants experience social isolation or ostracism.

This implementation of mapping instruments, structured grid, and semi-structured network and support measures also served to address some of the criticisms of the social support literature. In particular, this combination of general support items and specific examples helps to minimize recall bias (Knoke and Kuklinski, 1982). For example, participants first freely list their network and then are encouraged to remember other network or support sources by the category/domain probes and circumstance questions. Participants are also asked about support in general and then in particular contexts. In addition, the study attempted to reduce the potential for bias and increase the cultural appropriateness of the measures by carefully pretesting all questions.

Regarding the issue of "splitters" vs. "lumpers," or the fact that some participants will classify their support network into a wide range of categories while others will label network members' support at a similar level, the support context items were designed to delve into the specific roles of participants' support relationships. The series of scenario questions help to clarify participants' general support rankings on the social network grid by inquiring who would provide help in common situations. The structure of the questions makes it difficult for participants to "split" or "lump" their social network.

In addition to these techniques that gather information on the structure, function, and frequency of social network and support exchanges, the instrument also obtained data on participants' assessments of the most valuable members of their networks, i.e., whether friends or relatives are more reliable. Specifically, these questions asked 1)
whether friends or relatives tend to be more important and 2) which is relied on more and why. These questions directly address one of the principal research questions on the structure and function of social networks by asking participants to state whether there is a difference in the importance and support available from friends vs. relatives. Together, these final questions are an attempt to address the frequent criticism of the social network and support literature that many researchers fail to examine the meaning or context surrounding support, despite the fact that cultural context may heavily influence the perception and impact of support (Dressler, 1996).

Health Beliefs

The fourth study dimension primarily examined participants' explanatory models of their illness, i.e., their ideas concerning the etiology, transmission, symptoms, prevention, and treatments (both biomedical and traditional) for their TB (Kleinman, 1980). Close-ended and semi-structured questions explored participants' beliefs in detail. These questions were based on the cross-cultural TB literature (e.g., Carey, Oxtoby, and Nugyen, 1997; Menegoni, 1996; Nichter, 1994; Rubel and Garro, 1992), as well as published and unpublished research from Uganda (e.g., Bantebya-Kyomuhendo and Ogden, 1996; Kurn and Maurer, 1996; Wallman, 1996).

Participants' beliefs concerning the relationship between HIV and TB were also explored. As described in chapter 3, there is growing concern among TB researchers that TB may be viewed as a sign of HIV and this in turn may influence patients' treatment-seeking decisions or social isolation. To help clarify this issue, participants described whether AIDS changes the way TB occurs in a person as well as a person's ability to treat his/her TB. The instrument also inquired whether it is easy for people with AIDS to
get TB and vice-versa. As a supplemental measure of the extent to which participants view HIV and TB as the same or similar illnesses, close-ended (agree/disagree) questions on the symptoms and transmission of TB incorporated common characteristics of HIV. Due to ethical concerns, participants were not asked about their HIV status specifically, however, several voluntarily indicated that they were or were not HIV-positive.

Lastly, the study instruments gathered information on participants’ perceptions of their network members’ health beliefs. This was measured through questions regarding the importance that network members place on the participant’s TB treatment seeking, her perception of their fears about catching her illness, and their attitude or behavior towards other people with TB. These data helped to examine general attitudes and behaviors towards TB patients and the extent to which either the participant or other patients are ostracized.

**Economic resources**

Participants’ economic resources, the fifth study dimension, were assessed through semi-structured questions which measured 1) each participant’s overall socioeconomic status, 2) the economic impact of the participant’s illness, and 3) the participant’s economic decision-making power.

First, to examine the participant’s socioeconomic status, the instrument collected data on the participant’s education level, her income-generating activities, other sources of money, the ownership of farm animals, and the maintenance of a garden. In addition, similar to the method described by McGrath et al. (1993), a rough description of the participant’s home was recorded if the residence was visited, including the construction materials for the house and roof, the number of rooms, and the participant’s possessions.
Second, to explore the economic impact of the illness, data were gathered on the participant's economic activities and expenses before and after illness onset, whether the treatment seeking process has impacted her earnings, and whether treatment seeking has required her family to go without any items.

Third, participants' economic decision-making power was examined in terms of daily living and treatment seeking. For the daily living questions, participants were asked if they consulted with anyone if they wished to make a purchase, who decides what food to buy, and who pays for the food. To obtain information on economic decision-making regarding treatments, additional questions inquired who determines how much money can be spent to see the doctor and whether others have demanded specific treatments be sought as a condition of providing money.

_Treatment-seeking access_

The last study dimension, treatment-seeking access, explored participants' access to biomedical and traditional treatment. Access was measured both geographically and financially. For instance, participants described the local presence of a biomedical clinic, traditional healers, and traditional herb/medicine dealers. If they ever used traditional herbs or healers for their TB, they were asked to indicate the price of such items. The instruments then probed into the entire cost of obtaining biomedical TB treatment, including expenses for medication, transportation, childcare, and fees or "tips."

_DATA ANALYSIS_

A preliminary analysis of these data was conducted during the first months of fieldwork (August-September 1998). In particular, the initial and second interviews
collected during the first two months of data collection were examined to determine cultural themes (Spradley, 1979) related to the five dimensions described above. This analysis consisted of reviewing the interviews, and noting and tallying the primary themes. Along with identifying common points, this analysis also revealed areas that required additional probing. As described above, the third study instrument was designed from this analysis to further discuss and/or clarify these themes and issues.

Further data analysis was conducted from May 1999 until January 2001, using SPSS to manage and analyze the data. The quantitative data, i.e., the close-ended and numerical questions, were entered by the P.I. directly into SPSS using a codebook developed from the instruments.

In order to identify themes across the qualitative data, these data were transformed through a series of steps into categorical variables, similar to the method utilized by Korbin et al. (2000). First, for each qualitative question, or sets of similar items, the P.I. identified key themes or variables by reviewing a random sample of the interviews. The theoretical literature and informal ethnographic discussions also guided theme identification. These variables were recorded in a codebook, which was then used to enter the qualitative data into SPSS. This permitted the P.I. to note whether specific variables were absent or present in participants' responses. An unlimited number of themes could be entered.

Once all data were entered, SPSS was used to run descriptive frequencies of the data. These results are reported in chapters 6 through 9. In addition, chi-square tests of significance and t-tests were examined to determine if participants' responses differed significantly by district and other key variables. Finally, it should be noted that in order
to compare the composition of large vs. small social networks in chapter 9, new variables representing the proportion of different types of individuals within each network were created. This is similar to the analysis conducted by Tracy (1990).
Chapter 6: Sample Demographics

This chapter describes participants’ demographic characteristics, including age, ethnicity, marital status, household composition, and socioeconomic status (income, education, and material lifestyle). As discussed in the methodology chapter, participants were obtained from three national TB treatment centers using a convenience sampling strategy. Because of this recruitment method, the results are likely to be biased towards women who believe in the efficacy of biomedicine, have not been overwhelmed by the TB treatment process, and who do not have the funds to pay for private treatment. Participants’ demographic data, however, indicate that participants are comparable to the national average in terms of age, education and income.

Sample size

As described previously, the interview schedule demanded that participants complete three interview instruments. These were typically delivered on separate occasions. Participants’ demographic information was divided between the first and second interviews. Because it was not possible to locate some participants for follow-up, the sample size decreased for the second and third interviews. As a result, the number of respondents changes depending on the data being reported. Throughout this document, the total number of participants responding to a question is indicated parenthetically in all table titles.

Of the 224 female TB patients who were screened for study participation, 99 (44%) were eligible to participate. The most common reason for ineligibility was the patient’s ethnicity, with 85 (68%) of those screened being neither a Muganda nor a Musoga. Of the 99 who were eligible, ten (10%), all from Kampala, refused to
participate. Reasons for refusing included that the patient was busy, too ill, or that she did not want to risk her employer discovering her illness. Ultimately, 89 patients were eligible and agreed to participate: 64 from Mulago hospital in Kampala, 22 from Kawolo hospital, and three from Mukono Health Centre.

Out of this original 89, 43 (67%) of the Kampala participants and 22 (88%) of the Mukono participants were successfully traced for the second interview. A convenience subset of 20 Kampala participants and 20 Mukono participants were interviewed with the third instrument. Chi-square tests revealed that there were no significant differences in the demographic and basic treatment-seeking characteristics (e.g., time participant was symptomatic, length of time attending the TB clinic) of those who completed the second and third interviews vs. those who were lost to follow-up.

Participants’ TB statuses and NTLP clinic attendance

All participants currently were receiving biomedical TB treatment. Participants reported experiencing their TB symptoms for an average of 5.5 months and a median of 3.0 months prior to seeking treatment from the government TB clinic. Kampala participants were symptomatic an average of 5.8 months while Mukono participants had symptoms for an average of 4.6 months before attending the national TB clinic. This difference was not statistically significant.

The majority (71.9%) of participants had been attending the government TB clinic less than five months at the time of recruitment (Table 6-1). Two participants (2.2%), both from Mukono district, had been attending for over twelve months.

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Only four Kampala participants reported that they were experiencing an active TB infection for a second time. It is not possible to determine if the current symptoms were a result of re-infection or a resurgence of the previous infection.

**Ethnic identity**

Although an initial goal of the study was to interview Baganda women only, the final sample consisted of 84 Muganda (94.4%), two Musoga (2.2%), two Mutooro (2.2%), and one Munyankole. Because of difficulties in sample recruitment, the study was opened to Basoga, who are culturally very similar to the Baganda (Fallers, 1965). Few Basoga, however, were eligible and enrolled. The Munyankole and Batoro women were unintentionally recruited during the first days of the study, but their presence does not affect the results significantly.

**Age**

Seventy-four percent of the participants were aged 30 or younger (Table 6-2). Only one participant was over 45 years of age. As mentioned in chapter 2, many developing countries, including Uganda, are witnessing high incidences of TB in young and middle-age adults. Therefore the age distribution of this sample is not unexpected.
Table 6-2 Age of Participants (N=89)

<table>
<thead>
<tr>
<th>Age categories</th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total Participants N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;25 years</td>
<td>32 (50.0)</td>
<td>10 (40.0)</td>
<td>42 (47.2)</td>
</tr>
<tr>
<td>25-30 years</td>
<td>15 (23.4)</td>
<td>9 (36.0)</td>
<td>24 (27.0)</td>
</tr>
<tr>
<td>31-35 years</td>
<td>9 (14.1)</td>
<td>3 (12.0)</td>
<td>12 (13.5)</td>
</tr>
<tr>
<td>36-40 years</td>
<td>6 (9.4)</td>
<td>1 (4.0)</td>
<td>7 (7.9)</td>
</tr>
<tr>
<td>41-45 years</td>
<td>1 (1.6)</td>
<td>2 (8.0)</td>
<td>3 (3.4)</td>
</tr>
<tr>
<td>&gt;45 years</td>
<td>1 (1.6)</td>
<td>0</td>
<td>1 (1.1)</td>
</tr>
<tr>
<td>Total</td>
<td>64 (100)</td>
<td>25 (100)</td>
<td>89 (100)</td>
</tr>
</tbody>
</table>

Time lived in district

The parameters of the study also dictated that participants had to have lived in Kampala or Mukono districts for more than six months. As a result, 96.1% of participants had lived in their respective districts for more than twelve months; 39.5% of the women had lived in their district their entire lives (Table 6-3). Although participants occasionally leave the district to visit relatives in traditional homelands, only one participant indicated that she moved from Kampala to Mukono so that her mother could take care of her. In addition, one Kampala woman increased her visits to her mother’s house near Mulago hospital because she was obtaining treatment at the hospital. Her primary residence was at a school on Kampala’s distant boundary where she taught. Thus, the majority of participants were firmly incorporated within their districts, with established social networks and living arrangements.

Table 6-3 Number of months participant has lived in Mukono or Kampala (N=89)

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;=12 months</td>
<td>1 (1.9)</td>
<td>2 (8.3)</td>
<td>3 (3.9)</td>
</tr>
<tr>
<td>13-36 months</td>
<td>5 (9.6)</td>
<td>6 (25.0)</td>
<td>11 (14.5)</td>
</tr>
<tr>
<td>37-72 months</td>
<td>10 (19.2)</td>
<td>3 (12.5)</td>
<td>13 (17.1)</td>
</tr>
<tr>
<td>&gt;73 months</td>
<td>15 (28.8)</td>
<td>4 (16.7)</td>
<td>19 (25.0)</td>
</tr>
<tr>
<td>Entire life</td>
<td>21 (40.4)</td>
<td>9 (37.5)</td>
<td>30 (39.5)</td>
</tr>
<tr>
<td>Total</td>
<td>52 (100)</td>
<td>24 (100)</td>
<td>76 (100)</td>
</tr>
</tbody>
</table>

Missing 12 1 13
Marital status

Table 6-4 depicts the marital status of participants by district. Overall, the majority of participants were single. The primary difference between districts is that a greater percentage of Kampala women considered themselves married (42% vs. 36%) and a greater percentage of Mukono women were widowed (8% vs. 3%). The mean number of years married for all participants was 5.8 years. However, the differences in marital status and years married by district were not significant.

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>33 (51.6)</td>
<td>13 (52.0)</td>
<td>46 (51.7)</td>
</tr>
<tr>
<td>Married</td>
<td>27 (42.2)</td>
<td>9 (36.0)</td>
<td>36 (40.4)</td>
</tr>
<tr>
<td>Separated or Divorced</td>
<td>2 (3.1)</td>
<td>1 (4.0)</td>
<td>3 (3.4)</td>
</tr>
<tr>
<td>Widowed</td>
<td>2 (3.1)</td>
<td>2 (8.0)</td>
<td>4 (4.5)</td>
</tr>
<tr>
<td>Total</td>
<td>64 (100)</td>
<td>25 (100)</td>
<td>89 (100)</td>
</tr>
</tbody>
</table>

It should also be noted that of the 36 married women, 19.4% reported that their spouse does not live with them. This pattern of female-headed households is not unusual in Uganda.

Household composition

Although social networks and the role of the extended family are explored in further detail in chapter 9, the basic composition of participants’ households are described here. The majority of participants (59.6%) had between one and three children (Table 6-5). Although 15.7% were childless, only 14.9% reported living in households without children (Table 6-6). In addition, few participants (21.7%) lived in households without other adults (Table 6-7).
Table 6-5 Number of offspring per participant (N=89)

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No kids</td>
<td>11 (17.2)</td>
<td>3 (12.0)</td>
<td>14 (15.7)</td>
</tr>
<tr>
<td>1-3 kids</td>
<td>38 (59.4)</td>
<td>15 (60.0)</td>
<td>53 (59.6)</td>
</tr>
<tr>
<td>4-6 kids</td>
<td>13 (20.3)</td>
<td>5 (20.0)</td>
<td>18 (20.2)</td>
</tr>
<tr>
<td>&gt;6 kids</td>
<td>2 (3.1)</td>
<td>2 (8.0)</td>
<td>4 (4.5)</td>
</tr>
<tr>
<td>Total</td>
<td>64 (100)</td>
<td>25 (100)</td>
<td>89 (100)</td>
</tr>
</tbody>
</table>

Table 6-6 Number of children in household (N=89)

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No kids</td>
<td>7 (13.0)</td>
<td>4 (20.0)</td>
<td>11 (14.9)</td>
</tr>
<tr>
<td>1-3 kids</td>
<td>36 (66.7)</td>
<td>10 (50.0)</td>
<td>46 (62.2)</td>
</tr>
<tr>
<td>4-6 kids</td>
<td>9 (16.7)</td>
<td>6 (30.0)</td>
<td>15 (20.3)</td>
</tr>
<tr>
<td>&gt;6 kids</td>
<td>2 (3.7)</td>
<td>0</td>
<td>2 (2.7)</td>
</tr>
<tr>
<td>Total</td>
<td>54 (100)</td>
<td>20 (100)</td>
<td>74 (100)</td>
</tr>
<tr>
<td>Missing</td>
<td>10</td>
<td>5</td>
<td>15</td>
</tr>
</tbody>
</table>

Table 6-7 Number of Adults in household (N=89)

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant only</td>
<td>13 (21.3)</td>
<td>5 (22.7)</td>
<td>18 (21.7)</td>
</tr>
<tr>
<td>1-2 adults + participant</td>
<td>47 (77.0)</td>
<td>12 (54.5)</td>
<td>59 (71.1)</td>
</tr>
<tr>
<td>&gt;=3 adults + participant</td>
<td>1 (1.6)</td>
<td>5 (22.7)</td>
<td>6 (7.2)</td>
</tr>
<tr>
<td>Total</td>
<td>61 (100)</td>
<td>22 (100)</td>
<td>83 (100)</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>

Thus, in terms of basic demographics, the majority of participants' households include children and more than one adult. Although a few participants do not reside with all of their children, the majority clearly have contact with either their own or others' children.

Socioeconomic Status

While socioeconomic status is a difficult concept to measure precisely in any context, it is particularly problematic in Uganda. Not only is work often sporadic, with few official records or pay receipts, but individuals may underreport income because they...
fear being taxed by the government. Although participants expressed no such concerns, the potential for underreporting should be noted. In order to overcome some of the weaknesses inherit in using income alone to measure socio-economic status, this study examined a number of additional socioeconomic indicators, including education level, livestock, and dwelling type. An attempt was also made to note participants’ material possessions (e.g., radio, stove/cooker, or bicycle) on the 42 follow-up interviews that were conducted in the participant’s home.

Income

Regarding participants’ income, it should be noted that participants were asked to describe their income-generating activities, how much they earned from each of these “jobs”, and how their activities changed with their illness. These open-ended questions allowed participants to categorize their earnings as they deemed appropriate, whether the money was earned daily, weekly, monthly, or even seasonally. As a result, it is not possible to state specifically how much participants earned per month. Instead, the data portray participants’ income strategies, the relative security of their income, and the impact of their illness. It is also possible to evaluate participants’ incomes in relation to national income and in terms of participants’ abilities to support themselves independently.

Sixty-five participants completed the second interview with the income measurements. The income measures instructed participants to recall their employment and earnings both before they became symptomatic and currently. Forty-seven participants (72.3%) reported that they at least periodically earned money before their TB
symptoms began, while 18 participants (27.7%) indicated that they earned no income before falling ill.1

Table 6-8 describes participants’ primary employment activities. Although there were no significant differences between participants’ employment categories by district, a slightly greater percentage of Kampala participants were employed as office workers or teachers and a slightly greater percentage of Mukono participants were unemployed. This finding is expected and reflects the increased opportunities for office work and teaching in Kampala.

<table>
<thead>
<tr>
<th>Table 6-8 Participants’ employment categories (N=65)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Kampala</strong></td>
</tr>
<tr>
<td>N (%)</td>
</tr>
<tr>
<td>Sales (e.g., soda, beer, auto parts, handicrafts)</td>
</tr>
<tr>
<td>Office work/teacher</td>
</tr>
<tr>
<td>Restaurant/hotel industry</td>
</tr>
<tr>
<td>Housegirl</td>
</tr>
<tr>
<td>Cultivation/gardening (own garden or wage labor)</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Not working, including housewives</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>

To give a few qualitative examples of participants’ jobs, a 20 year old woman from Kampala sold soda in the hospital and earned between 2,000-5,0002 Ush on the days that she worked. Similarly, a 26-year-old Mukono woman at times earned 500-1000 Ush a day washing clothes. To quote another Kampala participant, a 38-year-old woman who had difficulty determining the amount she earned selling auto parts:

The business is like it is not operating. I could spend a whole week or even a month without selling a single...it’s like the business died.

---

1 Two of these participants who had no earnings reported that they were housewives.
2 1,000 Uganda shillings (Ush) equal approximately $1.00 U.S.
Other participants reported earning 20,000 Ush every two weeks for typing or 20,000 Ush per month, plus “allowances,” for teaching. Thus, there was some variation in participants’ incomes and only a few had a reliable, steady income.

Not surprisingly given the descriptions above, it is difficult to quantify how much participants earned annually. 54.8% of the 65 interviewed received a daily or weekly wage which fluctuated depending upon the number of customers (e.g., at a shop or hair salon) or the participant’s ability to raise funds to purchase materials to make and/or resell (e.g., beer, soda pop, knitting place settings, doilies, and other household goods). In addition, as stated above, it is possible that participants may have underreported their income because of poor recall or government tax concerns.

Nonetheless, it is useful to examine participants’ mean incomes by their earnings period in order to understand the basic subsistence level at which many participants live (Table 6-9). Participants whose income was earned daily average 4,680 Ush. per day. Monthly incomes average 37,368 Ush, but less than a third of the entire sample (N=65) received a monthly salary.

<table>
<thead>
<tr>
<th>Table 6-9 Mean incomes by earnings category (N=42)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>N (%)</td>
</tr>
<tr>
<td>-------</td>
</tr>
<tr>
<td>Per day</td>
</tr>
<tr>
<td>Per week</td>
</tr>
<tr>
<td>Per month</td>
</tr>
</tbody>
</table>

*Not included in these mean calculations are the eighteen participants who reported they were not employed and five other participants: two who did not specify their earnings period; one participant who reported that her work is seasonal; one participant who did not know her income; and one with missing data.

**One outlier, a participant earning 150,000-200,000 per day from selling new clothes was excluded from this calculation.
A t-test revealed that there were no significant differences in the mean incomes by district. The primary difference in reported incomes was that more Kampala participants had monthly incomes, possibly indicating a steadier salary than Mukono participants. Because Kampala participants more frequently reported working in schools and offices (jobs that typically have monthly salaries) this result is not surprising. It is also not unexpected that Kampala participants' monthly incomes were also greater on average than Mukono participants' (41,429 Ush per month in Kampala vs. 22,500 Ush per month in Mukono). In contrast to Kampala, Mukono participants more frequently reported daily incomes and they averaged greater daily incomes (7,750 Ush per day in Mukono vs. 2,633 Ush per day in Kampala).

Again, these daily and weekly incomes should not be interpreted as occurring each day or week or as representing participants' total income. Instead, the data should be viewed as participants' average earnings for the days or weeks when they earn income. It can be concluded, therefore, that not only do 27.7% of participants earn no income, but of those who do have jobs, less than half have a steady income or, as will be discussed next, continue to work after developing active TB.

The onset of active TB impacts many participants' ability to make a living. Of the 47 working participants described above, 34 (72.3%) indicated that their income or means of earning money changed after they became symptomatic – 12 Mukono participants (80.0%) and 22 Kampala participants (66.7%) experienced this change. Indeed, a total of 22 participants from both sites reported that they no longer earned money after falling ill.
Although the majority of participants did not specify why their income changed, some noted that it was due to being too weak to work or that the money that was previously used for merchandise or rent was now used for treatment seeking. Only one participant indicated that the decrease was due to changing jobs.

Finally, it should be noted that not all the change-in-income data were negative. For example, one participant indicated that her income increased, unrelated to her illness, and she now owns a bar instead of washing clothes. Other participants who were further along in their treatment seeking reported that they were able to return to their previous jobs once their health improved. In addition, two participants who were not working prior to their illness were now earning 1,000 Ush. per week, and 80,000 Ush. per month, respectively.

Although only limited national income and employment information are available to compare with these data, the per capita income in Uganda is $220, with urban households tending to be a little wealthier than rural households (World Bank, 1996). In terms of employment, the 1995 Uganda Demographic and Health Survey (Statistics Department, 1996) found that 39% of women were not employed. Forty-two percent were employed full-time, 15% worked seasonally, and 3% worked “occasionally” (Statistics Department, 1996). Although slightly more of this study’s participants were working, this increase is not unexpected given Uganda’s growing economy. Thus, overall the income and employment rates reported here are consistent with national data.

A final measure for evaluating participants’ incomes is whether they earn enough to be self-sufficient. Fifty-one (78.5%) reported that they were not able to pay all their bills. Furthermore, only two participants grew enough food on which they could subsist.
To overcome the gaps between their income and expenses, participants engaged in a range of strategies, many of which involved their social network members, as will be discussed in chapter 9.

To summarize, 72.3% of participants reported having income-generating activities prior to their illness. These activities ranged from the sporadic selling of handcrafted goods or sodas to regular employment in an office or school. Even before falling ill, however, few participants earned enough to support themselves without assistance from friends and family. As participants' TB symptoms progressed, many (72.3%) found that their level of work decreased or they were unable to work entirely. Participants either became too ill or had no money with which to maintain a business because their funds were diverted to support treatment seeking. While participants may be able to restart work once their symptoms improve, many had no personal income during the treatment-seeking process.

**Education level**

Sixty-three (96.9%) of the 65 participants interviewed reported that they had attended school. The highest education levels attended, but not necessarily completed, were slightly higher than the 1995 National Demographic Survey (Statistics Department, 1996), the most recent national education data available. However, the number of children entering and staying in school has increased dramatically over the past decade, which suggests that this sample as a whole is within the national average for education.

In brief, 41.9% of Kampala women and 40.9% of Mukono women attended some level of secondary school (Table 6-10). The Kampala women’s rates are comparable to the 1995 finding that 39.7% of urban women had attended secondary school. The 1995
survey, however, found that only 8.9% of rural women had attended secondary school (Statistics Department, 1996). It is possible that the Mukono TB patients in this study had greater access to schools than the rural population used in the demographic survey. Alternatively, educated rural patients may be more likely to seek treatment from the clinic than uneducated rural patients. However, over the last decade there has been a national effort to expand school attendance throughout the country, so it is also possible that Mukono participants' education levels reflect a national trend of increasing secondary school attendance rates.

Table 6-10 Highest education level attended (N=65)

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No schooling</td>
<td>2 (4.7)</td>
<td>0</td>
<td>2 (3.1)</td>
</tr>
<tr>
<td>P1-5</td>
<td>4 (9.3)</td>
<td>1 (4.5)</td>
<td>5 (7.7)</td>
</tr>
<tr>
<td>P6-7</td>
<td>15 (34.9)</td>
<td>12 (54.5)</td>
<td>27 (41.5)</td>
</tr>
<tr>
<td>S1-3</td>
<td>12 (27.9)</td>
<td>6 (27.3)</td>
<td>18 (27.7)</td>
</tr>
<tr>
<td>S4-6</td>
<td>6 (14.0)</td>
<td>3 (13.6)</td>
<td>9 (13.8)</td>
</tr>
<tr>
<td>Some college or technical diploma</td>
<td>4 (9.3)</td>
<td>0</td>
<td>4 (6.2)</td>
</tr>
<tr>
<td>Total</td>
<td>43 (100)</td>
<td>22 (100)</td>
<td>65 (100)</td>
</tr>
</tbody>
</table>

Livestock and gardens

An additional measure of participants' socioeconomic status is whether they own livestock, such as chickens, goats, or cows. Only 14 (21.5%) of the 65 participants interviewed reported owning animals – seven in Kampala (16.3%) and seven in Mukono (31.8%). Chickens were the most frequently owned animals, with seven Kampala participants and five Mukono participants owning 1 to 10 birds. An additional Mukono participant reported having 200 chickens. One Kampala participant and two Mukono participants owned 1 to 3 goats. The only participant who reported cattle ownership was the Mukono woman with 200 chickens; this participant also had five cows. Thus, less
than a quarter of Kampala participants and less than a third of Mukono participants owned livestock. The women who owned animals, with the exception of one, tended to have a few chickens or a goat. For the majority of participants, livestock is not an important form of income or nutrition. It is likely that many participants do not have the extra income to invest in livestock.

Regarding the use of gardens for personal consumption, participants were divided by district. Only eight Kampala participants (18.6%) tended a garden. However, ten Mukono participants (45.5%) reported having a garden. In both locations, participants frequently grew some combination of cassava, matoke (plantains), potatoes (white and sweet), and beans. For the majority of participants (88.9%), these gardens did not supply enough food to support the participant’s household. Only two participants, one in each district, indicated that they did not supplement their gardens with purchased foods. Thus, the majority of participants did not have extra income generators, resources or investments in the form of livestock or garden produce.

_Dwelling type and material possessions_

As a final indication of participants’ socioeconomic well being, information on participants’ dwelling type and material possessions was collected. These data were obtained by discretely cataloging characteristics of the participant’s dwelling and her possessions, particularly the presence of a radio, telephone, cooker (stove), bicycle, and electricity. This cataloging measure is similar to the technique employed by McGrath et al. (1993). Unfortunately, this information was collected only on the 42 participants (64.6%) who were interviewed at their home. Overall there was limited variation in
participants' material lifestyles, although a few had slightly larger dwellings and more possessions.

To give a few examples of the variation in possessions, only five participants (four in Kampala and one in Mukono) were observed to have television sets (although it is not known if this equipment was functioning), and four participants (again three in Kampala and one in Mukono) were observed to have telephones. Four participants (6.2%) were observed to have refrigerators, while 24 (36.9%) appeared to have electricity and 14 (21.5%) had radios.

In terms of dwellings, all of the participants interviewed at home lived in brick (either handmade or manufactured) structures with iron roofs. The number of rooms in the dwellings varied, with most consisting of one room divided by a curtain that shielded the sleeping area. Furnishings generally consisted of a few chairs or stools or a two-person sofa and chair, one or two coffee or side tables, and shelves or bureaus to hold possessions and cooking utensils. Wealthier participants had separate sitting and sleeping rooms and windows paned in glass.

Thus, the majority of participants interviewed in their homes had relatively uniform material possessions, although, just as with income, there were a few who appeared to have greater material wealth. While these data are useful for painting a picture of participants' living environments, it is not possible to compile the information to clearly distinguish participants' socioeconomic levels. First, the dwellings and material possessions of participants who were not interviewed in their homes cannot be estimated. Second, the data on material possessions does not correlate with the data on participants' income or their type of employment. Participants who have no income are
as likely to have material possessions as office workers/teachers and sales/crafts women.

Such results hint that social network support must play an important role for women without a personal income; however, this issue will be explored further in chapter 9.

In sum, participants cannot be divided into distinct socioeconomic categories based upon the current data. However, for those participants who are working, their incomes appear to cluster around the national average. At the same time, their incomes tend to fluctuate unpredictably and the majority experienced decreases in income as their TB progressed. Participants’ education levels, while slightly higher than previous studies, likely reflect the country’s increased emphasis on education, rather than the sample consisting of a more educated patient group. Overall, these participants have few livestock investments or extra resources in the form of gardens – the majority do not even have the funds to pay their daily living expenses.

Typical patient

To help conceptualize participants’ demographics and lifestyle, a “typical” patient is described below. “Margaret” is a 28 year old Muganda who has lived in Kampala for five years. She is married and has two children. She lives in a medium-sized, roughly 14 square foot room with her husband, children, and one of her younger sisters. Her home is constructed from mud bricks with a tin roof, one door, and one wood-shuttered window. It contains one small couch, two chairs, a coffee table and shelves for holding supplies. A curtain behind the couch separates the sleeping area that contains a bed and clothes bureau. There is no running water or electricity. Water must be carried from a nearby pump. Food is cooked outside on a portable charcoal stove.
Margaret’s neighborhood is quiet and removed from the urban center and slums. All of the homes are of a similar style to her own. Two nearby shops sell rice, beans, and other dry goods. It is a ten-minute uphill walk on a badly pitted dirt road to a primary paved road and the matatu or bus stop. While gardens, especially matoke plants, are growing between buildings and on any undeveloped land, Margaret does not have a garden.

Having attended level two of secondary school, Margaret is slightly more educated than other participants. She is also slightly more wealthy, earning 1500 Ush per day from working in a local restaurant. With this money, she can afford a maid who earns 10,000 Ush per month. Lately, however, the restaurant’s business has fallen, which often results in deductions (e.g., 500 Ush.) in her pay. Despite her income and maid, Margaret’s material lifestyle overall can be characterized as only marginally better than other participants.

To briefly describe her treatment seeking, Margaret had been on TB treatment at Mulago for over one month when she joined the study. Her symptoms began with piercing chest pain three months prior to attending Mulago. She originally sought treatment at a local clinic, and then elsewhere in Mulago, before she was referred to the Mulago TB clinic. The original clinic treatments cost 30,000 Ush., which was provided by her older sister.

Thus, the typical patient resides in a modest home and has limited material wealth. As in many Uganda communities, her neighborhood’s roads are not paved and water is not piped directly to homes. Although she may have an income, the amount earned may fluctuate daily. Her search for a treatment has involved both local clinics and
Mulago hospital, which, as will be described in the next chapter, is a trend with many patients.

Summary

The majority of participants are Baganda under the age of 30. Fifty-three percent have been attending the TB clinic for less than five months. Very few participants live alone, although only 40% report that they are married. All but two participants obtained some education, but the majority stopped before secondary school. Kampala women tend to report higher earnings than Mukono women. Few Kampala and Mukono participants, however, have extra financial resources in the form of gardens or animals. In general, participants’ education and income data are consistent with national demographic data on urban and rural Ugandans.
Chapter 7: Patients’ TB Health Beliefs

The concept of health beliefs refers to local perceptions of an illness’ symptoms, transmission routes, etiology, risk factors, and treatment. Patients frequently combine local health beliefs and information received from health care practitioners and family or friends to create an individualized, explanatory model for illness (Kleinman, 1980). As described in chapter 3, studies suggest that these health beliefs, along with other factors, including individuals’ political economic context and access to health care, may influence treatment-seeking behavior. This section examines participants’ TB health beliefs. In particular, it focuses on participants’ conceptualizations of their illness, their understandings of TB’s symptoms in general, and their own illness experience. It also examines participants’ ideas about TB’s transmission, the relationship between HIV/AIDS and TB, and the treatments that are available for TB. Because there are few differences between the health beliefs of rural and urban participants, these data are not presented by district. The statistically significant differences that do exist, however, are noted in the text.

As described in the methodology chapter, participants’ health beliefs were measured using open-ended questions that were then followed by close-ended questions. The majority of items examining participants’ TB health beliefs were located on the initial questionnaire, which had a sample size of 89. However, participants were not asked to define TB until the final questionnaire, which had a sample size of 40. This health belief question was added to the last instrument in order to understand how participants conceptualized or defined their illness once they were immersed in the biomedical treatment seeking process.
What is TB?

To begin with participants' conceptualizations of their illness, the majority of the 40 participants interviewed with the third instrument defined tuberculosis in terms of its symptoms. In response to the open-ended question, "what is TB," participants did not identify the disease's causal agent and less than a third of participants identified the illness by the organ it impacts, i.e., that it weakens or wounds the lungs (Table 7-1). Thirty percent of participants simply reported that they did not know what TB is.

### Table 7-1 What is TB? (N=40)*

<table>
<thead>
<tr>
<th></th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know what TB is</td>
<td>12 (30.0)</td>
</tr>
<tr>
<td>Lung wound/weak lungs/spoils lungs</td>
<td>11 (27.5)</td>
</tr>
<tr>
<td>Cough/non-stop coughing</td>
<td>11 (27.5)</td>
</tr>
<tr>
<td>Cough that won't cure</td>
<td>8 (20.0)</td>
</tr>
<tr>
<td>Chest pain</td>
<td>5 (12.5)</td>
</tr>
</tbody>
</table>

*participants were permitted to give more than one response

These data suggest that the majority of patients do not think of their illness as a bacterial infection, rather their conception is largely based on their experience with a cough or chest pain. This finding may have important implications for treatment adherence, as a reduction in symptoms may lead to treatment cessation (see Menegoni, 1996; Nichter, 1994). Further studies are needed to determine if patients who conceptualize their illness primarily in terms of their major symptoms, instead of as involving a larger, systemic infection, are more likely to stop treatment once the symptoms disappear.
TB’s Symptoms

To further determine participants’ health beliefs and conceptualizations of their illness, participants’ understanding of TB’s symptoms in general were examined. Multiple measures were used to examine the signs of TB. The first measure asked participants to explain, “what happens to the body when you are infected with TB?” Of the 89 participants interviewed, chest pain was reported by 51.7%, while 50.6% indicated that there is a cough, 31.5% stated there is a fever or a feeling of being hot or cold, and 25.8% reported general weakness as a symptom.

Participants then indicated whether a list of ten symptoms, which included common symptoms of both HIV/AIDS and TB, were found with TB. Participants’ answers mirrored their responses to the open-ended question, with an overwhelming majority agreeing that thin appearance/wasting, general weakness, chest pain, night sweats, and fever were symptoms of TB (Table 7-2).

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes (N) (%)</th>
<th>No (N) (%)</th>
<th>Don’t know (N) (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thin Appearance/ Wasting</td>
<td>84 (94.4)</td>
<td>4 (4.5)</td>
<td>1 (1.1)</td>
</tr>
<tr>
<td>General Weakness</td>
<td>82 (92.1)</td>
<td>5 (5.6)</td>
<td>2 (2.2)</td>
</tr>
<tr>
<td>Chest Pain</td>
<td>78 (87.6)</td>
<td>8 (9.0)</td>
<td>3 (3.4)</td>
</tr>
<tr>
<td>Night Sweats</td>
<td>75 (84.3)</td>
<td>11 (12.4)</td>
<td>3 (3.4)</td>
</tr>
<tr>
<td>Fever</td>
<td>68 (76.4)</td>
<td>11 (12.4)</td>
<td>10 (11.2)</td>
</tr>
<tr>
<td>Backache</td>
<td>44 (49.4)</td>
<td>39 (43.8)</td>
<td>6 (6.7)</td>
</tr>
<tr>
<td>Rash</td>
<td>18 (20.2)</td>
<td>68 (76.4)</td>
<td>3 (3.4)</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>15 (16.9)</td>
<td>69 (77.5)</td>
<td>5 (5.6)</td>
</tr>
<tr>
<td>Sores/Blisters</td>
<td>6 (6.7)</td>
<td>81 (91.0)</td>
<td>2 (2.2)</td>
</tr>
<tr>
<td>Dementia</td>
<td>3 (3.4)</td>
<td>83 (93.3)</td>
<td>3 (3.4)</td>
</tr>
</tbody>
</table>

These results are quite striking. First, a majority of participants report that chest pain is a symptom of TB, despite the fact that, as mentioned in chapter 2, chest pain is typically an “uncommon” symptom of TB (Ormerod, 1994). Second, participants
suggest that many of the local signs of HIV are also TB symptoms. Thin appearance (wasting) and general weakness in particular are locally recognized signals of HIV infection (see e.g., participants’ descriptions of their HIV symptoms in McGrath, et al., 1994). The association between HIV/AIDS and TB symptoms should not be overstated, however, as the majority of participants do not link TB with other local symptoms of HIV, including sores/blisters, rashes, and dementia. Nonetheless, these data suggest that while there are clearly distinguishable symptoms between TB and HIV/AIDS, e.g., sores/blisters around the mouth signaling HIV/AIDS and chest pain suggesting TB, other symptoms of the two diseases may overlap in local health belief systems.

When examined by district, additional patterns in participants’ TB symptom models emerge. Kampala participants are significantly more likely to mention difficulty breathing as a general symptom of TB (see Appendix H), although as noted below, they are not more likely to have experienced this problem personally. Mukono participants, on the other hand, are significantly more likely to agree or report that they don’t know if weakness, diarrhea, dementia, and thin appearance are symptoms of TB; in addition, the number of participants reporting sores as a general symptom of TB approaches statistical significance (see Appendix H). While interpretations should be made cautiously due to small cell sizes, these data suggest that Mukono participants are more likely to agree or not know whether TB’s symptoms parallel HIV’s symptoms.

Participants’ personal initial illness experience

Although not all participants personally experienced the symptoms described above, many indicated that similar symptoms occurred with the initial onset of their
illness\(^1\) (Table 7-3). The majority of the 89 patients interviewed reported that a cough was their first symptom, while 49% reported fever and 44% described chest pain as additional early symptoms. There were no significant differences in participants’ reports of their first symptoms by district.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cough</td>
<td>73 (82.0)</td>
</tr>
<tr>
<td>Fever/Feeling hot or cold/Sweating/Nightsweats</td>
<td>44 (49.4)</td>
</tr>
<tr>
<td>Chest/Rib Pain</td>
<td>39 (43.8)</td>
</tr>
<tr>
<td>Flu</td>
<td>9 (10.1)</td>
</tr>
<tr>
<td>Cough blood</td>
<td>8 (9.0)</td>
</tr>
<tr>
<td>General weakness</td>
<td>7 (7.9)</td>
</tr>
<tr>
<td>Difficulty breathing</td>
<td>6 (6.7)</td>
</tr>
<tr>
<td>Other (headache, vomiting, loss of appetite)</td>
<td>11 (12.4)</td>
</tr>
</tbody>
</table>

*participants were permitted to report more than one symptom

Participants’ symptoms are consistent with traditional, biomedical descriptions of TB’s course (see chapter 2). For example, cough, especially persistent cough, which the majority of participants list as an initial symptom, is indeed the characteristic first symptom of pulmonary TB. However, it is alarming that many patients also report uncommon or advanced symptoms of infection as primary symptoms, e.g., almost half of all patients report chest or rib pain as one of their first symptoms. Likewise, 49% report fevers or sweating as initial symptoms, which may be a sign of disease progression (Ormerod, 1994). Thus, participants frequently do not recognize a cough alone as an early symptom of TB. Instead, sickness is recognized once the disease has progressed beyond the initial stages of infection and more serious symptoms occur.

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\(^1\) Instrument questions were carefully placed to avoid influencing participants’ responses. For example, participants described their personal, initial symptoms in the beginning of the interview, while questions on TB’s symptoms in general were located at the end of the interview.
Factors in TB Susceptibility and Transmission

Another critical component of patients' health belief models is patients' understanding of disease transmission. In general, participants did not know the source of their infection, but they did believe that certain conditions, e.g., smoking or drinking alcohol, could lead to the illness.

Regarding the source of their infection, 65 of the 89 participants interviewed (73%) indicated that they did not know how they became infected, while 18 (20%) reported that a family member, friend, or neighbor had TB and they suspected that he or she was the source of the illness. Only 5 (6%) stated that the route of transmission was through the air. For example, to quote a 23-year old Kampala woman, “the disease is airborne, so you can’t really know.” Other participants mentioned miscellaneous additional factors as contributing to their illness, including smoking (either by the participant or those around her), dust, HIV, having a husband who died of AIDS, being in the cold, and drinking too much alcohol. Interestingly, two participants reported that they developed TB as a result of their participation in studies conducted by Case Western Reserve University’s medical school².

Participants also reported whether twelve specific activities cause or facilitate infection with TB in general (Table 7-4). Participants’ responses indicate that both local beliefs about the disease and standard public health messages influence common understanding of TB risk factors. For example, 92% of participants agree that smoking can be a factor in TB infection, hinting at a local belief in a connection between cigarettes

² These two participants felt they contracted TB as a result of their contact with TB patients in the waiting “room” of Case Western Reserve University’s clinic. The waiting room, however, is an open air waiting area – the exchange of air reduces the risk of TB transmission. It is more likely that these patients had
and TB. Similarly, 54% of participants agree that dusty air, which is commonly blamed for the flu and other respiratory ailments, can bring TB. At the same time, participants also accept public health transmission models, as 89% agree that TB can be obtained by sharing eating utensils. The majority of participants clearly have internalized clinic workers' advice to separate their cups, plates, and silverware.

Table 7-4  TB Transmission Routes (N=89)

<table>
<thead>
<tr>
<th></th>
<th>Yes/ Sometimes N (%)</th>
<th>No N (%)</th>
<th>Don't Know N (%)</th>
<th>Missing N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking</td>
<td>80 (92.0)</td>
<td>3 (3.4)</td>
<td>4 (4.6)</td>
<td>2</td>
</tr>
<tr>
<td>Using eating utensils of someone with TB</td>
<td>79 (88.8)</td>
<td>5 (5.6)</td>
<td>5 (5.6)</td>
<td>0</td>
</tr>
<tr>
<td>Talking to others with TB</td>
<td>61 (68.5)</td>
<td>16 (18.0)</td>
<td>12 (13.5)</td>
<td>0</td>
</tr>
<tr>
<td>Drinking too much alcohol*</td>
<td>59 (66.3)</td>
<td>20 (22.5)</td>
<td>10 (11.2)</td>
<td>0</td>
</tr>
<tr>
<td>Contacting blood of someone with TB</td>
<td>56 (63.6)</td>
<td>14 (15.9)</td>
<td>18 (20.5)</td>
<td>1</td>
</tr>
<tr>
<td>Breathing dusty air**</td>
<td>48 (53.9)</td>
<td>27 (30.3)</td>
<td>14 (15.7)</td>
<td>0</td>
</tr>
<tr>
<td>Having sex with someone with TB***</td>
<td>46 (51.7)</td>
<td>17 (19.1)</td>
<td>26 (29.2)</td>
<td>0</td>
</tr>
<tr>
<td>Living in a dirty house****</td>
<td>44 (49.4)</td>
<td>35 (39.3)</td>
<td>10 (11.2)</td>
<td>0</td>
</tr>
<tr>
<td>Having sex without a condom</td>
<td>32 (36.0)</td>
<td>32 (36.0)</td>
<td>25 (28.1)</td>
<td>0</td>
</tr>
<tr>
<td>Working too hard</td>
<td>18 (20.2)</td>
<td>62 (69.7)</td>
<td>9 (10.1)</td>
<td>0</td>
</tr>
<tr>
<td>Insufficient sleep</td>
<td>10 (11.2)</td>
<td>72 (80.9)</td>
<td>7 (7.9)</td>
<td>0</td>
</tr>
<tr>
<td>Poor Nutrition (“poor feeding”)</td>
<td>11 (12.4)</td>
<td>74 (83.1)</td>
<td>4 (4.5)</td>
<td>0</td>
</tr>
</tbody>
</table>

*Some participants indicated that this is due to sharing straws when drinking local beer.

**Dust is commonly associated with the spread of the “flu” and the common cold, especially during the dry season, as dust becomes prevalent both indoors and outdoors. Participants and key informants, however, were unable to clarify whether it is the dust particles themselves that cause illness, or whether the dust spreads pathogens that are in the dirt (e.g., from people spitting).

***Participants clarified that TB could be transmitted during sex due to close breathing during intercourse, and not necessarily through the act of intercourse itself.

****Participants qualified that living in a dirty house causes TB due to lack of ventilation in the house.

In addition to agreeing that both biomedical and locally-defined variables are factors in disease transmission or susceptibility, over half the participants also agreed that inactive TB infections prior to their participation in the study. At least one of these participants was also HIV-positive, which may have contributed to the development of active disease.
TB could be passed through routes similar to HIV, i.e., through blood and sexual intercourse. However, some participants clarified that TB could be transmitted during intercourse due to close breathing, rather than through the act of sex itself. Mukono participants were significantly more likely to agree or not know if specific activities or conditions, i.e., sexual intercourse with a TB patient, sex without a condom, or the blood of a TB patient, could transmit TB (see Appendix H). Similar to the results regarding TB's symptoms, these data are difficult to interpret because of small cell size. While it is possible that Mukono participants are very aware of TB's airborne transmission and therefore the risk of close sexual contact, an alternative interpretation is that Mukono participants do not have a clear understanding of the differences between HIV and TB.

TB's etiology

Participants' ideas concerning the etiology of TB echo the routes of transmission described above. Although 43% of the 40 participants who completed the third interview did not know the cause of TB, 40% indicated that the disease is spread through the air (Table 7-5). Participants also suggested that talking to someone with TB, drinking unboiled milk, and sharing cups, plates, or leftover food can cause TB. There were no significant differences in participants' responses by district.

<table>
<thead>
<tr>
<th>Table 7-5 Etiology of TB (n=40)*</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don’t know cause</td>
<td>17 (42.5)</td>
</tr>
<tr>
<td>From or in air</td>
<td>16 (40.0)</td>
</tr>
<tr>
<td>Talking to someone with TB</td>
<td>3 (7.5)</td>
</tr>
<tr>
<td>Drinking unboiled milk</td>
<td>3 (7.5)</td>
</tr>
<tr>
<td>Sharing cups, plates, or leftover food</td>
<td>3 (7.5)</td>
</tr>
<tr>
<td>Other (breathing dusty air, poor feeding, genetic, HIV)</td>
<td>5 (12.5)</td>
</tr>
</tbody>
</table>

*participants were permitted to give more than one cause of TB
Thus, in addition to having difficulty defining TB beyond its symptoms, many
participants did not know the cause of TB. For the remaining participants, etiology is
expressed in terms of the disease's transmission, which may be based on public health
messages and/or local contagion beliefs.

Fears of Transmission

Along with agreeing that a number of factors might contribute to the spread of
TB, the majority of participants were concerned that their illness might spread to others.
When asked if they were worried that someone might catch their TB, 64 participants
(72%) were worried while 25 (28%) were not. Among those who were concerned, 30%
explained that they were worried because they live with other individuals. Twenty-seven
percent of participants were concerned about the children that are frequently in their
presence. An additional 27% expressed anxiety due to the disease's ability to spread
through the air (Table 7-6).

<table>
<thead>
<tr>
<th>Reason</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stays with other adults, children, or grandchildren</td>
<td>19 (29.7)</td>
</tr>
<tr>
<td>Worried about children – children are always with her</td>
<td>17 (26.6)</td>
</tr>
<tr>
<td>Spreads through the air</td>
<td>17 (26.6)</td>
</tr>
<tr>
<td>Participant shares or others use her cups/utensils</td>
<td>12 (18.8)</td>
</tr>
<tr>
<td>Participant’s children already have TB or cough</td>
<td>6 (9.4)</td>
</tr>
<tr>
<td>Disease is infectious: the participant caught and can therefore give it</td>
<td>5 (7.8)</td>
</tr>
<tr>
<td>Would feel bad if spread it because it would cause others to suffer</td>
<td>4 (6.3)</td>
</tr>
<tr>
<td>Can spread unknowingly</td>
<td>2 (3.1)</td>
</tr>
<tr>
<td>Delayed seeking treatment</td>
<td>2 (3.1)</td>
</tr>
<tr>
<td>Other (e.g., takes long to cure; breastfeeding; must be careful; must isolate self)</td>
<td>8 (12.5)</td>
</tr>
</tbody>
</table>

*participants were permitted to report more than one response
In contrast, the majority of participants who were not worried about the communicability of their illness explained that they had taken action to prevent the disease's spread. For example, 40% stated that the disease will not spread if someone is on treatment; 32% of participants have isolated their eating and drinking utensils; and 24% stated that she and her friends/family are careful to avoid transmission, with no further specification of how they are careful (Table 7-7). These data suggest that, while there is tremendous concern among patients about the contagious nature of TB, some patients do feel that they are able to control the disease's spread.

Table 7-7 Reasons not worried TB will spread (N=25)*

<table>
<thead>
<tr>
<th>Reason</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease doesn't spread once on treatment</td>
<td>10 (40.0)</td>
</tr>
<tr>
<td>Participant isolates her utensils</td>
<td>8 (32.0)</td>
</tr>
<tr>
<td>Participant and those around her are careful to avoid transmission</td>
<td>6 (24.0)</td>
</tr>
<tr>
<td>Not worried because lives alone</td>
<td>2 (8.0)</td>
</tr>
<tr>
<td>It is God's decision/plan whether someone will be infected</td>
<td>2 (8.0)</td>
</tr>
<tr>
<td>Other (e.g., not coughing; not transmissible; not sure has TB; knows how TB is spread; not thought about it)</td>
<td>5 (20.0)</td>
</tr>
</tbody>
</table>

*participants were permitted to report more than one reason

Preventing TB

Echoing the data above, participants were mixed in their belief whether TB could be prevented. Of the 65 participants who were asked if TB could be prevented, 35 (54%) believed that TB could be prevented. Twenty (31%) thought it could not be, and 10 (15%) did not know. Among the 35 participants indicating that transmission can be prevented, 25 (71%) limited transmission by not sharing cups, plates, or leftover food. The other prevention mechanisms offered by participants included not staying/sharing sleeping space with TB patients, and covering one's mouth when coughing. Of the 20...
participants who said it could not be prevented, the most frequent explanation was reported by seven subjects (35%) who indicated that it is because the disease is airborne.

Together the data on TB’s transmission and prevention suggest that many participants are aware of public health control measures, and believe their actions can limit the disease’s spread. Other participants, however, are concerned that TB is airborne and that there is little that can be done to limit the risk to those surrounding the participant. These participants appear to have embraced the public health message concerning TB’s primary route of transmission, but not the message regarding their ability to control the disease through proper treatment.

Participants’ sources of information

Participants generally construct their beliefs regarding TB based upon hospital/clinic or non-biomedical sources. Although participants undoubtedly learned about TB from multiple people, when the 89 participants were asked how they knew the information regarding TB transmission specifically, they tended to report only one source type. The most frequent of sources were the TB clinic, doctors, and nurses (Table 7-8), but 31% of participants indicated that they learned from unspecified “people” around them.

<table>
<thead>
<tr>
<th>Table 7-8 Sources of information on TB/TB transmission (n=89)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>TB clinic/other doctor or nurse</td>
</tr>
<tr>
<td>“People”/no specific place/nowhere</td>
</tr>
<tr>
<td>Other patients</td>
</tr>
<tr>
<td>Non-clinic (Friends/Family/School)</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
<tr>
<td><strong>Missing</strong></td>
</tr>
</tbody>
</table>

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Kampala participants were significantly more likely to report that their information came from a medical source than Mukono participants ($X^2 = 9.8; V = .33; p = .002$). This likely reflects differences in patient education across the study sites. There was no statistical association, however, between participants' source of information and their beliefs regarding transmission. A chi-square test indicated only the belief that insufficient rest is a factor in transmission was associated with the source of information ($X^2 = 9.5; V = .34; p = .009$), i.e., participants who heard information from non-biomedical sources were more likely to agree or not know that lack of sleep influences an individual's vulnerability to TB.

These differences should be interpreted cautiously due to the small cell sizes and the absence of consistent differences across participants’ beliefs. Thus, this finding suggests that further research is needed to determine the extent of differences in TB education levels by treatment site and whether there is an association between patients’ information sources and TB education, and their TB health beliefs.

**Relationship between HIV/AIDS and TB**

Along with obtaining participants’ health beliefs about TB in general, data were also collected from 65 participants on how local belief models link TB and HIV/AIDS, and whether an association between the two diseases impacts attitudes towards treatment seeking. To begin, 36 participants (55.4%) believed that it is easy for a person with TB to get HIV/AIDS, while 50 participants (76.9%) believed that it is easy for a person with HIV/AIDS to develop TB.

Only 9 participants (13.8%) did not believe that it is easy for a person with TB to get HIV/AIDS, while 20 (30.8%) did not know. One participant (1.5%) did not believe
that it is easy for a person with HIV/AIDS to get TB, while 14 (21.5%) did not know. Thus, the vast majority of participants believed that it is easy for a person with HIV/AIDS to get TB, and over half believed that it is easy for a person with TB to get HIV/AIDS.

To explain why it is easy for a person with TB to get HIV/AIDS, 42% indicated that it is because they are the same disease, that they come together, or that HIV is a symptom of TB (Table 7-9). Twenty-five percent, however, suggested that TB patients can become infected with HIV similarly to non-TB patients, e.g., through sexual intercourse; therefore, the risk to TB patients is no greater than the great risk that exists for everyone.

<table>
<thead>
<tr>
<th>Why it is easy for person with TB to get HIV/AIDS (N=36)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV/AIDS and TB are the same disease/all come at once/HIV is a symptom of TB</td>
</tr>
<tr>
<td>Individuals with TB can be infected with HIV/AIDS through the same route as everyone else</td>
</tr>
<tr>
<td>TB weakens the body, making it easy to get HIV</td>
</tr>
<tr>
<td>Don't know why it is easier</td>
</tr>
<tr>
<td>Other (e.g., TB can cause AIDS)</td>
</tr>
</tbody>
</table>

*participants were permitted to report more than one response

In the reverse, when describing why it is easy for a person with HIV/AIDS to get TB, 48% indicated that HIV/AIDS weakens an individual and/or their lungs (Table 7-10). Five participants (10.0%) reported that it is because TB is airborne and cannot be avoided. Interestingly, 16% reported that the diseases are the same or there is little difference between them, and 14% indicated it is because they have witnessed or have been told that the two diseases occur together. To quote a 20-year old Kampala patient, “they say that HIV always brings a cough which does not cure – thus [it is] TB.”
Another Kampala patient similarly mentioned, it is “because when an AIDS patient gets flu and cough, when they [doctors] examine her, they find TB in her.”

<table>
<thead>
<tr>
<th>Table 7-10 Why it is easy for person with HIV/AIDS to get TB (N=50)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>N (%)</td>
</tr>
<tr>
<td>HIV/AIDS weakens a person and/or their lungs</td>
</tr>
<tr>
<td>HIV/AIDS and TB are the same illness</td>
</tr>
<tr>
<td>Frequently have seen or are told the two diseases occur together</td>
</tr>
<tr>
<td>TB is airborne and therefore unavoidable</td>
</tr>
<tr>
<td>Don’t know why it is easy, it just is</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

*participants were permitted to report more than one response

When the explanations for why it is easy for a person with HIV/AIDS to get TB and why it is easy for a person with TB to get HIV/AIDS are combined, it becomes clear that over a quarter of patients feel that the two diseases are the same. Nineteen (29.2%) of the 65 participants who completed the questions indicated in response to one or both of the questions that HIV/AIDS and TB are the same illness.

Participants were split in their belief that HIV/AIDS changes the nature or course of a TB infection. Twenty-five participants (38.5%) agreed that AIDS does change the way TB occurs in an individual, explaining that it may lead to more severe symptoms or specific conditions. Twenty-six participants (40.0%), however, believed that HIV/AIDS does not change TB’s progression, while fourteen participants (21.5%) did not know if HIV/AIDS changes TB.

Regarding HIV/AIDS patients’ ability to treat a TB infection, 39 participants (60.0%) believed that HIV-positive patients could be treated for a TB infection. Only 14 (21.5%) reported that HIV/AIDS changes a patient’s ability to be treated for TB. Twelve participants (18.5%) did not know. It is interesting that the fourteen participants who
believed AIDS changes a patient’s ability to treat TB were divided on whether HIV/AIDS patients should treat TB. Seven (10.8%) indicated that TB should be treated in order that patients remain with one disease (HIV/AIDS), while seven (10.8%) indicated that TB should not be treated because there is no cure for HIV.

One other subject, in addition to the seven reported above, reported elsewhere that comorbid patients should not be treated. Thus, altogether, eight participants expressed the idea of hopelessness in their interviews, i.e., only 12.3% of the 65 participants indicated in their interviews that there was no point in treating HIV/AIDS or TB and no potential to be cured. Thus, few participants expressed that treatment should be abandoned with comorbidity.

Treatments for TB

Belief in Biomedicine

A final critical dimension of a patient’s health belief model is his/her ideas regarding appropriate treatment. The majority of participants tended to indicate that biomedicine, rather than home remedies or traditional medicine, should be used to treat TB. Indeed, 87.6% of the 89 participants reported that there are biomedical treatments for TB, with tablets being the form of biomedicine most frequently mentioned (Table 7-11). Of the eleven participants who did not know what treatments are available for TB, six had been attending the biomedical clinic for less than one month. It is likely that these participants were unsure of biomedicine’s ability to treat TB because of they had only recently begun clinic treatment.
Table 7-11 Treatments available for TB (n=89)*

<table>
<thead>
<tr>
<th>Biomedical treatments</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tablets:</td>
<td>75 (84.3%)</td>
</tr>
<tr>
<td>Injections</td>
<td>40 (44.9%)</td>
</tr>
<tr>
<td>Hospitals</td>
<td>2 (2.2%)</td>
</tr>
<tr>
<td>Prescriptions</td>
<td>1 (1.1%)</td>
</tr>
<tr>
<td>Traditional healers</td>
<td>1 (1.1%)</td>
</tr>
<tr>
<td>Don't know</td>
<td>11 (12.4%)</td>
</tr>
</tbody>
</table>

* participants were permitted to report more than one response

These results are similar to a separate question that asked what is the most effective treatment for TB. Forty-nine (75.4%) of the 65 participants stated biomedicine, in the form of treatment from hospitals or doctors, is the most effective TB treatment. Fifteen participants (23%) reported that they did not know what treatment has the greatest efficacy, while one response was missing. These data highlight, as stated in chapter 6, the potential bias that exists within the sample because it was collected from TB clinics. Over three-quarters of participants are firm that the best treatment for TB comes from biomedical practitioners.

Participants were divided, however, regarding whether biomedical treatment works for everyone. Of the 49 who indicated that hospitals or medical doctors have the best treatment, 23 (46.9%) believed that biomedicine works for everyone, and 23 (46.9%) did not know.

Only three participants stated that biomedicine does not work for everyone. Their responses were based upon personal observation, i.e., each had witnessed a relative,
neighbor, or other patients with TB receive biomedical treatment without being cured. To quote an 18 year-old Kampala woman, "Treatment did not help my neighbor. He was admitted to Mulago, given 60 injections, but did not cure. He died. That shows it doesn't work for everyone."

Beliefs in traditional remedies

It interesting that even with this otherwise strong support for biomedicine, some participants also maintain beliefs in non-biomedical treatments. For example, when asked specifically if there are home remedies for TB or if traditional healers can treat TB, the majority of the 89 participants who responded indicated that these are not sources of TB treatment. However, 13 participants (14.6%) reported that there are home remedies. The types of home remedies reported included a healthy diet or eating specific foods (e.g., fish, beans, passion fruit, pineapple, or milk), and traditional medicine or herbs (Table 7-12). When asked about traditional healers specifically, seven (7.9%) of the 89 participants stated that traditional healers could treat TB, while 22 participants (24.7%) reported that they did not know.

<table>
<thead>
<tr>
<th>Types of home remedies* (n=13)</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthy diet/specific foods</td>
<td>9 (69.2)</td>
</tr>
<tr>
<td>Traditional medicines</td>
<td>4 (30.8)</td>
</tr>
<tr>
<td>Prayer</td>
<td>1 (7.7)</td>
</tr>
</tbody>
</table>

*Participants could give more than one answer

These data on participants' treatment beliefs should be interpreted cautiously. It is possible that participants were reluctant to mention herbal medicine or traditional healers because the hospital and clinic staff discourage their use. Although the interviews were not conducted by or in the presence of hospital personnel, participants who
previously had been chastised by the staff may have been reluctant to mention their beliefs. In addition, they may also have had a desire to report the “correct” response. Participants’ descriptions of their treatment-seeking actions, which are examined in the following chapter, however, reveal that participants are willing to discuss non-biomedical treatment seeking. Furthermore, most have experienced a decrease in symptoms since beginning biomedical treatment. Thus, while a few patients may have felt the need to modify their answers, the majority believe in biomedicine’s ability to treat tuberculosis—most likely because their own health has improved through biomedical treatment.

Summary

To summarize participants’ TB health beliefs overall, the majority of participants tend to conceptualize their illness in terms of its primary symptoms. Many participants also view typically advanced symptoms of infection as part of the complex of initial symptoms. This suggests that patients may overlook critical early warning signs of an active infection and delay seeking treatment, although they may be infectious. Participants’ concerns about contagion are mixed, with some participants expressing tremendous fears for those around them, while others feel they are able to limit transmission through their treatment-seeking or specific control actions. These health beliefs and illness conceptualizations are formed from information provided by biomedical practitioners as well as advice from those around the participant.

The results concerning the association between TB and HIV/AIDS are mixed. Although some of the vague or generic symptoms that participants associate with TB (e.g., weakness) are also local signs of HIV, the majority of participants do not associate TB with more specific, locally-defined HIV signals (e.g., sores/blisters). Cell sizes are
small, but Mukono participants are significantly more likely to agree or not know if HIV symptoms may also be symptoms of TB.

While the majority of participants state that patients with either HIV or TB may be more vulnerable to the other disease, with HIV-positive individuals being particularly defenseless, few express that comorbidity is a hopeless situation. There are many strong beliefs that patients should still seek treatment for TB – and that this treatment will be effective.

Finally, regarding TB’s treatment in general, the vast majority of participants believe in the efficacy of biomedicine, but there are a few participants who suggest that home remedies and traditional healers may also help cure or at least reduce symptoms. While these results may hint that TB is locally considered a “biomedical” as opposed to traditional illness, and therefore requires biomedical treatment (see chapter 3), it is also possible that participants are reluctant to reveal their belief in non-biomedical healers or that this clinic-based sample is biased towards those who are committed to biomedical treatment.
Chapter 8: Participants' TB Treatment Seeking

As noted in chapter 3, the treatment seeking literature suggests that treatment seeking is a process of stages that may incorporate both lay and professional, biomedical and traditional healing systems. This chapter examines the results regarding participants' treatment seeking. It first describes patients' use of traditional remedies and then the multiple dimensions of their biomedical treatment seeking. Along with exploring patients' efforts at finding a cure, this chapter evaluates the financial and personal costs of treatment seeking, and patients' satisfaction with both their clinical care and their TB therapy. The limited differences in participants' treatment seeking activities and opinions by district are noted. Finally, this chapter explores patients' suggestions for improving the TB clinics and increasing patient adherence. The data presented in this chapter help to reveal the process of care seeking for Ugandan women, their patterns of resort, and some of the barriers to successful biomedical TB treatment.

Participants' treatment seeking was initially measured using open-ended questions. These questions were followed by probes regarding specific activities. Responses were analyzed together in terms of their overall themes, e.g., participants' use and views of specific types of therapies. In addition, it should be noted that questions measuring similar dimensions of treatment seeking were included on each of the three interviews in order to minimize participants' fatigue. Because the number of participants interviewed in the follow-up questionnaires decreases, the number of participants reported in these analyses changes by item.
Participants’ Use of Traditional Medicine

Traditional herbs

As reviewed in chapter 3, traditional medicine in Uganda can include both the lay use of medicinal herbs and/or the consultation of a professional traditional healer. Although traditional healers are somewhat controversial players in Uganda’s health care system, these data suggest that the use of local herbs as home remedies is common. Thirty-one (47.7%) of the 65 participants interviewed with the second instrument reported using some type of herb or plants to cure their cough. Eight (12.3%) participants reported that such a treatment was recommended but they did not try it. There were no significant differences in the number of participants reporting use of medicinal herbs by district.

Of the 31 participants who tried medicinal herbs, 28 reported that social network member(s) recommended trying the herb or plant treatment. Fifteen participants (53.6%) indicated that parents, sisters, in-laws, and grandparents advised the treatment, while 11 (39.3%) received the advice from friends or neighbors. There were no differences in the number of participants reporting relatives vs. friends between the districts.

The local plants that are believed to relieve and/or cure a cough include mango leaves, bottlebrush leaves, and eucalyptus. Often the leaves or bark of a medicinal plant are boiled with water to produce a tea for the patient to drink. Patients and/or their family members may harvest their own herbs/plants or purchase plants or brews in trading centers or in the Kampala taxi park. Thus, herbal remedies, which may be free or relatively low cost, are one of the first steps both Kampala and Mukono patients take to
cure their cough. This therapy is often begun at the suggestion of social network members.

**Traditional healers**

Although many participants indicated that they have used traditional herbs for their cough, very few reported that they consulted a traditional healer. Indeed, only four participants (6.2%), all from Kampala, visited a traditional healer for their cough. One participant (1.5%) reported that she planned to start seeing a healer because her cough was not diminishing. Thirty-one (47.7%) of the 65 participants who were asked about traditional healers noted, however, that they have heard that traditional healers can treat TB or that others have used a traditional healer; 14 participants (21.5%) have not heard or did not know if traditional healers can treat TB. Thus, while few participants reported using a traditional healer, many acknowledged that others will use traditional healers.

The 61 participants who had not used a traditional healer for their TB offered a number of explanations for their decision. For example, fifteen participants (24.6%) indicated that they did not believe in “witchcraft.” Thirteen (21.3%) noted that traditional healers cannot heal a cough. Seven participants (11.5%) reported that they are now “saved” or “Christian” and therefore do not use traditional healers. Other miscellaneous answers included that doctors have the best cough treatments or that traditional healers deceive in general.

In contrast, of the four participants who used a traditional healer, three (75%) indicated that it was because their cough would not cure. Participants who visited a healer indicated that the healer tended to prescribe traditional medicine, but no participants reported that they were currently using this therapy. Either the treatment did
not help, or as one participant noted, the treatment was too expensive. The four participants who had consulted a healer reported that the cost ranged from 2,000 to 10,000 to over 200,000 Ush. Each of these participants indicated that the expense of consulting a traditional healer was greater than the cost of (government-run) biomedical treatment.

Thus, while it is clear that the majority of participants did not report using a traditional healer for their TB, many heard of people attending traditional healers for coughs. In addition, 31 of the 65 participants (47.7%) responded that they would take other illnesses to traditional healers and 18 (27.7%) reported that their family members have attended traditional healers. The diseases or conditions that would be taken to a traditional healer include being bewitched or charmed ("amologogo"/ "ebilogolo"), after "jumping over" a harmful substance ("etalo"), headache, or illnesses that won’t cure. These responses suggest that traditional healers are an important part of the Baganda health care system. Although not necessarily consulted by participants for coughs, participants and/or others may consult healers for unexplained or persistent illnesses (e.g., headache) as well as for many locally defined conditions.

Non-TB clinic biomedical treatment seeking

Along with using traditional herbs, many of the 65 participants reported trying biomedical treatments before attending the TB clinic. More specifically, 34 participants (52.3%) reported trying at least one biomedical treatment before attending the TB clinic. Twenty-seven participants (41.5%) consulted or utilized at least two different treatment sources. The type of biomedical treatments ranged from over the counter chest rubs to
treatment for other illnesses, like malaria. Patients often sought these treatments on their own or based on the recommendation of friends and family.

To give a few examples of these non-TB clinic treatments, 18 participants (27.7%) tried over-the-counter remedies from pharmacies or other salespersons, including Vick's Vapor Rub and the antibiotic ampicillin; 56 participants (86.2%) consulted at least one other clinic or hospital in the area. It should be noted, however, that these data likely underestimate participants' biomedical treatment seeking, as many participants may have visited the same clinic more than once as their symptoms persisted. Participants also may not have distinguished whether they visited several clinics in their area, instead responding that they visited "clinics" for assistance. The exact number of clinics cannot be determined.

The majority of patients who received clinical care outside of the TB clinic reported that treatment did not relieve their symptoms, i.e., of the 56 who utilized outside biomedical practitioners, 38 (67.9%) indicated that the non-TB clinic treatments did not help. Thirteen (23.2%) reported that the treatments helped temporarily or relieved specific symptoms (i.e., reduced the cough or fever). Only five (8.9%) replied that that the non-TB clinic biomedical care was helpful.

Given that participants generally reported that treatment outside the TB clinic was not successful, it is not surprising that only two of the 56 (3.6%) reported that they were still utilizing these treatments. When asked specifically why they were not taking the treatments, however, the most frequent response was that they were now on treatment from the hospital. Others indicated that they stopped the treatment because it did not work or because they believe only TB clinic drugs will cure TB (Table 8-1).
### Table 8-1 Reasons for stopping non-TB clinic treatment (N=54)*

<table>
<thead>
<tr>
<th>Reason</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receiving treatment from the hospital</td>
<td>30 (55.6)</td>
</tr>
<tr>
<td>Treatments did not work/only hospital treatment will work</td>
<td>16 (29.6)</td>
</tr>
<tr>
<td>Drugs from other location finished</td>
<td>2 (3.7)</td>
</tr>
<tr>
<td>Other</td>
<td>6 (11.1)</td>
</tr>
<tr>
<td>Not applicable**</td>
<td>6</td>
</tr>
<tr>
<td>Missing</td>
<td>5</td>
</tr>
</tbody>
</table>

*participants were permitted to report more than one response

**This includes the four participants who did not seek non-TB clinical care and the two who have not stopped this care

### Total pre-TB clinic treatment-seeking/patterns of resort

When the data on the participants’ treatment-seeking activities prior to visiting the TB clinic are combined, the results are striking. Of the 65 participants interviewed, 18 (27.7%) reported trying at least one treatment, either traditional or biomedical, before attending the TB clinic, while 44 (67.7%) reported trying two or more treatments. Seventeen (26.2%) of these participants reported using three to five different treatments or clinics. Only three participants (4.6%) indicated that they did not seek any other treatment besides the TB clinic. There were no significant differences in the non-TB clinic treatment-seeking behaviors of participants by district. As noted above, these estimates are conservative, as they do not take into account whether participants may have visited the same clinic repeatedly or if participants did not distinguish attending different clinics or healers in their responses.

Thus, a pattern emerges which suggests that once a cough develops, female TB patients may go to great lengths to cure their illness using local remedies, including traditional herbs, commercial non-prescription cough and flu remedies (e.g., Vicks vapor rub) or antibiotics, and by consulting local pharmacists, clinics, or hospitals. Participants
seek treatment from multiple sources before they are willing to consider that the symptoms may be TB and/or before they are referred to a TB clinic. This is despite the fact that these non-TB clinic treatments rarely bring long-term relief. Because treatment seeking can be quite costly, as will be discussed below, participants often may waste limited resources on these activities.

Patients generally indicated that they discontinue their non-TB clinic treatments once they are on treatment at the TB clinic. It is interesting that less than a third of patients verbalized that they stopped non-TB clinic treatments because they do not cure TB.

**TB clinic treatment seeking**

Participants generally began TB clinic treatment seeking after trying other treatment options without success. Participants experienced their symptoms 5.5 months on average before coming to the TB clinic (SD=7.3 months). Whereas 11 participants (13.6%) reported seeking treatment from the TB clinic within two to three weeks of experiencing symptoms, 70 participants (78.7%) waited from one month to 41 months (eight responses were missing). There were no significant differences by district in the number of months participants had their symptoms before attending the TB clinic. There were also no significant differences by demographic variables, including whether the participant had children or was living with other adults.

Participants’ motivations for attending the TB clinic were fairly straightforward. When asked why they came to the TB clinic, the most common explanation from the 89 participants was that they wanted to get treatment (37.1%; N=33). Thirty-five percent similarly indicated that they originally came to the clinic because they were in need of a
diagnosis or cure (Table 8-2). A numbers of participants also noted specifically that treatment from other clinics or hospitals had not worked, their symptoms were beginning to be unbearable, or that the TB clinic’s medications are free.

<table>
<thead>
<tr>
<th>Table 8-2 Why participants came to the TB hospital/clinic*</th>
</tr>
</thead>
<tbody>
<tr>
<td>(N=89)</td>
</tr>
<tr>
<td>Get treatment</td>
</tr>
<tr>
<td>Heal/Cure/diagnosis</td>
</tr>
<tr>
<td>Referred by other hospital, clinic, doctor, nurse</td>
</tr>
<tr>
<td>Other clinics or hospitals failed</td>
</tr>
<tr>
<td>Symptoms—in pain, coughing too much (no longer bearable)</td>
</tr>
<tr>
<td>Free/others expensive</td>
</tr>
<tr>
<td>Clinic is known for treating TB</td>
</tr>
<tr>
<td>Last resort — all others failed</td>
</tr>
<tr>
<td>Other (e.g., home treatment did not work; clinic is near home; advised by friends; other medicine finished)</td>
</tr>
</tbody>
</table>

*participants offered more than one response

These data suggest that patients are motivated to attend the TB clinic by an extreme need for treatment and/or because the TB clinic is a last resort. Many seek treatment at a TB clinic only after their symptoms have been occurring for a number of weeks, if not months, the symptoms have become quite painful or debilitating, and other treatments have not worked, often at considerable expense. The patient must also be willing to face the social implications of a diagnosis of TB. Again, it is not the case that the majority of patients necessarily believe that the TB clinic is the only place that can provide treatment, rather, no other therapy has yet to result in a permanent cure.

TB Medication Satisfaction

Once beginning TB clinic treatment, participants expressed high satisfaction with both the effectiveness of the drugs and their handling at the TB clinics. Of the 57 patients who had attended the clinic for more than two weeks at screening and therefore had had
an opportunity for the medication to take effect, 50 (87.7%) indicated that they liked how the drugs were working, i.e., there had been improvement in their condition. Only three (5.3%) participants reported that there had been no change in their symptoms, despite taking the drugs for one month, three months, and 23 months, respectively. Four participants (7.0%) reported that there had been minor or sporadic improvement. Thus, the majority of participants who had been attending the clinic for more than two weeks overwhelmingly indicated that they felt the drugs had a positive effect on their illness.

Many participants also expressed that their improvement happened relatively quickly, with 36 (66.7%) of the 62 who had experienced a change in their symptoms indicating that it occurred within one month of beginning treatment. Nine of the 36 further reported that the improvement was immediate. The remaining participants indicated that it took longer before they felt a change for the better, with fourteen of the 62 participants (22.6%) feeling better within three months and the remaining three (4.8%) improving within six months. Thus, for the participants who were willing to bear the inconvenience of taking the drugs despite the side effects (see below), a subjective improvement in health was experienced within a few weeks of the start of treatment.

**TB Clinic Satisfaction**

Along with noticing improvements from the medications, participants generally were very satisfied with their treatment by the doctors, nurses and the clinic (see Appendix I for patients’ comments). In reference to clinic doctors, participants were particularly positive. For example, 62.5% stated that the doctors were good and "handled" participants well. The only negative response regarding doctors was from one participant who reported that the doctor “shouts and does not listen.”
Participants were slightly less positive towards the nurses (see Appendix I). Although 65.0% reported that the nurses handle patients well, seven suggested that the nurses could be rude and/or shout at patients.

The majority of comments regarding the clinic overall were also complimentary (Appendix I). Along with indicating the clinics handled patients well in general, a number of participants specified that the clinics were good because they have medication or because the medication and services are free. The negative comments about the clinics centered on the lack of resources at the clinics, e.g., the absence of inpatient and/or outpatient furniture, the long wait for service, and the clinic’s heavy case load. To quote the comments of a 26-year old participant from Kampala, “[the clinic’s] not bad, but the problem is too many patients at the pharmacy. They [have to] stay for so long, yet sometimes they are very weak.”

Simultaneous resort practices in connection with biomedical TB treatment

As described above, once participants began treatment at the TB clinic, they tended to stop their previous treatments. When asked specifically if they had begun other treatment seeking while under care of the TB clinic, 57 (87.7%) of the 65 participants reported that they were not employing other therapies. In part, the lack of simultaneous resort practices is due to financial constraints. Indeed, the majority of participants reported that they cannot afford their preferred treatment therapies. Fifty-five participants (84.6%) felt that they did not have enough money to obtain the treatments they would like. Of the 55, 34 (61.8%) would change their diet, e.g., adding fruit, greens, milk, beans, or meat. To quote a 38-year old Kampala woman, “the doctor said to drink a lot of water, eat porridge and a lot of greens… I would have liked to eat like they told me
to drink milk—but I have no money. If I get money to buy the food, then I don’t have money to buy the sauce.”¹ Seven of the 55 patients (12.7%) would buy other needed prescriptions or purchase a full dose instead of one-half a dose. Two patients would return to the hospital more frequently or as needed. The remaining eight patients offered miscellaneous other treatment actions that are currently prevented because of lack of funds.

To verify that participants did not begin simultaneous resort practices later in their therapy, an additional question on concurrent treatments was included on the final questionnaire. Once again, 35 (87.5%) of the 40 participants completing the third instrument indicated that they were not engaging in other treatments for their TB. This number is actually much higher, as two participants who reported supplemental activities were referring to unspecified tablets that they received from the TB clinic. Two participants reported that they purchased over-the-counter, commercial flu/cough medications and antibiotics. The remaining participant used a traditional herbal medicine of guava leaves, mango leaves, and honey, which she received from her sister-in-law. As for participants’ pre-TB clinic treatment-seeking, there is evidence that patients are not opposed to alternative or supplemental treatments, although many are not able to afford multiple therapies at one time, even in the form of a healthier diet.

The types of supplemental therapies that participants were engaging in were either free or involved more general lifestyle changes. For example, one participant indicated

¹ Sauce refers to a meat or bean-based stew which is commonly used over a starch (frequently steamed, mashed plantains (matoke), cornmeal mash (posho) or cassava). Although there may be very little beans or meat in the sauce especially in poorer households, it can be an important source of protein and other nutrients. Participants who cannot afford sauce subsist primarily on carbohydrates with very little protein or green vegetables.
that she prays to God to cure her as she takes her TB medication. Another participant reported that she has been told to stop consuming alcohol in order to get cured. Six participants indicated that in addition to their TB drugs, they are trying to follow the clinic’s recommendation to drink juices, milk, and eat well. For example, to quote a 26-year old Mukono woman, “No, I don’t do anything, but I try to buy milk because the doctor said to drink milk.”

Patient adherence

Although patient adherence was not a central question of this research, the 65 patients surveyed reported very high rates of compliance with their biomedical treatment regimens. For example, when asked if they were able to take all the drugs they had been given, 62 (95.4%) indicated that they were; two indicated that they were not, and one answer was missing. When the subgroup of 40 participants were asked on the third interview whether they were able to take all their medications the past month, 35 (87.5%) indicated that they were, and five reported that they were not. These data should be interpreted cautiously, however, as patients were likely to have inflated their actual adherence because of poor recall or concerns about providing the “correct” answer.

Because of the potential for reporting bias, it is useful to look at participants’ reasons for taking all their medications. Forty-nine (79.0%) of the 62 participants who reported taking their medications insisted that they took all their drugs in order to cure, improve, or heal faster. The remaining participants reported that they took their drugs because they were told they must finish the dose or that if they miss they have to start the whole course again. To quote a 25-year old Kampala woman’s discussion, “at first I had problems, but now I can [take all the pills]. I would vomit when I first started, but the
sickness just increased. They started pounding [the pills] for me, but now I am used [to
them].”

These data suggest that participants are receiving instructions from hospital staff
about the importance of taking all their medications in order to be cured successfully. At
the same time, there was no independent confirmation of participants’ compliance. Thus,
these data should be interpreted as indicating that many patients understand that they
should take their medications as directed and many have a strong desire to be cured.

A cautious interpretation of this high compliance is particularly warranted
because these data also reveal that a number of factors influence both patients’ ability to
take their drugs daily as well as their long-term adherence to treatment. This information
is gleaned from the five participants who acknowledge that they did not always take their
TB medication, as well as from difficulties reported by other participants. Because
participants mentioned problematic conditions that the literature indicates are widespread,
it is likely that these factors impact more patients than the data initially suggest.

The first problem was reported by a 26-year old Kampala patient. She indicated
that she skips tablets when she has nothing to eat or drink with the tablet. To quote:

When I have no food, I feel like not taking the drugs because they make me feel
weak... When I use water, I feel like vomiting or sometimes vomit...[so] when I
have nothing to drink during and after swallowing, I miss [taking the drugs]
because the drugs make me feel dizzy”

Nine (22.5%) of the 40 participants mentioned that pills “get stuck” when taken without
juice, although they don’t specify that these reactions deter their pill-taking. Four
(10.0%) reported that they either cough while swallowing, or that the taste of the
medication causes them to vomit. The repeated mentioning of these unpleasant side
effects, however, raises the possibility that some patients may skip their pills when there
is nothing to consume with their medication. The potential importance of this problem should not be overlooked. The majority of these participants and the government clinic attendees have very limited economic resources; as described above, many indicate that they cannot afford the clinic’s recommended foods or juices. It is possible that numerous women may have days in which there is little to consume with their drugs – further research is needed to determine the extent to which lack of food may constrain therapy adherence.

The second factor influencing adherence was revealed by a participant who forgot to bring her medication when she was visiting family members in the village. It is not clear from the participant’s response if this was an intentional or accidental oversight. While the data offer no insight into how frequently participants may travel and risk skipping their medication, the literature suggests that travel to and from Kampala to a rural homeland is not uncommon and that these visits may last several days or weeks. Although uninterrupted therapy is central to a successful cure, many patients lack a discrete method for carrying their medication when traveling and/or a mechanism for obtaining replacement prescriptions for those times when a prescription is forgotten.

A third issue impacting adherence is whether the clinic has the TB medications for patients and whether they are given the supply needed until the following appointment. Two participants reported that they finished their supply from the clinic early and one participant stated that the clinic did not have the drugs available. This last participant’s response is echoed elsewhere in the interviews of seven other participants (10.8%) who reported that the clinic at times did not have their TB medications. A fourth problem with the TB medications is that, as one participant reported, her tablets “spoiled”
after being exposed to moisture. Clinic staff warn patients to keep their tablets dry; however, tablets are frequently distributed in paper envelopes that offer little protection from moisture. This is problematic given Uganda’s tropical climate and at times, frequent rain. Thus, despite patients’ efforts to obtain TB medication, other factors, including inadequate clinic supplies and weather conditions, can impact their success.

A final factor that may influence patient adherence is the extent of drug side effects. Thirty-six participants (55.4%) reported that they had experienced side effects from their TB medication. The number of side effects that each participant described varied, but on average 1.7 symptoms were reported per person affected. The most common side effect was dizziness, followed by a feeling of weakness, and a change in appetite (Table 8-3). Fifteen participants also listed other miscellaneous symptoms, including stomach pain, skin problems, and urine color change.

Table 8-3 Problems encountered with taking TB medication (N=36)*

<table>
<thead>
<tr>
<th></th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dizziness</td>
<td>14 (38.9)</td>
</tr>
<tr>
<td>Weakness</td>
<td>10 (27.8)</td>
</tr>
<tr>
<td>Change in appetite</td>
<td>8 (22.2)</td>
</tr>
<tr>
<td>(gain or loss)</td>
<td></td>
</tr>
<tr>
<td>Joint pain or body aches</td>
<td>6 (16.7)</td>
</tr>
<tr>
<td>Skin itching</td>
<td>6 (16.7)</td>
</tr>
<tr>
<td>Other side effects</td>
<td>15 (41.7)</td>
</tr>
</tbody>
</table>

*Participants could report more than one symptom

While these side effects are relatively common and largely innocuous from a biomedical perspective (e.g., Winstanley, 1994), many participants found the medications and their side effects very unpleasant, particularly during the first weeks of treatment. To quote a 21-year old Kampala participant, “When I had just started using the drugs, they weakened me a lot... The smell of the medicine made me feel like throwing up.”
Despite these unpleasant symptoms, no patients indicated that drug side effects had a long-term impact on their adherence. Of the 36 participants who experienced side effects, 33 (91.7%) reported that they continued to take their TB medication. Twenty-seven of these participants consulted the clinic about their new symptoms. The doctors changed the drugs of seven participants. Ten were advised to eat or drink more when consuming the tablets, six were told the side effects were expected, and four were informed that the side effects would cease. The remaining participant was told to stop treatment because her sputum was clear, but she restarted treatment after her TB symptoms reappeared (two responses were missing). It should be noted, however, that this sample is likely to be biased towards participants who were willing to accept the side effects and were not overwhelmed by them. Participants who found the medication side effects unacceptable would not have been at the clinic for inclusion in the sample.

Thus, although these data indicate there is a high adherence to biomedical TB treatment, they also reveal that a number of factors may influence whether a patient takes her medication on any given day, e.g., the availability of food and drink and whether her pill supply is present and viable. While drug side effects did not influence participants’ long term commitment to treatment-seeking, it is possible that this sample is biased towards patients who are able to tolerate the physical, psychological, and social repercussions of biomedical TB treatment, in addition to the financial costs discussed next.

The financial and time costs of TB treatment-seeking

A final variable that may impact adherence is the cost of treatment seeking. Although TB medications frequently are free, there are many costs associated with
treatment seeking, including fees for diagnostic services, transportation, and personnel/time costs. The sections below examine the costs associated with traditional and non-TB clinic biomedical treatment, followed by an exploration of the multiple economic costs of TB clinic treatment seeking. An important issue is whether these costs serve as a barrier to consistent biomedical treatment seeking and whether using funds for treatment seeking reduces a participant’s or her social network’s financial resources.

Costs of traditional treatments

As described above, traditional treatment may involve the consumption of medicinal plant-based teas, or the consultation of a traditional healer. Herbs often are harvested by participants or their family members from local plants. They also may be purchased from local healers for a nominal price, typically less than 1,000 Ush., depending on the product or plant. Exact data on the amount participants spent on medicinal plants were not collected.

Traditional healers, again as noted above, tend to be relatively expensive. The participants who reported visiting a traditional healer indicated that these professionals are more expensive than biomedical clinics. Participants reported the cost ranged from 2,000 to 10,000 to over 200,000 Ush., depending on the healer and the diagnosis. To quote a 21-year old Kampala participant’s description of her visit to a healer,

He gave me medicine which was mixed with alcohol.\(^2\) It did not help at all. After giving me the medicine, he asked for so many things which I could not afford – a sheep and 20,000 Ush. I had little money, so I paid 2,000 Ush. and was given the medicine only. I decided to go to my sister – if it’s my time for death, then let me die. I was firm. I went to my sister and got money to go to hospital.

\(^2\) The alcohol was “tonto,” which is then distilled to make waragi, a popular banana-based alcohol.
Thus, traditional cough therapies range in their expense. While some traditional plants may be readily available at no charge from a friend or relative's local garden, traditional healers may charge considerable sums for their services, which few participants may be able to afford.

Costs of non-TB biomedical treatment

Although participants tend to report that traditional healers are more expensive than biomedicine, non-TB biomedical treatment seeking may also be quite costly. Of the 56 participants who engaged in non-TB biomedical care, 75% spent a minimum of 10,000 Ush. on these treatments (Table 8-4). The number of participants spending over 10,000 Ush. may actually be higher, as some participants reported the amount spent per visit or per week rather than the total amount spent. For example, a 28-year old Mukono participant reported that she paid 8,000 Ush per week for non-TB clinic treatment. While she did not indicate the number of weeks that she was on this treatment, it is likely to have been more than one week. A 32-year old Kampala woman similarly paid 8,000-10,000 Ush. per week to a clinic for an unspecified number of weeks. Only two participants from Kampala who sought non-TB clinic biomedical treatment reported that there was no charge for this treatment.
Table 8-4 Minimum amount participants spent on non-TB clinic biomedical treatments (N=56)

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 – treatment was free</td>
<td>2 (5.7)</td>
<td>0</td>
<td>2 (3.9)</td>
</tr>
<tr>
<td>2,000-10,000</td>
<td>7 (20.0)</td>
<td>4 (25.0)</td>
<td>11 (21.6)</td>
</tr>
<tr>
<td>10,100-30,000</td>
<td>12 (34.3)</td>
<td>9 (56.3)</td>
<td>21 (41.2)</td>
</tr>
<tr>
<td>30,100-50,000</td>
<td>5 (14.3)</td>
<td>3 (18.8)</td>
<td>8 (15.7)</td>
</tr>
<tr>
<td>&gt;50,000</td>
<td>9 (25.7)</td>
<td>0</td>
<td>9 (17.6)</td>
</tr>
<tr>
<td>Total</td>
<td>35 (100)</td>
<td>16 (100.1)</td>
<td>51 (100)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Not applicable*</td>
<td>5</td>
<td>4</td>
<td>9</td>
</tr>
</tbody>
</table>

*These participants did not engage in non-TB clinic biomedical treatment

These 56 Mukono and Kampala participants obtained money for their non-TB biomedical treatment from similar sources (Table 8-5). Participants reported that they alone, their husbands/boyfriends (including individuals described as the "father of participant’s children"), and/or other family members subsidized their treatment seeking. However, more Mukono participants than Kampala participants self-funded. It is also not unexpected and in keeping with the social network data described in the following chapter that Kampala participants indicated financial support from sources that are not found in Mukono, i.e., borrowing from friends and/or the workplace.

Table 8-5 Funding sources for non-TB clinic biomedical treatment (N=56)*

<table>
<thead>
<tr>
<th>Funding Source</th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant funded herself/from her savings or salary</td>
<td>11 (30.6)</td>
<td>7 (35.0)</td>
</tr>
<tr>
<td>Husband/boyfriend/father of the children</td>
<td>13 (36.1)</td>
<td>8 (40.0)</td>
</tr>
<tr>
<td>Family or other relatives</td>
<td>11 (30.6)</td>
<td>6 (30.0)</td>
</tr>
<tr>
<td>Friends (e.g., church)/Other (e.g., work, paying back through salary deductions)</td>
<td>3 (8.3)</td>
<td>0</td>
</tr>
</tbody>
</table>

*Participants could report more than one funding source

Thus, both Kampala and Mukono participants sought non-TB clinic biomedical treatments before attending the TB clinic. These therapies were relatively costly, and...
over two-thirds of participants had to rely on social network members to cover the
expense.

Costs of biomedical treatment

While TB medication is available at no charge from Uganda’s National TB and
Leprosy Control Programme clinics, TB patients may incur a number of expenses as they
seek biomedical TB treatment. To determine the financial burden facing patients seeking
treatment from a TB clinic, both direct financial expenditures (e.g., travel costs or
treatment-related charges for supplemental medications, x-rays, or under the table “tips”)
and indirect costs (i.e., loss of income due to travel time and/or clinic wait times) must be
considered.

Travel Expenditures

One of the primary costs associated with clinic attendance is for transportation to
and from the clinic. Out of 89 participants, 76 (85.4%) travel to the clinic via a “matatu”
taxi (the local bus system). Only ten participants (11.2%) have no travel costs because
they walk to the clinic – six of these participants are from Mukono district and four are
from Kampala. Three participants both walk and use taxis. One participant noted that she
is driven by a relative who owns an automobile, but on the days that she takes a taxi, she
pays 800 Ush (.80 cents).

For participants using taxis, the cost of coming to the clinic ranged from 400 Ush
(.40 cents) to 5,800 Ush ($5.80) (see Table 8-6). Slightly more than half of the
participants paid between 1,000 and 2,500 Ush for each trip. This sum is not
insignificant for women with limited earnings – and finding actual cash can be a
challenge. It should also be noted that some participants pay more than is reported because if they did not indicate whether the sum was one-way or round-trip, it was included as the round-trip price.

Not unexpectedly, the mean cost of transportation for participants in Mukono district was higher than the average cost for Kampala participants. In Kampala, the mean cost of transportation was 1,367 Ush. (SD=817). The average cost in Mukono district was 2,063 Ush. (SD=1,509). This difference approaches statistical significance (p=.068). The fact that Mukono women tend to have higher transportation costs is significant from a practical stance because they report regular incomes less frequently and they have smaller networks on which they can rely for money. The difference in cost is likely to be due to the fact that taxi service often costs more in rural areas and the Mukono women on average are traveling slightly further distances.

| Table 8-6 Round-trip cost of taxi (bus) to TB clinic (N=89) |
|---------------------------------|-------------------|-------------------|
| **Uganda shillings** | **Kampala N (%)** | **Mukono N (%)** |
| <=1,000                   | 25 (41.7)         | 9 (47.4)          |
| 1100-2500                 | 29 (48.3)         | 5 (26.3)          |
| 2600-4000                 | 5 (8.3)           | 3 (15.8)          |
| >4000                     | 1 (1.7)           | 2 (10.5)          |
| **Total**                 | 60 (100)          | 19 (100)          |
| **Not applicable (walk)** | 4                 | 6                 |

The primary source of travel funds for 64.9% of Kampala and Mukono participants is either their partner or other relatives. Only 27.0% of participants pay their own travel expenses (Table 8-7). Thus, as with non-TB biomedical treatment seeking expenses, social networks play an important supportive role by providing transportation funds.
Table 8-7 Sources of travel money (N=89)

<table>
<thead>
<tr>
<th>Source</th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Combined N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant's own money</td>
<td>17 (30.4)</td>
<td>3 (16.7)</td>
<td>20 (27.0)</td>
</tr>
<tr>
<td>Husband or boyfriend</td>
<td>16 (28.6)</td>
<td>5 (27.8)</td>
<td>21 (28.4)</td>
</tr>
<tr>
<td>Other Relatives</td>
<td>19 (33.9)</td>
<td>8 (44.4)</td>
<td>27 (36.5)</td>
</tr>
<tr>
<td>Friends from school, church, work, or</td>
<td>4 (7.1)</td>
<td>2 (11.1)</td>
<td>6 (8.1)</td>
</tr>
<tr>
<td>unspecified</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>56 (100)</td>
<td>18 (100)</td>
<td>74 (100)</td>
</tr>
<tr>
<td>Not applicable (participants walk)</td>
<td>4</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Missing</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

TB drug costs

A second cost that patients may incur is the cost of medications. As discussed in chapter 3, the NTLP clinics have a mandate to provide TB drugs at no charge to patients. However, if the clinic runs out of drugs or if a patient requires a drug that is not standard TB therapy, the patient may have to purchase their drugs from a pharmacy. It is only in the last few years that the NTLP clinics, especially the Mulago clinic, have established a steady drug supply to accommodate the hundreds of patients that arrive on clinic days. Although the Mukono clinics all reported having enough drugs for patients, consistent drug supplies may still be problematic for more remote, rural clinics, especially in northern Uganda or in areas where there is civil conflict.

Patients' responses regarding how frequently they purchase their drugs largely confirmed the reports of the medical officers at the TB clinics. Thirty-eight (88.4%) of 43 Kampala participants and 17 (77.3%) of 22 Mukono participants indicated that the clinic had the drugs each time they attended. Only four Kampala participants (6.2%) and three Mukono participants indicated that the clinic did not have the drugs on at least one occasion. Three participants (4.7%) felt they did not know as they had started treatment.
too recently. Thus, for the majority of participants, TB medications are available for free from the TB clinic.

However, despite the general availability of free drugs, 12 of the 65 participants (18.5%) indicated that they have purchased the drugs on at least one occasion; three of the participants were from Mukono and nine were from Kampala. The price of drugs ranged from 1,500 Ush ($1.50) to 15,000 ($15.00). There was no significant difference in the number of participants purchasing drugs or the amount spent by district.

In describing why they had purchased drugs, four participants reported that they bought their TB medications when the hospital did not have the drugs or had prescribed drugs that were not available. Three purchased drugs when they were feeling ill and had exhausted their drug supply, while two other participants purchased drugs when their supply had finished before their day to return to the clinic. Finally, three participants indicated that they had been referred by the Mulago TB clinic to a TB outpatient clinic in Kisenyi, a Kampala neighborhood. To obtain drugs at the Kisenyi clinic, the participants had to pay 2,000 Ush. per month ($2.00). Thus, although the majority of patients are able to obtain their TB drugs at no charge, there are occasions when patients must purchase medication. While the price of medication is relatively low, ranging from $1.50 to $15.00, women with limited cash incomes may not be able to cover the expense. Indeed, participants indicated that they will delay or fail to purchase medications if they are unable to raise the necessary funds.

Participants were divided in their source of money for TB medications. Four participants usually paid for the TB medication themselves. Three participants obtained money from their partner, while three others were helped by their brother(s) and/or
sister(s). Two additional participants relied on both their own funds and their brother or sister for TB drugs. Thus, similar to transportation costs, participants who are unable to afford the cost of TB medications will primarily turn to their immediate family, i.e., partners or siblings, for assistance.

"Tips" to health care providers

An additional cost that the literature suggests may be associated with treatment seeking is the need for "tips" or discrete financial gifts to health care providers. Only five (7.7%) of the 65 participants surveyed, however, reported that they had ever given cash gifts or tips to nurses or doctors in the TB clinic. One participant was from Mukono district; the remaining four were from Kampala. The gift amounts ranged from 2,000 to 16,000 Ush.

To determine how widespread the practice of tipping is, participants were also asked if they had heard of others giving tips. Six participants indicated that they had heard of other patients giving tips to staff. The amounts reported ranged from 1,000-2000 Ush— with one participant not knowing how much is given and one response missing.

The reasons for tipping were similar for both participants who tip and those who had heard of others tipping. In general, participants give tips because they feel they will obtain better or quicker service or that it will ensure that they see the doctor. Tips are usually given either on the first visit or once in a while, as needed; one participant noted that she tipped every visit.

Hospital authorities officially condemn the practice of tipping. In Kawolo hospital, for example, there are signs in some waiting areas addressing the issue of
tipping and informing patients of the official fees. As a result of these efforts to control tipping, participants may be reluctant to reveal its occurrence. Thus, although the number of participants reporting tips is not significant, these results suggest that the practice continues in health care facilities. It likely occurs at a higher rate than reported, and it may be a potential treatment seeking cost to patients and their families who see it as a means for obtaining higher quality or expedited care.

*Indirect costs – travel time/wait time*

Along with the direct financial demands associated with treatment seeking, treatment seeking may have an indirect economic cost through the amount of time needed to travel to and from the clinic and the wait time at the clinic. Such travel and waiting time can result in lost wages and/or lost economic opportunity.

The time it generally takes the 89 participants who completed the second interview to travel from their home to the TB clinic is reported in Table 8-8. Thirty-seven participants (41.6%) spend up to 30 minutes traveling to the clinic, while 42 (47.2%) spend between 30 minutes to an hour traveling to the clinic (one way). On average, it takes Mukono residents slightly more time to travel to the clinic than Kampala participants, although this difference is not statistically significant. The mean travel time for Kampala participants is 47.97 minutes, with a standard deviation of 34.88. The mean travel time for Mukono participants is 48.20 minutes, with a standard deviation of 41.17. Because some participants walk to the clinic while others ride matatus, this variable is not an indication of the distance that participants live from the clinic; rather it is a measure of the time required to travel to the clinic. Determining the total travel time for participants would require doubling the times listed in Table 8-8.
To further determine the personal time cost expended in treatment seeking, patients indicated how much time they usually wait to be served at the clinic. Overall, the average wait time was 90.70 minutes, with a standard deviation of 77.61. Over 70% of participants report waiting over 30 minutes on their clinic visits - which often just involves picking up a prescription with no physical check-up (see Table 8-9). This is in addition to the time spent traveling to and from the clinic. It should also be noted that waiting time does not tend to vary according to how long patients attend the clinic. A Pearsons Correlation test revealed that there was no relationship between how long participants had been attending the clinic and the amount of time they reported waiting.

Waiting times varied by district. The mean wait time in Kampala was significantly longer than the mean wait time in Mukono district (p=.001). The mean wait time for Kampala participants was 110.71 minutes, with a standard deviation of 83.62 minutes. The mean wait time that Mukono participants reported was 52.50 minutes, with a standard deviation of 45.69 minutes. Thus, over half of the Mukono participants report waiting 30 minutes or less, compared to only 16.3% of Kampala participants. It is likely that the extended wait time in Kampala is due to the higher volume of cases at the clinic.
Table 8-9 Wait time at the TB clinic (N=65)

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;=30 minutes</td>
<td>7 (16.3)</td>
<td>12 (54.5)</td>
<td>19 (29.2)</td>
</tr>
<tr>
<td>31-60 minutes</td>
<td>16 (37.2)</td>
<td>7 (31.8)</td>
<td>23 (35.4)</td>
</tr>
<tr>
<td>61-120 minutes</td>
<td>8 (18.6)</td>
<td>1 (4.5)</td>
<td>9 (13.8)</td>
</tr>
<tr>
<td>&gt;120 minutes</td>
<td>11 (25.6)</td>
<td>2 (9.1)</td>
<td>13 (20.0)</td>
</tr>
<tr>
<td>Depends on when you go</td>
<td>1 (2.3)</td>
<td>0</td>
<td>1 (1.5)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>43 (100)</strong></td>
<td><strong>22 (100)</strong></td>
<td><strong>65 (100)</strong></td>
</tr>
</tbody>
</table>

It should be noted that these responses are the times that participants report as the general wait time. For participants who indicated that the wait time may range, this is the minimum wait time they reported. The data on maximum wait time magnifies the difference between Kampala and Mukono participants. One Mukono participant reported a maximum wait time of 30 minutes; four reported a maximum of 60 minutes; and one indicated the wait time could extend to 120 minutes. The average was 65.0 minutes, with a standard deviation of 29.5. For the Kampala sample, one participant reported a maximum wait time of 60 minutes; four reported 120 minutes, and 13 stated that at times they may have to wait over 120 minutes. The longest wait time reported by a Kampala participant was 420 minutes. The average maximum wait time of Kampala participants was 196.67 minutes, with a standard deviation of 84.37.

Combining the travel time and wait time involved with a clinic visit reveals that each clinic visit costs patients a **minimum** of 1.5 hours. For over 20% of participants, a clinic visit took three to four hours. These personal time costs, as well as the direct financial cost of travel, are ongoing, occurring per visit to the TB clinic. To determine the extent of patients’ costs, then, it is important to consider how frequently patients must return to the clinic and how long they are on treatment.

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Frequency of clinic visits

The biomedical treatment seeking process requires that participants return to the clinic at regular intervals in order to refill their TB medications and to verify that the medication is effective. Forty-four participants report that they must return to the clinic for medication every four weeks (79.1% from Kampala and 45.5% from Mukono). The remaining participants report returning each week (two participants), every two weeks (eight participants), after three weeks (one Kampala participant) and every two months (eight participants). The range of time that participants report may in large part be due to the type of treatment they are receiving. However, the standard NTLP protocol recommends that patients receive a four week supply of tablets over the course of eight months - if the patient adheres to the treatment regimen and has no complications or drug-resistant TB. Patients, however, may visit the clinic more frequently for sputum tests, x-rays, side effects, or additional drug supplies. Thus, patients must incur the financial and time costs associated with biomedical TB treatment seeking a minimum of once per month for at least eight months.

Nonetheless, the majority of patients understand the need to return to the TB clinic for medication. For example, when asked about their ability to travel to the clinic, the majority of participants (93.8%) indicate that they are able to return to the clinic as recommended for treatment. To paraphrase one participant’s explanation of the importance of returning to the clinic, “if you miss some days without tablets, then you go back to square one,” i.e., a patient must start the treatment regimen again.

However, barriers to traveling to the TB clinic do exist. In particular, the financial costs of traveling prevents a few participants from returning regularly. For
example, three of the four participants who reported that they are unable to return to the clinic as recommended cite insufficient travel funds as the reason. An additional participant who stated that she generally is able to attend the clinic added that she would be unable to return if she lacked the funds. Participants noted elsewhere that they will also limit their treatment-seeking costs by not obtaining follow-up sputum tests and x-rays.

An additional factor that may prevent participants from returning to the clinic is if they are not feeling well. Two participants reported that they will not return to the clinic if they are not feeling well; however, one added that she will send someone to obtain the drugs for her. Indeed, the process of traveling to the clinic can be exhausting, involving rising early, walking or riding to the clinic, and then waiting for treatment, often without food. Thus, patients' treatment seeking may be influenced by their health and the presence of a social network member who can obtain the medication if the participant is unable to travel.

Although not statistically significant, these results reveal a number of factors that may influence a patient's ability to maintain consistent treatment seeking. These barriers include transportation costs, clinic fees, and the patient's health status and social network resources.

It should also be noted that because the study participants were recruited from the TB clinic, this sample may be biased towards patients who are not overwhelmed by these factors. It is likely that the number of patients who have difficulty raising transportation funds or other clinic fees, or tolerating the physical process of treatment seeking is actually much higher.
Impact of treatment seeking expenses

Although the government has attempted to limit the cost of TB treatment seeking by supplying free medication, treatment associated expenses can be substantial. These costs are often absorbed by participants' family, as choices must be made between treatment and other purchases. Forty-five of 65 participants (69.2%) reported that their family goes without things because of the participant's illness and treatment needs. Of these 45 participants, 35 (77.8%) indicated that their family goes without food, e.g., without meat or "sauce." Seven participants (15.6%) reduced their clothing expenditures. Other participants mentioned doing without household items (soap, paraffin, and Vaseline), entertainment, and school fees. Thus, even the seemingly low cost of seeking treatment from government TB clinics is difficult for patients to absorb and these expenses have an impact on overall household spending. It is thus not surprising that patients also are rarely able to afford the diet or extra medications that would reduce drug side effects and aid their recovery.

Summary

The data indicate that participants often try numerous traditional and biomedical treatments once their TB symptoms begin. The majority report proceeding to the TB clinic only after other treatments have failed and/or their symptoms have not relented for months. Once on TB treatment, few participants simultaneously use other therapies, although this is likely due to the costs of supplemental treatment, rather than reflecting participants' health beliefs. Indeed many of these participants from the government TB
clinic cannot afford to purchase the fruit juice, milk, or extra food that would reduce their medication side effects.

The costs of treatment seeking can be substantial. While traditional therapies, unless they involve the use of a traditional healer, may be minimal, participants may pay a considerable amount in repeated trips to private clinics and pharmacies. In terms of TB treatment seeking specifically, both direct and indirect expenses were examined. The direct costs include fees for transportation, diagnostic services, extra medications, and unofficial tips. While these costs may vary by clinic visit, on average participants must spend $1.30 to $2.00 on transportation. This expense is continuous over the course of treatment, as participants may have to visit the clinic a minimum of once per month, with additional visits occurring for x-rays, sputum tests, to replace medication, or to seek assistance with drug side effects or new symptoms.

Indirect costs include the transportation time and clinic wait time. Participants may spend sixty minutes to four hours traveling to and from the clinic, and then anywhere from thirty minutes to four hours at the clinic. A clinic visit often requires rising early, and without eating, walking to the bus stop, if not the clinic itself, and then enduring a crowded bus ride, and in Kampala, a transfer in Kampala’s bustling taxi park (bus terminal). For patients who are still quite ill, this journey can be exhausting; for those who are working, it may take considerable time from their employment activities. Ultimately, patients can only absorb the ongoing direct and indirect costs of TB treatment seeking through the assistance of social network members. The role of family and friends throughout the treatment seeking process is explored more thoroughly in the following chapter.
Chapter 9: Patients’ Social Networks and Social Support

This chapter examines participants’ social networks and their perceptions of social support. Social networks were measured in terms of their size, composition, and stability, while social support was conceptualized as an individual’s perception of emotional, informational, and tangible/concrete exchanges with network members. As described in chapter 5, a combination of techniques were used to obtain participants’ perceptions of their social networks and their social support. Participants were asked about their networks through an open-ended “domain” elicitation technique and a close-ended “grid” (see Appendix G). Supplementing this social network grid were questions or scenarios regarding the context of support exchanges. Participants’ social networks and social support exchanges were measured both overall and specifically in terms of their illness.

This chapter explores participants’ social networks first, i.e., the characteristics of their social network grid. It then provides a more detailed exploration of the support exchanges identified through the scenario questions. The goals of this chapter are 1) to describe the social networks and social support systems of female Baganda TB patients; 2) determine if there are urban and rural differences in the definition of social networks and the perception of social support; 3) examine the role of social networks and social support in the treatment seeking process; and 4) determine the extent to which participants have been ostracized from their social support networks as a result of their TB. The literature suggests that social network members, particularly extended family members, provide important coping support during a family member’s illness (e.g., Barnett and Blaikie, 1992; McGrath et al., 1993). The literature also questions, however,
whether participants' social isolation may increase because of the stigma associated with TB (Saunderson, 1995).

It should be noted that the two participants who were from Kampala but attended the Mukono hospital and the three participants who were from Mukono but attended the Kampala hospital have been removed from these analyses. These participants are not included because they do not meet the requirement of living in the same district as their recruitment hospital, and would potentially obscure understandings of district differences in social network and social support. Thus, for the majority of these results, the Kampala sample consisted of 40 female patients, while the Mukono sample consisted of 20. The total sample size is 60.

Social network structural characteristics

Network Size

The characteristics of participants' social networks were measured using an open-ended network "domain" mapping technique in connection with a close-ended "grid." This combination of tools collected data on networks' absolute size, composition, and stability (i.e., how long participants had known members). This instrument also examined participants' evaluation of the quality of the relationship, i.e., the perceived support, reciprocity, degree of criticism, and closeness. This section first describes the structural characteristics (size, composition, stability) of participants' social networks, highlighting the urban-rural differences; second, it explores participants' evaluations of the qualities of their relationships.
Table 9-1 presents the range, mean, and median sizes of Kampala and Mukono participants’ social networks. The mean number of people in Kampala women’s social networks was 4.3, while the mean size for the rural sample was 3.3 (p<.05).

<table>
<thead>
<tr>
<th>Table 9-1 Social Network Size characteristics (N=60)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Mean network size</td>
</tr>
<tr>
<td>Standard deviation</td>
</tr>
<tr>
<td>Median network size</td>
</tr>
<tr>
<td>Range</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

**Network composition**

To describe the composition of participants’ social networks, it is useful to examine the proportions of relatives vs. non-relatives within the network. As discussed in chapter 5, using proportions controls for differences in network sizes, and allows the composition of small networks to be compared with large networks. The proportions of relatives vs. non-relatives included in participants’ social networks are listed in Table 9-2.

<table>
<thead>
<tr>
<th>Table 9-2 Proportion of relatives vs. relatives in social networks</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>No relatives included (all non-relatives)</td>
</tr>
<tr>
<td>1/3 to ½ of network consists of relatives</td>
</tr>
<tr>
<td>Over ½ to ¾ of network consists of relatives</td>
</tr>
<tr>
<td>Over ¾ of network consists of relatives (less than ¼ consists of friends)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>

As indicated in the table, Mukono participants’ social networks tend to consist of greater proportions of relatives, but a Student’s t-test reveals that this difference is not statistically significant. On average, Kampala networks consist of 70% relatives while Mukono networks contain 79% relatives. Despite the lack of statistical significance, it is
interesting that the only networks that consist entirely of non-relatives are found in Kampala and only 35% of Kampala participants’ networks consist of over 75% relatives, whereas 55% of Mukono participants report networks of over 75% relatives. In terms of the types of relatives that were included, the most frequently mentioned were siblings and parents, with 36 participants (60%) listing at least one sibling and 33 participants (55%) including at least one parent.

Table 9-3 describes the proportional structural characteristics of participants’ social networks on average. For example, Mukono networks on average contain a larger proportion of parents. A Student’s t-test indicates that this difference approaches statistical significance (p=.07). Significant others, whether husbands or boyfriends, were listed less frequently than siblings and parents. Eight Mukono participants (40%) and eleven Kampala participants (28%) included a significant other in their social network.

Finally, Kampala participants tended to list more types of relatives than Mukono participants. Twenty-four Kampala participants (60%) included one to four non-sibling, non-parent relatives in their network, whereas only nine Mukono participants (45%) included one to three non-sibling, non-parent relatives. This difference in the absolute number of additional relatives is statistically significant (p=.05), however, there is not a significant difference in the proportion of “other relatives” included in Kampala vs. Mukono networks (Table 9-3).
Table 9-3 Social Network Structural Characteristics (N=60)

<table>
<thead>
<tr>
<th></th>
<th>Kampala X SD</th>
<th>Mukono X SD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Network Composition:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion relatives</td>
<td>.70 .28</td>
<td>.79 .21</td>
</tr>
<tr>
<td>Proportion siblings</td>
<td>.25 .26</td>
<td>.23 .22</td>
</tr>
<tr>
<td>Proportion parents</td>
<td>.14 .17</td>
<td>.26* .26</td>
</tr>
<tr>
<td>Proportion significant other</td>
<td>.06 .11</td>
<td>.11 .16</td>
</tr>
<tr>
<td>Proportion other relatives</td>
<td>.26 .26</td>
<td>.19 .27</td>
</tr>
<tr>
<td>Proportion non-relative</td>
<td>.27 .25</td>
<td>.21 .21</td>
</tr>
<tr>
<td><strong>Network Stability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion known since childhood</td>
<td>.56 .31</td>
<td>.68** .22</td>
</tr>
<tr>
<td>Proportion known &lt;1 year</td>
<td>.04 .16</td>
<td>.03 .12</td>
</tr>
<tr>
<td><strong>Contact Frequency</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion seen daily</td>
<td>.57 .32</td>
<td>.65 .33</td>
</tr>
<tr>
<td>Proportion seen weekly</td>
<td>.17 .23</td>
<td>.09 .16</td>
</tr>
<tr>
<td>Proportion seen monthly</td>
<td>.17 .20</td>
<td>.21 .23</td>
</tr>
<tr>
<td>Proportion seen yearly</td>
<td>.09 .17</td>
<td>.05 .12</td>
</tr>
<tr>
<td><strong>Geographical Proximity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion within 10 min.(including in household)</td>
<td>.55 .35</td>
<td>.66 .32</td>
</tr>
<tr>
<td>Proportion specifically in household</td>
<td>.31 .27</td>
<td>.43 .34</td>
</tr>
<tr>
<td>Proportion &gt;60 minutes away</td>
<td>.14 .21</td>
<td>.10 .20</td>
</tr>
</tbody>
</table>

*p=.072  
**p=.083

Thus, to summarize the overall composition of participants’ networks, on average, relatives constituted a major proportion of participants’ networks at both sites. Kampala participants tended to include a greater range of relatives, e.g., grandparents, cousins, and aunts. In addition, Kampala participants tended to mention friends more frequently than Mukono participants, both in terms of absolute numbers and in proportion to the rest of the network – with two networks consisting entirely of friends.

Network stability

In addition to size and composition, social network structure was examined in terms of stability or how long participants have known network members, frequency of
contact, and the physical proximity of network members. To briefly describe each of these results, first, stability was operationalized as the proportion of the network that the participant has known since childhood and the proportion that the participant has known less than one year. On average, Kampala participants have known 56% of their network members since childhood while Mukono participants have known 68% since childhood (Table 9-3). This difference in the mean proportion of network members known since childhood approaches statistical significance (p=.08). Furthermore, all of the Mukono networks contained individuals that the participant had known since childhood while five Kampala participants (13%) did not include anyone from childhood.

The second measure of stability, the proportion of network members known less than one year, indicates that very few participants included individuals that they have known less than one year as part of their social network. Only three Kampala (8%) and two Mukono (10%) participants included an individual that they have known for less than one year. These results suggest that both Kampala and Mukono networks tend to be fairly stable, with participants knowing the majority of network members for most of their lifetimes, and few including individuals that they have known for less than one year. Whether participants frequently replace individuals known from childhood with others known from childhood is unknown, however, only three participants reported that there had been a change in their network in the past year.

*Frequency of contact*

The data on frequency of contact are reported in Table 9-3. On average, Kampala participants saw 57% of their network members daily while Mukono participants had
contact with 65% of their network daily. Furthermore, ten Kampala participants (25%) and eight Mukono participants (40%) reported that they saw all of their social network daily. Only two Kampala (5%) and one Mukono (5%) reported that they saw none of their network members daily. Participants' social networks therefore tended to consist in large part of individuals with whom participants had regular, usually daily, contact. There were no significant differences in contact by district.

These results are consistent with measures of network members' geographical proximity. The majority of participants included people from within their household or close by, rather than individuals who live far away. Twenty-seven Kampala participants (63%) and fifteen Mukono participants (75%) reported that at least 50% of their social network lives within ten minutes (walking or driving) of the participant. Furthermore, twelve of these Kampala participants (30%) and ten of the Mukono participants (50%) indicated that household members constitute 50% or more of their social network. T-tests indicate that the mean proportion of network members living within ten minutes or within the household are not significantly different by district (Table 9-3). These results suggest that both Kampala and Mukono participants tend to have networks consisting of individuals who live nearby and with whom they have regular contact.

Ultimately, the primary difference between the structure of Kampala vs. Mukono networks is that Kampala networks tend to be bigger and more frequently include larger numbers of relatives beyond siblings and parents. Kampala participants may show a pattern of having more friend based networks, but this difference is not statistically significant. There is no overall difference in the length of time that participants have
known network members, the level of contact, or the geographical location of network members.

Additional network characteristics

In addition to describing the composition and basic characteristics of their social networks, participants also evaluated members’ criticism, closeness, and the exchange of emotional, informational, and concrete support. These data are reported in Table 9-4. In brief, participants generally indicated social network members are hardly ever critical – the mean proportion of Kampala network members that are hardly ever critical is 97% while the mean proportion of Mukono network members is 98%. In terms of absolute numbers, no Mukono participants reported that a network member was always critical whereas only four Kampala participants reported that one member is always critical.

Generally, both Kampala and Mukono participants rated many of their network members as sort of or very close emotionally, and only a very small proportion on average were considered not close (Table 9-4). Twenty-seven (67.5%) of the 40 Kampala participants and 14 (70%) of the 20 Mukono participants had at least two social network members reported to be very close. However, a statistically significant greater proportion of Mukono network members were rated as very close ($p=.045$). Thus, there is a difference in the proportion of emotionally close network members by district, but individuals in both locations do not lack emotionally close ties.
Table 9-4 Social Network Exchange Characteristics (N=60)

<table>
<thead>
<tr>
<th></th>
<th>Kampala</th>
<th>Mukono</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>X</td>
<td>SD</td>
</tr>
<tr>
<td><strong>Critical of participant</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion hardly ever</td>
<td>.97</td>
<td>.09</td>
</tr>
<tr>
<td>Proportion sometimes</td>
<td>.01</td>
<td>.05</td>
</tr>
<tr>
<td>Proportion almost always</td>
<td>.02</td>
<td>.08</td>
</tr>
<tr>
<td><strong>(emotionally) close to participant</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion not close</td>
<td>.09</td>
<td>.20</td>
</tr>
<tr>
<td>Proportion sort of close</td>
<td>.42</td>
<td>.27</td>
</tr>
<tr>
<td>Proportion very close</td>
<td>.50</td>
<td>.26</td>
</tr>
<tr>
<td><strong>Emotional support provided</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion hardly ever</td>
<td>.13</td>
<td>.23</td>
</tr>
<tr>
<td>Proportion sometimes</td>
<td>.37</td>
<td>.27</td>
</tr>
<tr>
<td>Proportion almost always</td>
<td>.50</td>
<td>.28</td>
</tr>
<tr>
<td><strong>Informational support provided</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion hardly ever</td>
<td>.20</td>
<td>.27</td>
</tr>
<tr>
<td>Proportion sometimes</td>
<td>.42</td>
<td>.28</td>
</tr>
<tr>
<td>Proportion almost always</td>
<td>.38</td>
<td>.24</td>
</tr>
<tr>
<td><strong>Concrete support provided</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion hardly ever</td>
<td>.27</td>
<td>.32</td>
</tr>
<tr>
<td>Proportion sometimes</td>
<td>.32</td>
<td>.25</td>
</tr>
<tr>
<td>Proportion almost always</td>
<td>.42</td>
<td>.26</td>
</tr>
<tr>
<td><strong>Direction of exchanges</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion Reciprocal</td>
<td>.50</td>
<td>.33</td>
</tr>
<tr>
<td>Proportion usually give to participant</td>
<td>.48</td>
<td>.35</td>
</tr>
<tr>
<td>Proportion to whom participant usually gives</td>
<td>.01</td>
<td>.07</td>
</tr>
<tr>
<td><strong>Illness interaction</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proportion knowing participant is ill</td>
<td>.80</td>
<td>.32</td>
</tr>
<tr>
<td>Proportion offering advice on illness</td>
<td>.63</td>
<td>.41</td>
</tr>
</tbody>
</table>

*p=.045

Social network exchanges – using the social network grid

Table 9-4 also describes participants' evaluation of their networks' exchanges of emotional, informational, and concrete support. On average, 50% of Kampala participants' social network members provided emotional support “almost always,” while
63% of Mukono participants’ social networks provided emotional support “almost always.” The mean proportion providing informational support almost always decreased to 38% and 32% for Kampala and Mukono, respectively. Finally, concrete support was almost always provided by a large proportion of participants’ networks – the mean proportion of Kampala network members providing concrete support almost always was 42%, while the mean Mukono proportion was 44%. These exchanges, without regard to the type of support, tended to be either reciprocal or involved the social network member giving support to the participant.

To summarize, the social network grid data indicate that both urban and rural participants are embedded tightly in social networks and the majority of participants in both groups reported that there are people they can always count on for emotional, informational, and concrete support. It appears that Kampala participants tend to include significantly more informational support relationships in their networks. It is also possible that these individuals are not as emotionally close to participants, given the finding that a significantly greater proportion of Mukono network members are considered very close. “Extra” relationships are with both extended family members and non-relatives, but it is not the case that Kampala participants have significantly greater proportions of non-relatives in their networks.

Social support “scenarios”

The data described above were obtained through a close-ended social network instrument. More detailed information on the roles that friends and family members play was obtained through semi-structured questions regarding the provision of social support in various contexts. This section examines the data on the types of relationships that are
associated with specific support exchanges. Emotional support exchanges are discussed first, followed by informational support, and then concrete support.

*Emotional support exchange scenarios*

The emotional support scenarios examined who participants tend to discuss difficult issues with, i.e., who participants can approach with their problems, who they can talk to about their children, and who they can talk to about their partner. Because social support may or may not involve reciprocal exchange, participants also indicated if anyone came to them to discuss each issue. The presence of reciprocal exchange is also an indication of the extent to which others voluntarily contact the participant and the participant's level of stigmatization.

Not surprisingly, given the close networks described above, most participants talked to someone about their problems. Both Kampala and Mukono participants turned to siblings, parents, and friends for emotional support. For example, when asked who they talk to about their problems in general, 33% participants talked to their siblings about their concerns (Table 9-5), while less than 25% mentioned their parents or friends. The primary difference by district is that Mukono participants were less likely to mention non-siblings and non-parent relatives.

*Table 9-5 Types of people to whom participants talk about their own problems (N=60)*

<table>
<thead>
<tr>
<th>Type of Support</th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister(s) and/or Brother(s)</td>
<td>13 (32.5)</td>
<td>7 (35.0)</td>
<td>20 (33.3)</td>
</tr>
<tr>
<td>Mother and/or Father</td>
<td>9 (22.5)</td>
<td>4 (20.0)</td>
<td>13 (21.7)</td>
</tr>
<tr>
<td>Other relatives</td>
<td>13 (32.5)</td>
<td>2 (5.0)</td>
<td>15 (25.0)</td>
</tr>
<tr>
<td>Husband/boyfriend/father of children</td>
<td>5 (12.5)</td>
<td>5 (25.0)</td>
<td>10 (16.7)</td>
</tr>
<tr>
<td>Friends/coworkers/neighbors/church friends</td>
<td>9 (22.5)</td>
<td>4 (20.0)</td>
<td>13 (21.7)</td>
</tr>
<tr>
<td>Talk to no one</td>
<td>3 (7.5)</td>
<td>2 (10.0)</td>
<td>5 (8.3)</td>
</tr>
</tbody>
</table>

*participants could list more than one response*
The results regarding worries about children are similar. Eighteen participants (36% of those with children) talked to their siblings about their concerns about their children. Thirteen (26%) mentioned talking to their mother and/or father. Seven Mukono participants (39%) and one Kampala participant (3%) talked to no one (see Appendix J, Table 1). Thus, siblings and parents play a key role in providing advice on child rearing, but Mukono participants are more likely than Kampala participants to state that they do not receive such support.

This pattern of Mukono participants listing less support holds with regard to concerns about their partners/significant others. Ninety percent of the Mukono participants who had a significant other reported that they talked to no one about any relationship difficulties, while 26% of Kampala participants with a partner talked to no one. Kampala residents again cited siblings as an important source of support, followed by other relatives (Table 9-6).

| Table 9-6 Who can you talk to about your concerns about your partner (N=37)* |
|-------------------------------------|-----------------|-----------------|-----------------|
|                                    | Kampala N (%)   | Mukono N (%)    | Total N (%)     |
| Sister(s) and/or Brother(s)       | 11 (40.7)       | 0               | 11 (29.7)       |
| Other relatives (cousins; aunts; grandparents; children) | 5 (18.5)       | 0               | 5 (13.5)       |
| Friends/coworkers/neighbors/church friends | 4 (14.8) | 1 (10.0) | 5 (13.5) |
| Talk to no one                     | 7 (25.9)        | 9 (90.0)        | 16 (43.2)       |

*participants could give more than one response; 13 Kampala and 10 Mukono participants did not currently have partners and did not respond to this question

This difference in women’s discussions of their relationship problems is intriguing. Although it is possible that Mukono women have no problems to discuss, there is no reason to believe that they have fewer problems than Kampala women. It is more likely that Mukono women, as discussed in chapter 2, may have a more traditional
social role than Kampala women and may face greater prohibitions against complaining about their partner. Because of their lower social status and power dynamics, Mukono women may be unable to vocalize, let alone address, relationship problems. Further research is needed to determine more precisely the reason for participants’ lack of confidants regarding their partner.

In order to understand the complete dynamics of emotional support relationships and as a measure of participants’ isolation, who approaches the participant for support must also be examined. Although the majority of participants go to others for emotional support on difficult issues, participants are less likely to have people approach them for emotional support. For example, 45% of Kampala participants and 75% of Mukono participants reported that no one comes to them with their worries (Appendix J, Table 2).

Interestingly, among participants who reported being approached, friends were most frequently mentioned as asking for advice, followed by siblings and other relatives. A similar pattern is found with who comes to the participant regarding children. Nineteen Kampala participants (49%) and 17 Mukono participants (85%) reported that no one comes to them for advice about children (see Appendix J, Table 3). Among participants who did report that others approach them for advice about children, non-relatives were mentioned as seeking this assistance more frequently than relatives.

One explanation for participants reporting that they do not provide emotional support or advice to others is the fact that many are currently recovering from a major illness. Their potential role as a support-giver has been overshadowed by the demands of their illness. Although only three participants (5%) indicated that their social network has changed over the last six months, a subtle shift in exchanges may have occurred for
the remaining participants. Further studies are needed to determine whether TB patients' support-giving increases as they shed their sick role and their social and economic life normalizes.

Together these data indicate a number of issues regarding emotional support. First, few people consistently report no source for emotional advice – although there is variation in the types of individuals approached, depending on the type of advice needed, i.e., advice on worries or children vs. relationship problems. Generally, siblings are mentioned as a source of emotional support. Second, participants in both locations more frequently report that they go to people for emotional advice rather than advising others. This finding is not entirely surprising given the participants' sick role and the taxing nature of TB. Third, consistent with the analyses of social network structure, Kampala participants mention “other” relatives more frequently than Mukono participants. These qualitative data indicate relatives beyond siblings and parents play an increased role in providing emotional support for Kampala participants compared to Mukono participants.

*Informational support scenarios*

The informational support scenarios examined whether participants have anyone to talk to for advice when making important decisions or concerning jobs as well as who comes to the participant for this information. As with emotional support, participants most frequently mentioned siblings, followed by parents, husbands, other relatives, and friends as the people who provide this support (Table 9-7). At the same time, 15% of Kampala participants and 30% of Mukono participants reported that there is no one from whom they seek advice when making important decisions.
An even greater number of participants reported talking to no one for advice regarding employment; 33% of Kampala participants and 58% of Mukono participants report talking to no one (Appendix J, Table 4). While these data suggest that many Kampala and Mukono participants do not have key employment information resources, the data may be a result of participants’ inability or decisions not to work; alternatively they may also be due to the country’s widespread unemployment and limited job opportunities. Participants’ responses may reflect that there is no use in discussing jobs with relatives and friends who are unemployed and likely have no employment information. Among those participants who do discuss job opportunities, they most frequently turn to non-relatives, with 33% of Kampala participants and 25% of Mukono participants receiving this support from friends, neighbors, and other non-relatives (Appendix J, Table 4).

When the two data sets on informational support are combined, 5% of Kampala participants and 25% of Mukono participants reported no sources of informational support, regardless of the issue (Table 9-8). Siblings, parents, and non-relatives play important roles for both sets of participants.
As a measure of the reciprocal nature of informational support, few participants reported that other individuals come to them for such support. Fifty-five percent of Kampala participants and 90% of Mukono participants reported that no one asks them for advice when making important decisions (Table 9-9). The information seekers most frequently mentioned by Kampala participants are siblings while the most frequently mentioned information seekers for Mukono participants are non-relatives. This pattern of siblings seeking information from Kampala participants but not Mukono participants is also found in the data on who comes to participants for information about jobs (Appendix J, Table 5).

Table 9-8 Sources of informational support (N=60)*

<table>
<thead>
<tr>
<th>Source of Information</th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister(s) and/or Brother(s)</td>
<td>16 (40.0)</td>
<td>6 (30.0)</td>
<td>22 (36.7)</td>
</tr>
<tr>
<td>Mother and/or Father</td>
<td>6 (15.0)</td>
<td>7 (35.0)</td>
<td>13 (21.7)</td>
</tr>
<tr>
<td>Other relatives (cousins; aunts; grandparents; children)</td>
<td>10 (25.0)</td>
<td>1 (5.0)</td>
<td>11 (18.3)</td>
</tr>
<tr>
<td>Husband/boyfriend/father of children</td>
<td>8 (20.0)</td>
<td>3 (15.0)</td>
<td>11 (18.3)</td>
</tr>
<tr>
<td>Friends/coworkers/neighbors/church friends</td>
<td>15 (37.5)</td>
<td>7 (35.0)</td>
<td>22 (36.7)</td>
</tr>
<tr>
<td>No one</td>
<td>2 (5.0)</td>
<td>5 (25.0)</td>
<td>7 (11.7)</td>
</tr>
</tbody>
</table>

*participants could give more than one response

Table 9-9 Who comes to participant for advice when making important decisions (N=59)*

<table>
<thead>
<tr>
<th>Source of Information</th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister(s) and/or Brother(s)</td>
<td>9 (22.5)</td>
<td>0</td>
<td>9 (15.3)</td>
</tr>
<tr>
<td>Other relatives (cousins; aunts; grandparents; children)</td>
<td>4 (10.0)</td>
<td>0</td>
<td>4 (6.8)</td>
</tr>
<tr>
<td>Friends/coworkers/neighbors/church friends</td>
<td>7 (17.5)</td>
<td>2 (10.5)</td>
<td>9 (15.3)</td>
</tr>
<tr>
<td>No one</td>
<td>22 (55.0)</td>
<td>17 (89.5)</td>
<td>39 (66.1)</td>
</tr>
<tr>
<td>Missing (who not specified)</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

*participants could give more than one response
Concrete support scenarios

The concrete support scenarios examined who provides participants with financial and nutritional assistance, along with the people to whom participants offer this support. As indicated in chapter 6, 67% of participants did not have enough money to pay all their bills. Twelve additional participants (19%) who reported no income, however, did not respond to this question. Because participants who have no income are unlikely to be able to pay their bills without assistance, it is more likely that over 80% of participants are not economically self-sufficient. The data suggest that social network members play a critical role in filling the gap between participants’ everyday expenses and their income.

In order to pay their major expenses, e.g., food, rent, children’s needs, including school fees, personal items and/or business demands, 26 (65%) of the 40 Kampala participants and 14 (70%) of the 20 Mukono participants reported using their own money. At the same time, 22 Kampala participants (55%) and nine Mukono participants (45%) reported that social network members contribute money to the household. Significant others were mentioned more frequently than other types of relationships as providing these contributions, with seven Kampala participants and four Mukono participants mentioning their husband, boyfriend, or father of their children. Not surprisingly, friends rarely were mentioned as providing financial support to the household, with only two Kampala participants mentioning non-relatives and one Mukono participant mentioning non-relatives.

Regarding food purchases specifically, only nine Kampala participants (23%) and six Mukono participants (30%) stated that they alone pay for their food purchases.
Significant others bought food for eleven Kampala women (28%) and six Mukono women (30%), while four parents in Kampala and five in Mukono made these purchases for the participants. Miscellaneous other relatives (e.g., aunts, uncles, and grandparents) made these purchases for the remaining individuals.

Thus, the majority of participants are not economically self-sufficient and are dependent upon relatives to maintain their households and families. It should also be noted that participants engaged in a number of creative methods for meeting household expenditures, including obtaining money from former significant others, delaying payments, paying expenses in installments, or reducing expenses by removing children from school.

In addition to the above methods for managing their concrete needs, fifteen Kampala participants (38%) and five Mukono participants (25%) have borrowed funds. This money was used for a range of purposes, including treatment seeking, business expenses, food, and to cover their child(ren)'s needs. Ten of the Kampala participants (67%) and four of the Mukono participants (80%) borrowed from non-relatives. The remaining participants borrowed from a range of relatives, including siblings, parents, and cousins.

The amount borrowed ranged from 200 to 200,000 Ush., depending on the context. The mean amount borrowed was 32,537 Ush and the median was 10,000 Ush. Kampala participants tended to borrow higher amounts than Mukono participants (medians 18,500 vs. 8,000). In general, participants mentioned friends as the people from whom they have borrowed money. This suggests that friends may tend to exchange
money with the intent to repay, while family members may assist each other financially without an explicit expectation that the funds will be returned.

At the same time that the majority of participants are not able to pay all of their expenses, are often dependent upon others for food, and may borrow funds, 17 Kampala participants (43%) and six Mukono participants (30%) have provided financial support to other family members. Seven Kampala participants (18%) likewise reported they will lend money to their partner when he is in need. The frequency and reasons for supplying money varied. For example, ten participants (43%) supply money occasionally or when family members have problems or ask for assistance; five (22%) bring or send money to relatives when they or others travel to the “home” village; and two (9%) assist with paying school fees regularly. These data suggest that networks tend to be circular, with participants and social network members exchanging resources based upon immediate need and the availability of funds, rather than an individual’s overall economic well being.

An additional measure of the reciprocal nature of concrete assistance is whether participants distribute food to others. The data on food exchanges suggests that the majority of participants do not have a surplus that can be offered to others regularly. Fifty-three participants (88%) did not give food to any other individuals, with two specifying that they did not have extra to share, and two indicating that they were too weak to keep a garden to share. The five Kampala participants who shared food do so with friends or neighbors, while the three Mukono participants reported that they share with their mother, sister, and/or brother. Thus, these scenarios suggest that when possible
participants will assist relatives and non-relatives with tangible support, but they frequently are not in a position to provide such favors.

Ultimately, the majority of participants are not economically independent. Social networks are critical in order for participants to meet food and household needs. Participants in both locations tend to rely on relatives for concrete support, but will borrow funds from non-relatives. At the same time that few participants are self-sufficient, they also tend to give financial support to others depending on their own resources and others’ need. Further research is needed to determine the extent to which an individual who is supported by others may simultaneously give aid to others who are in need.

In conclusion, these data follow a similar pattern to the structured social network grid. Siblings play an important role for both samples, but Kampala participants tend to mention non-sibling, non-parent relatives more frequently than Mukono participants. Likewise, Mukono participants more frequently report that they go to no one for support. Because cell sizes are relatively small, it is difficult to determine the statistical significance of such differences.

**Treatment seeking support**

Social networks play numerous roles over the course of participants’ illnesses and in the treatment seeking process. Some social network members play a very active role, e.g., accompanying the participant on her clinic visits and providing support in daily living, while others mainly provide illness related emotional support. Similar to the discussion above, the role of the social network in treatment seeking is examined in terms
of emotional, informational, and tangible support. First, however, participants’
perceptions of their social networks’ overall support of treatment seeking are explored.

**Overall support of the treatment seeking process**

The data indicate that participants generally believe that social network members
are supportive of the treatment-seeking process. For example, of the 89 participants who
were asked whether their partner supports the participant’s treatment decisions, 46 (94%
of those with partners) agreed that their partner is supportive.

In addition, of the 60 participants interviewed for the scenario data, 39 from
Kampala (98%) and 17 from Mukono (85%) believed that their social networks think it is
important that they seek treatment. The remaining four participants did not know or had
never asked those around them. Forty-three percent stated that their social networks
believe it is important because participants can be cured and patients will survive if they
receive treatment. Thirty-seven percent believed their social networks are motivated
because TB is contagious and can spread – with more Kampala participants expressing
network members’ concerns about contagion than Mukono participants (Table 9-10).

### Table 9-10 Why others think it is important for the participant to seek treatment for TB (N=60)

<table>
<thead>
<tr>
<th>Reason for Seeking Treatment</th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>In order to get cured/can still live with treatment</td>
<td>11 (34.4)</td>
<td>10 (58.8)</td>
<td>21 (42.9)</td>
</tr>
<tr>
<td>Because TB is contagious/in order to not spread the disease</td>
<td>14 (43.8)</td>
<td>4 (23.5)</td>
<td>18 (36.7)</td>
</tr>
<tr>
<td>TB kills if not treated/TB kills quickly</td>
<td>3 (9.4)</td>
<td>2 (11.8)</td>
<td>5 (10.2)</td>
</tr>
<tr>
<td>Other (e.g., lost family member to TB)</td>
<td>4 (12.5)</td>
<td>1 (5.9)</td>
<td>5 (10.2)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>32 (100.1)</strong></td>
<td><strong>17 (100)</strong></td>
<td><strong>49 (100)</strong></td>
</tr>
</tbody>
</table>

**Missing** | 7 | 0 | 7
**Not applicable** | 1 | 3 | 4
Emotional and Informational support in treatment seeking/illness management

Illness related emotional support was measured primarily in terms of whether and with whom participants talked about their illness experience. Table 9-11 describes the types of individuals to whom participants talked about their TB. Only 12% have talked to no one about their illness; the majority of participants spoke to family members, especially sisters and/or brothers. Participants less frequently reported talking to friends, neighbors, and coworkers about their TB.

Table 9-11 Types of individuals to whom participants talk about their TB illness (N=60)*

<table>
<thead>
<tr>
<th>Types of Individuals</th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister(s) and/or Brother(s)</td>
<td>19 (47.5)</td>
<td>11 (55.0)</td>
<td>30 (50.0)</td>
</tr>
<tr>
<td>Mother and/or Father</td>
<td>12 (30.0)</td>
<td>6 (30.0)</td>
<td>18 (30.0)</td>
</tr>
<tr>
<td>Other relatives (cousins; aunts; grandparents; children)</td>
<td>10 (25.0)</td>
<td>2 (10.0)</td>
<td>12 (20.0)</td>
</tr>
<tr>
<td>Husband/boyfriend/father of children</td>
<td>5 (12.5)</td>
<td>4 (20.0)</td>
<td>9 (15.0)</td>
</tr>
<tr>
<td>Friends/coworkers/neighbors/church friends</td>
<td>4 (10.0)</td>
<td>1 (5.0)</td>
<td>5 (8.3)</td>
</tr>
<tr>
<td>Medical personnel (doctors, nurses, counselors)</td>
<td>1 (2.5)</td>
<td>1 (5.0)</td>
<td>2 (3.3)</td>
</tr>
<tr>
<td>Talk to no one</td>
<td>5 (12.5)</td>
<td>2 (10.0)</td>
<td>7 (11.7)</td>
</tr>
</tbody>
</table>

*participants could give more than one response

These data thus follow a similar pattern to the non-illness emotional support described above in which siblings played an important role in both districts and in which a greater percentage of Kampala participants reported turning to non-sibling, non-parent relatives.

The types of illness and treatment seeking emotional support that participants received primarily revolved around discussions of participants' pain or symptoms (n=35; 66%), although participants also reported receiving encouragement and advice to take their medicine and not to miss their daily dose, to eat well, and not to worry/to be strong.
For two participants, this included discussions on accepting their HIV status and the relationship between HIV and TB.

Although the majority of participants appeared to discuss their illness, 26 (43%) reported that they have not received treatment-seeking information from others (Table 9-12). It is possible these participants did not receive treatment advice because they have determined that their cure lies in the TB clinic. Of those participants who have received advice, the source of advice was distributed relatively equally between different types of social network members. Overall, participants were more likely to obtain advice from relatives – only 18% of the Kampala sample reported receiving treatment advice from non-relatives.

Table 9-12 Types of individuals from whom participants receive treatment advice (N=60)*

<table>
<thead>
<tr>
<th>Type of Individual</th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister(s) and/or Brother(s)</td>
<td>5 (12.5)</td>
<td>2 (10.0)</td>
<td>7 (11.7)</td>
</tr>
<tr>
<td>Mother and/or Father</td>
<td>3 (7.5)</td>
<td>4 (20.0)</td>
<td>7 (11.7)</td>
</tr>
<tr>
<td>Other relatives (cousins; aunts; grandparents; children)</td>
<td>5 (12.5)</td>
<td>0</td>
<td>5 (8.3)</td>
</tr>
<tr>
<td>Husband/boyfriend/father of children</td>
<td>3 (7.5)</td>
<td>3 (15.0)</td>
<td>6 (10)</td>
</tr>
<tr>
<td>Friends/coworkers/neighbors/church friends</td>
<td>7 (17.5)</td>
<td>0</td>
<td>7 (11.7)</td>
</tr>
<tr>
<td>Medical personnel (doctors, nurses, counselors)</td>
<td>3 (7.5)</td>
<td>4 (20.0)</td>
<td>7 (11.7)</td>
</tr>
<tr>
<td>Other (many people)</td>
<td>0</td>
<td>1 (5.0)</td>
<td>1 (1.7)</td>
</tr>
<tr>
<td>Talk to no one</td>
<td>18 (45.0)</td>
<td>8 (40.0)</td>
<td>26 (43.3)</td>
</tr>
</tbody>
</table>

*Participants could give more than one response

Seven participants stated this emotional/informational support consisted of advice only and has not influenced or assisted their treatment-seeking decisions. The overall role of the social network in providing concrete support is described next.
Concrete support in illness management and treatment seeking

The third role of participants’ social networks is providing tangible support for participants’ treatment seeking and illness management, including caring for the household and children while the participant is unwell (Table 9-13). In terms of treatment seeking, 67% received financial or physical assistance with transportation to treatment. Forty percent specifically received money to pay for treatment, treatment-seeking transportation, or other health related needs. In addition to treatment-seeking assistance, 82% of participants received food or drinks from others – as described in the treatment-seeking chapter, food and drink are critical as participants may not take their medications without them. Social network members assisted 67% of participants with clothes and dish washing, as well as care in personal bathing. Along with the concrete support described in the table, eight participants reported receiving assistance from relatives when they were hospitalized. Only two Kampala participants (5%) and one Mukono participant (5%) reported no tangible assistance of any kind.

Table 9-13 Tangible Assistance Received by Participants (N=60)*

<table>
<thead>
<tr>
<th>Tangible Assistance</th>
<th>Kampala</th>
<th>Mukono</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food/Drinks purchased or cooked</td>
<td>32 (80.0)</td>
<td>17 (85.0)</td>
<td>49 (81.7)</td>
</tr>
<tr>
<td>Transportation assistance /accompanied in treatment seeking</td>
<td>27 (67.5)</td>
<td>13 (65.0)</td>
<td>40 (66.7)</td>
</tr>
<tr>
<td>Washing clothes, dishes, or self</td>
<td>25 (62.5)</td>
<td>15 (75.0)</td>
<td>40 (66.7)</td>
</tr>
<tr>
<td>Help with housework, carrying water, gardening (digging)</td>
<td>18 (45.0)</td>
<td>13 (65.0)</td>
<td>31 (51.7)</td>
</tr>
<tr>
<td>Assistance with medications (purchasing.obtaining drugs)</td>
<td>16 (40.0)</td>
<td>8 (40.0)</td>
<td>24 (40.0)</td>
</tr>
<tr>
<td>Care/feeding of children</td>
<td>8 (20.0)</td>
<td>4 (20.0)</td>
<td>12 (20.0)</td>
</tr>
<tr>
<td>Money for treatment, transportation or other needs</td>
<td>9 (22.5)</td>
<td>10 (50.0)</td>
<td>19 (31.7)</td>
</tr>
</tbody>
</table>

*participants could give more than one response

The primary providers of tangible assistance were relatives. For example, looking at the data on household support specifically (e.g., cooking, washing, child care), only
three Kampala participants (8%) mentioned that non-relatives provided this type of support (Table 9-14). In addition, in response to all questions regarding tangible assistance (i.e., care of household or self, assistance obtaining medication or transportation), only two Mukono participants (10%) and six Kampala participants (15%) mentioned that non-relatives provide this support.

### Table 9-14 Types of people providing tangible support in care of household (N=60)*

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister(s) and/or Brother(s)</td>
<td>10 (25.0)</td>
<td>6 (30.0)</td>
<td>16 (26.7)</td>
</tr>
<tr>
<td>Mother and/or Father</td>
<td>7 (17.5)</td>
<td>7 (35.0)</td>
<td>14 (23.3)</td>
</tr>
<tr>
<td>Other relatives (cousins; aunts; grandparents; children)</td>
<td>9 (22.5)</td>
<td>3 (15.0)</td>
<td>12 (20.0)</td>
</tr>
<tr>
<td>Husband/boyfriend/father of children</td>
<td>8 (20.0)</td>
<td>3 (15.0)</td>
<td>11 (18.3)</td>
</tr>
<tr>
<td>Friends/coworkers/neighbors/church friends</td>
<td>3 (7.5)</td>
<td>0</td>
<td>3 (5.0)</td>
</tr>
<tr>
<td>Other (all of SN grid)</td>
<td>1 (2.5)</td>
<td>0</td>
<td>1 (1.7)</td>
</tr>
<tr>
<td>No one</td>
<td>8 (20.0)</td>
<td>5 (25.0)</td>
<td>13 (21.7)</td>
</tr>
<tr>
<td>Not applicable (lives with parents, does not care for household)</td>
<td>1 (2.5)</td>
<td>0</td>
<td>1 (1.7)</td>
</tr>
</tbody>
</table>

*participants could give more than one response

**Reciprocal treatment-seeking support (from participants to others)**

To fully understand social support dynamics and participants' isolation, again it is important to examine the extent to which relationships are reciprocal. This exchange from participants to others was primarily measured in terms of the information that participants provide others about treatment seeking. Fifty-four (93%) of participants reported that no one comes to them for information about doctors or medicine (Table 9-15). In fact, only five Kampala participants reported that others ranging from their siblings to “many people” came to them for advice about doctors or medicines. Thus, despite participants’ sick role and familiarity with the hospital and clinics, they were not necessarily seen as a source of advice. It is possible, however, that once participants
successfully shed the sick role, their status as individuals who can advise on health care may increase.

**Table 9-15 Who comes to participant for information about doctors or medicines (N=60)**

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister(s) and/or Brother(s)</td>
<td>2 (5.1)</td>
<td>0</td>
<td>2 (3.4)</td>
</tr>
<tr>
<td>Mother and/or Father</td>
<td>1 (2.6)</td>
<td>0</td>
<td>1 (1.7)</td>
</tr>
<tr>
<td>Friends/coworkers/neighbors/church friends</td>
<td>1 (2.6)</td>
<td>0</td>
<td>1 (1.7)</td>
</tr>
<tr>
<td>Many people (unspecified)</td>
<td>1 (2.6)</td>
<td>0</td>
<td>1 (1.7)</td>
</tr>
<tr>
<td>Talk to no one</td>
<td>35 (89.7)</td>
<td>19 (100)</td>
<td>54 (93.1)</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

*p* participants could give more than one response

**Stigmatization of TB patients**

The final goal of this chapter was to examine whether participants felt they have been stigmatized by their illness. To measure patient stigmatization, this study examined participants’ own experience, their knowledge of how others with TB are treated, and the typical conversations surrounding TB patients.

To discuss participants’ observations of local conversations about TB first, 23 Kampala participants (58%) and six Mukono participants (30%) have heard people around them discuss other TB patients. The topics of conversations are listed in Table 9-16.

**Table 9-16 Local conversations about other TB patients (N=29)**

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual’s symptoms/TB status</td>
<td>9 (39.1)</td>
<td>2 (33.3)</td>
<td>11 (37.9)</td>
</tr>
<tr>
<td>Individual’s HIV/AIDS status</td>
<td>4 (17.4)</td>
<td>2 (33.3)</td>
<td>6 (20.7)</td>
</tr>
<tr>
<td>Contagion control measures (e.g., isolate dishes/eating utensils)</td>
<td>3 (13.0)</td>
<td>0</td>
<td>3 (10.3)</td>
</tr>
<tr>
<td>Extreme contagion control (e.g., burying material possessions)</td>
<td>1 (4.3)</td>
<td>1 (16.7)</td>
<td>2 (6.9)</td>
</tr>
<tr>
<td>Other or don’t know</td>
<td>6 (26.1)</td>
<td>1 (16.7)</td>
<td>7 (24.1)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>23 (100)</td>
<td>6 (100)</td>
<td>29 (100)</td>
</tr>
</tbody>
</table>

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Participants' responses suggest that individuals with TB generally are not the target of malevolent gossip, although 21% noted that individuals' HIV statuses may be discussed and 7% have heard that extreme measures, e.g., burying a TB patient's material possessions, are needed to avoid the pathogen's transmission. More often, however, conversations centered on the individual's symptoms and well-being.

Regarding participants' knowledge of how others are treated, 14 Kampala participants (35%) and five Mukono participants (25%) reported that they know someone else with TB. Ten of these Kampala participants (71%) and three of these Mukono participants (60%) reported that others are not unkind to this person, while five of the participants indicated that they did not know if others are unkind. Only two participants, both from Mukono, reported that this person is avoided. Three Kampala participants reported that the patient receives mixed treatment with some but not all individuals avoiding this person.

Thus, these data suggest that while some participants have witnessed a few TB patients experiencing some stigmatization and local conversations do associate HIV/AIDS and TB, isolation and avoidance are not consistent and overriding reactions to TB patients, either in Mukono or Kampala.

In terms of participants' own experience with stigmatization, it is important to first note that 39 Kampala participants (98%) and 19 Mukono participants (95%) have told social network members about their illness. The majority of participants have not hidden their illness, although many indicated they are discrete about who they tell. Seventeen Kampala participants (44%) and twelve Mukono participants (63%) believed that others fear catching their illness; however, only fourteen Kampala participants (36%)
and seven Mukono participants (58%) reported that social network members’ interaction has changed. These changes included isolating the participant’s dishes or sleeping space. Two Kampala participants and two Mukono participants reported that people no longer socialized with them. In addition, one participant reported that she now refrains from visiting others because she fears being isolated. Interestingly, only eleven participants (28%), all from Kampala, regretted having told others about their illness.

At the same time that participants did not report experiencing widespread isolation or stigmatization, 33 Kampala participants (83%) and 17 Mukono participants (85%) had no plans to tell anyone else about their TB. Nineteen participants indicated that this is because either all of their family or the other people for whom it matters already know. Additional reasons for not telling others included not wanting to worry others, others won’t help even after being informed of her illness, and the negative impact of the information, i.e., people will gossip, business clients will decrease, people will react badly, or she has been warned not to tell others.

Summary

This chapter explores the data on social network structure and support exchanges by district. Although the differences by district are not consistently statistically significant, they do suggest a number of trends. First, Kampala networks, although bigger, consist of more “additional” relatives but not necessarily additional non-relatives. Second, Mukono participants are as likely as Kampala participants to turn to non-relatives in certain situations, e.g., for information about jobs or to borrow money; however, more Mukono participants than Kampala participants report going to no one for informational or concrete support. Indeed, the majority of Mukono participants report
that no support exists for those contexts or issues. Third, Mukono participants are less likely to report that their social support exchanges are reciprocal – few individuals come to these participants for support. Finally, it is clear that social network members play a critical role in the provision of treatment-seeking support. The majority of participants in both locations receive advice and information on treatments as well as concrete assistance with their personal care, treatment seeking, and upkeep of their households.

These data also indicate that few participants have kept their diagnosis a secret from everyone around them. While participants believe that others are concerned about contagion, such fears have resulted in behavioral changes for only a little over a third of participants. In six cases (10%), this behavioral change has resulted in social isolation and the dissolution of a relationship or the participant choosing to isolate herself. In the remaining cases, however, behavioral change has primarily involved measures for contagion control that are commonly recommended by hospital personnel, e.g., separating TB patients’ eating utensils and dishes. Ultimately, participants are aware that those around them have concerns regarding contagion, that there is a need to be careful about revealing their illness, and the stigmatization of patients exist, but a majority of patients do not report experiencing consistent personal isolation or stigmatization nor do they regret having confided their illness in others.
Chapter 10: Discussion and Conclusions

This study had five primary objectives in its exploration of Ugandan women's TB treatment seeking:

1) Describe participants’ TB health beliefs and explanatory models, particularly regarding TB’s transmission, treatment, and relationship with HIV, in order to understand the impact of such beliefs on the treatment-seeking process;

2) Identify the patterns of care and process of treatment seeking of female Baganda TB patients;

3) Determine whether there are differences in the social network structure and social support exchanges of urban vs. rural patients;

4) Identify the role(s) of social network members throughout the treatment-seeking process and in supporting the participant through her illness; and

5) Determine whether TB patients are isolated and stigmatized because of their active TB infection and/or the disease’s association with HIV.

This chapter discusses the study’s findings in relation to these goals. Participants’ health beliefs and explanatory models are examined first, followed by their patterns of treatment seeking, including the findings on patients’ adherence. Finally, the structure and function of participants’ social networks, the social network’s role in treatment seeking, and participants’ social isolation experiences are discussed.

TB health beliefs and explanatory models in Uganda

Female, Baganda TB patients’ explanatory models are complex, constructed in large part from their experience with TB, but also incorporating local ideas and biomedical perspectives on transmission. Participants primarily conceptualize their illness in terms of their symptom experience, e.g., as a disease involving cough or chest pain, and few specifically state that it is an overarching infection that affects the lungs.

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Participants' explanatory models also associate more advanced or uncommon symptoms of TB, such as chest pain or fever, with the initial stages of the disease.

In addition, participants' health beliefs concerning TB's transmission routes tend to follow western biomedicine's descriptions. The majority believe that sharing eating utensils (including plates and cups) can transmit TB – and many report isolating their plates as a result. Despite these actions, participants also express concern that others in their household are at risk of contracting their illness. Only ten participants (11%) report that they are not worried about the disease's communicability because they are aware that patients on treatment are not infectious.

These findings are consistent with Kleinman's (1980) report that patients' explanatory models tend to blend personal experiences, local beliefs, and biomedical advice. A patient's TB health beliefs accumulate over the course of the treatment seeking process, and are revised as new information is acquired. Although there remains considerable debate within the literature concerning the relative influence of health beliefs vs. treatment access on treatment seeking (e.g., Young and Garro, 1994; Farmer, 1997), this study suggests participants' explanatory models dictate treatment preferences. Whether these preferences are actualized depends upon the availability of funds.

For example, the majority of participants believed in the power of biomedicine and viewed traditional healers as either charlatans or as having skills to treat illnesses besides TB. The few who believed in traditional healers' ability to heal TB indicated that the cost of traditional therapy prevented them from pursuing this option. As a result of these combined factors, only a limited number of participants sought treatment from traditional healers.
Once participants are on treatment, it is not possible to determine from the current study whether patients who define TB in terms of their symptoms are more likely to stop treatment once those symptoms disappear. Evidence from other researchers, however, suggests that patients' motivations to seek treatment decrease once their symptoms improve, and that adherent patients tend to have greater belief in the need for long term treatment (e.g., Menegoni, 1996). Similar to Menegoni's work in Mexico, Nichter (1994) reported from the Philippines that many patients purchase over-the-counter TB medication only until their symptoms diminish, especially if the drugs are costly. Further study in Uganda is critical to determine specifically if symptom-based beliefs limit patients' treatment-seeking adherence, as lapses in treatment can lead to a patient's renewed infectiousness and the development of drug-resistant bacteria.

The findings are also clear that many participants do not recognize or acknowledge that they are seriously ill until the disease progresses beyond a persistent cough. Menegoni (1996) noted a comparable trend in Highland Chiapas, Mexico. Few of her participants recognized the seriousness of their initial persistent cough, which subsequently led to long delays before TB treatment was received. Such findings have serious public health ramifications, as delays in treatment can lead to the continued spread of the disease and increased patient suffering.

Finally, regarding TB's transmission, it is critical to note again from a public health perspective that participants do integrate the advice of clinic staff into their explanatory models of TB — TB education impacts patients' health beliefs. For example, common messages at the TB clinics are that the disease is communicable, with a patient's children at particular risk, and that it is important to separate the patient's dishes. At the
same time, few of these female patients are aware that they cannot transmit their disease once they are on treatment. This inconsistency suggests that the critical second half of the public health message, i.e., that participants have the ability to prevent the spread of TB through treatment, is either not being delivered or its delivery is ineffective.

Whether patients have selectively included transmission information or such details are not consistently part of a patient's education is not clear. However, information on how patients can eliminate the risk of infection through medication could both greatly reduce patients' anxiety and motivate them to complete their drug program. It is critical, therefore, that TB education programs assess whether they are delivering complete information on TB transmission and prevention, and whether they can help to empower participants through infection control knowledge. The ability of female patients to comprehend biomedical perspectives on TB's transmission and prevention should not be underestimated.

Thus, health beliefs, operating as explanatory models, determine when participants perceive that their symptoms require treatment. Explanatory models that minimize the seriousness of symptoms may lead to delays in treatment seeking; models that are primarily experience-based may lead to the premature termination of treatment. Although treatment costs, as discussed below, do influence treatment efforts and may limit treatment options, health beliefs also dictate treatment choice.

Ultimately, these findings suggest that there is a need for a convergence in the debate regarding the role of cultural congruence vs. barriers to treatment. While Young and Garro (1994) and Sargent (1982, 1989) began a trend of examining the multiple social, economic, and illness belief factors which are weighed in treatment decisions,
within the TB literature, there is still a tendency to reduce treatment decisions to issues of economic access (e.g., Farmer, 1997). However, when TB treatment seeking is viewed as a process that occurs over time, it is apparent that TB patients continually assess their symptoms and the need for treatment. Patients’ health beliefs along with their economic resources are the criteria used for these evaluations. From both an anthropological and public health perspective, there is a need to view both sets of factors as forming an interlinked set of assessment guides which dictate when and where treatment will be both sought and/or discontinued.

Health beliefs regarding HIV and TB

Kampala and Mukono participants believe that HIV increases an individual’s risk of developing TB, i.e., that HIV weakens the body, making it susceptible to TB, but participants do not view having both HIV and active TB as an irreparable situation. The majority of participants report that individuals with both diseases should seek TB treatment and that their TB can be cured.

Kampala and Mukono participants do differ, however, in their beliefs regarding the extent to which TB’s symptoms and routes of transmission parallel HIV. Significantly more Mukono participants than Kampala participants either don’t know or tend to agree that certain symptoms (e.g., weakness, diarrhea, and dementia) or routes of transmission (e.g., sexual intercourse, blood of a TB patient) that are typically found with HIV may be characteristics of TB.

Although this difference must be interpreted cautiously due to small cell sizes, it is possible that more Mukono participants are HIV-positive than Kampala participants. There is no reason, however, to suspect a higher incidence of HIV among Mukono
participants and most epidemiological data suggests that there is a higher prevalence of HIV in Kampala than in outlying areas (UNAIDS, 2000). Alternatively, the Kawolo Hospital HIV/AIDS clinic holds individual counseling sessions in the late mornings and early afternoons after the TB clinic. As in Kampala, many Mukono TB patients are HIV-positive; they may visit with counselors or see fellow patients with counselors when they come for their TB drugs. This combined treatment seeking/counseling does not occur as readily among Kampala participants and may account for some of the confusion among Mukono patients. Regardless of the explanation, Mukono participants’ health belief models do not fully separate the symptoms of HIV and TB. Public health messages regarding the symptoms of TB are not delivered consistently across Uganda, which may result in harmful misconceptions.

In addition, while it is also possible that Mukono participants believe that sexual intercourse can spread TB because sex generally requires close contact and shared breathing space, Mukono participants do not respond more frequently that TB spreads through the air. Mukono participants are also not more likely to report that talking to someone can be a transmission route. Thus, Mukono participants do not consistently indicate that personal contact can result in TB transmission. This finding again hints that Mukono participants may associate TB with HIV and/or sexual activity, rather than viewing TB as a distinct illness that is transmitted through the air.

Saunderson (1995) argued that HIV/AIDS and TB are so closely linked in Uganda that they should be managed as one “disease-complex.” While he logically suggested that TB health education and treatment should be integrated with HIV counseling to increase cost-effectiveness, medical practitioners and counselors must be careful to
distinguish the diseases in order to minimize the misconceptions created within participants' explanatory models.

Health educators and medical practitioners must also continue to teach that HIV weakens the immune system, making the body vulnerable to numerous other infections, but that effective treatment is still possible. Indeed, further research is needed to examine whether there are patients who are not attending the TB clinic because their explanatory models link HIV/AIDS and TB, but not the knowledge that HIV-positive individuals can be cured for TB.

Thus, it can be questioned whether programs that emphasize the link between HIV and TB, as opposed to the association between HIV/AIDS and numerous illnesses, unwittingly mislead patients. While participants were convinced of HIV-positive patients' ability to treat TB, programmers and practitioners who distinguish TB as the inevitable result of an HIV infection may unnecessarily discourage other community members who have coughs from seeking appropriate treatment. Health care workers must keep in mind that female patients do listen to their advice and the information becomes selectively integrated into patients' beliefs and explanatory models. Therefore, workers must be careful to convey accurate, but positive and empowering messages.

The treatment seeking process – patterns of care

This study identified that participants' treatment choices followed a general pattern. In addition, these treatment choices are influenced by participants' underlying health beliefs as discussed above, their social networks, and clinic access/expenses. In brief, the onset of symptoms, typically a cough, leads female patients to drink teas made from medicinal plants, and/or purchase non-prescription cough treatments (e.g., Vick's...
Vapor Rub). Frequently, patients then consult local pharmacies or clinics for cough treatments. As their cough persists, patients may visit numerous private clinics and non-governmental hospitals. As this search for a cure continues, participants may have their symptoms for weeks, if not months, before attending the TB clinic.

Family, friends, or other health care providers may refer female patients to the TB clinic, while other females may consult the TB clinic on their own as all other treatments fail. There is no pattern regarding referral to the TB clinic. However, the primary motivation for seeking treatment from the clinic is to be cured. Participants believed that the TB clinic has tablets and injections to treat TB, but these treatments do not necessarily work for everyone. While perhaps predisposed to believing in the efficacy of biomedicine, participants are not necessarily convinced of the power of the TB clinic.

Nonetheless, participants are satisfied with the care provided by the TB clinics. The majority are also pleased with the efficacy of the TB drugs, feeling some improvement within a few weeks of beginning treatment. It should noted, however, that these women may be unwilling to complain about 1) male doctors or 2) the clinic on which they are dependent. Indeed, the complaints that are raised primarily revolve around the resources at the clinic (i.e., lack of furniture) and the high patient volume, which leads to long wait times.

This treatment seeking can be characterized as “hierarchical-exclusive” (Kleinman, 1980), which starts with easily-accessible, inexpensive cough therapies but ultimately proceeds from local clinics or hospitals to the specialized TB clinic. During this search for a cure, participants may alternate between traditional and biomedical health care sectors; these treatments are usually sought consecutively as the vast majority
cannot afford simultaneous treatment seeking. Indeed, once on treatment at the TB clinic, many do not have the extra funds to purchase milk or other food supplements that would help ease the TB medication side effects.

Similar treatment-seeking patterns have been reported both in Uganda and elsewhere. Sebudde and Nakku (1994), as mentioned, found that Ugandan mothers treat the coughs of their children with medicinal herbs before seeking help from a clinic. From his work in Haiti, Farmer (1997) provided the case study of “Robert David,” who also initially tried local herbs for his TB. Only after more severe symptoms developed was he taken to a major referral hospital. Finally, Molyneux, Mung’ala-Odera, Harpham, and Snow (1999) found similar patterns of self-treatment with local herbs and over-the-counter drugs before clinics are sought in their study of childhood fevers in Kenya.

This process of treatment seeking can be relatively expensive. Not only do female patients spend large amounts on treatments outside of the TB clinic, but the lengthy “free” TB treatment itself can be difficult to afford. For example, although local medicinal plants are relatively inexpensive, the majority spent over 10,000 Ush. on non-TB clinic biomedical care. The actual amount is likely much higher, as patients may have made repeat trips to local clinics or hospitals in the search for a cure. While TB medication can be acquired for free from the TB clinic, the costs associated with clinic treatment seeking are substantial. Not only must the majority of patients find round-trip transportation funds, but they must also pay for diagnostic and follow-up tests or x-rays, and supplemental drugs. Depending on the clinic and whether the patient has complications, a patient will have TB treatment expenses a minimum of every month, if not every one to two weeks, for eight months. Patients may incur additional costs through
lost wages due to the extensive travel and clinic wait times. Including travel, a single
clinic visit easily may take three to four hours.

Few participants have sufficient independent income to cover these expenses. As
a result, the majority must rely on family members for assistance. Similar to Nichter’s
(1994) findings, participants’ households frequently sacrifice other purchases, including
meat or green vegetables, in order to pay for the range of treatment related expenses.
Farmer (1997; 1992) likewise noted that families in Haiti dread a diagnosis of TB
because of the long-term costs of care.

Together, these findings reveal that female TB patients’ search for a cure is often
quite lengthy and expensive, and may not address the fundamental cause of their illness:
TB bacteria. Indeed, this preliminary treatment seeking may drain all of a family’s
savings or other resources, which then limits their ability to manage the expenses of TB
clinic treatment.

From these findings, the question becomes why do patients engage in this process
rather than seeking treatment from the TB clinic directly? Yet from patients’
perspectives, these treatment choices flow logically from their beliefs and cultural and
economic context.

First, these female patients do not resist seeking TB clinic treatment because they
doubt the power of biomedicine. The findings regarding participants’ health beliefs
suggest that the majority believe that biomedicine can treat TB. However, patients do not
recognize that their initial, persistent cough is a sign of TB, and that it requires
specialized treatment at the TB clinic.
Second, previous research in Uganda and elsewhere suggested that patients frequently view private clinics and non-governmental hospitals as superior to government clinics (e.g., Akin and Hutchinson, 1999; see also Lonnroth, et al., 2001). This study’s participants who initially seek care from pharmacies or private clinics are quite likely obtaining the cure or practitioner that they think will be most effective. Many are so convinced of the skills of these health care workers that they will commit large amounts of money to the treatment. It is the health care practitioners, then, who either do not recognize the early symptoms of TB and/or do not refer the patient to the TB clinic. Instead, they use influenza, malaria, and simple cough medicines to treat TB patients. Only after these treatments do not work will the patient try or be referred to the government TB clinic.

To reduce the time, money, and energy spent on non-TB clinic treatment seeking, health care planners need to improve the image of and the public’s confidence in the government TB clinics. Clearly, many female TB patients are satisfied with the government’s care and the clinics have greatly improved over the last few decades. These improvements and the existence of many “satisfied customers” should be communicated to the community at-large in order to promote government clinics as the premiere service providers and the first choice for care. In addition, although many public service messages currently indicate that individuals with a persistent cough should seek treatment from the TB clinic specifically, this effort should be increased. These findings suggest that many female patients have not incorporated such messages into their initial explanatory models. Finally, there is a critical need for pharmacists, private clinics, non-governmental hospitals, and even traditional healers and herbalists to receive
training on the signs of TB infection. Combined with an incentive program to encourage
direct referrals to the government TB clinic, such an effort may quickly reduce the delay
between the onset of patients’ symptoms and their presentation at the TB clinic. This
would limit both the amount of time that patients are infectious and increase the funds
patients can put towards TB treatment itself. This training could be joined with current
efforts to professionalize traditional healers and increase biomedical practitioners’
competencies (see also Uplekar, Juvekar, Morankar, Rangan, and Nunn, 1998).

Patient adherence

Although examining female patient adherence was not a primary goal of this
study, it is worth noting that the findings reveal a number of subtle factors that influence
whether female patients adhere to the TB clinic’s recommendations once they begin
treatment. Perhaps the most important of these factors is the expense associated with
“free” TB treatment. Even this study’s highly motivated patients indicated that raising
funds for the treatment-associated expenses described above can be problematic. Many
patients relied on their social network, particularly close family members, for financial
assistance and help. Earlier research in Uganda found a similar reliance on family
members (Wamai, 1993). This barrier to treatment needs to be brought to the forefront of
discussions on treatment access and clinic services.

Second, whether participants have food with which to take their drugs influenced
their adherence from day to day. Similar findings were reported in an earlier study on
treatment adherence among Mulago hospital TB patients (Pekovic, 1996). Third, patients
also had difficulty maintaining the viability of their drugs in Uganda’s tropical climate
and/or carrying their drugs when traveling. Patients clearly need to identify or be
provided with a container that would help preserve the drugs and that could be carried discretely. Patients who leave their drugs behind when traveling or whose drugs become spoiled need an easy mechanism for replacing their missing drugs.

These data support the argument described previously that patients’ failure to adhere to biomedical recommendations is not necessarily due to belief consistency, but rather it is also influenced by logistical or pragmatic concerns (e.g., Farmer, 1997). In this case, these concerns include the cost of treatment seeking, the effects of the drugs when taken without food, or the drugs’ accidental exposure to moisture.

Although Uganda’s health care system is currently overwhelmed with the demands of addressing multiple epidemics, international donors and TB program designers must take these obstacles into consideration. While eliminating these barriers will not be easy, the current response that female patients, whose households have already made great sacrifices to obtain the treatment itself, should simply “eat and drink more” is insufficient.

Rural vs. urban women’s social networks and social support

To summarize the findings regarding social networks, Kampala participants on average have bigger social networks than the Mukono women due to the inclusion of a greater range of relatives. Despite this difference, overall both kin and non-kin relationships are important support sources for both urban and rural women. Although conclusions must be made cautiously due to the small sample sizes, these results support the recent argument of Aguilar (1999; see also Bell and Coleman, 1999) that anthropologists must not overlook the role of friendships as a result of the discipline’s traditional emphasis on kinship. Both types of relationships are firmly a part of social
rural and urban networks in East Africa. Indeed, urban women are not more likely than rural women to have friends in their social networks, as might be expected from earlier studies of urbanization (e.g., Gutkind, 1969).

At the same time, urban women do have an advantage over rural women in that they are able to establish relationships with a greater range of relatives in addition to friends. For urban women, these relationships may not be as emotionally close, however, whether rural women benefit from having higher levels of close ties is unclear, given Mukono women’s lack of confidants. These data suggest that there is a need for anthropologists to rethink conceptualizations of the composition of and support provided by rural women’s networks. The stereotype of rural women as firmly nestled in traditional, supportive, extended kin-based social networks clearly is not accurate in this case. Rural settings, along with urban environments, are continually changing, and rural women may not be sheltered in an extended family nucleus.

The findings on urban women’s networks also contrast with the recent work of Wallman (1996). In her examination of a Kampala neighborhood, Wallman found that non-kin ties are critical, and as noted previously, a common expression is “a good neighbor is better than a relative.” This study, however, did not find a similar emphasis on non-kin among urban women. In fact, when asked who can you rely on more and who is more important, friends or relatives, the majority of urban and rural participants responded that it is relatives. In part, this discrepancy may be due to the differences in the samples. Wallman’s research was neighborhood based, while this study’s sample was drawn from a clinic and all participants were suffering from a very serious infectious disease. It is not known whether participants’ responses would differ in the absence of
the disease and whether participants have activated their kinship networks because of their illness. Nonetheless, as discussed below, it is clear that relatives, as opposed to friends, play numerous roles in the treatment seeking process for these female patients.

Thus, just as social anthropologists in the 1950s and 1960s critiqued earlier sociological theories on urban development (e.g., Epstein, 1961; Gutkind, 1963), an update of social anthropology's conceptualization of urban vs. rural social organization is now needed. While these early social anthropologists were correct that urban life is hardly filled with "anomie" (Wirth, 1938), it is not the case that urban social networks have expanded to include work and association-based relationships and rural networks have remained unchanged. Rather, social relationships in both settings may be based upon consanguineal, affinal, or associative ties. This is not to suggest that extended family networks are being replaced by friendships, rather that the role of friendship deserves further attention. Rural and urban friends in this study tend to be sources of informational and emotional advice for up to one-third of all participants. Furthermore, future studies may find that exchanges with friends increase dramatically when the participant is not maintaining a sick role.

Treatment-seeking support

Regarding treatment seeking support specifically, participants feel that their social network members, typically relatives, are very supportive of their treatment seeking. This support may include emotional or informational exchanges or concrete assistance in treatment seeking or in the care of the household. In terms of the household, for example, relatives often provide and prepare food, fetch water, and care for a participant's children. Relatives also serve as nurses to these female patients, e.g.,
bathing her when she is feverish. In addition, throughout the search for a cure, participants are dependent upon social network members for transportation money, funds to cover other treatment-related expenses, and at times, physical assistance in making the journey to the TB clinic or other treatment center.

Thus, for these female patients who are managing TB clinic treatment seeking, social network support has been critical. Not only do relatives provide advice and encouragement, but they ensure that she visits the clinic and receives her medications. In light of these findings, it would be interesting to compare the social network support available to patients who are unable to endure the demands of TB clinic treatment seeking. These data are also striking because of their implication regarding the extent of participants’ social isolation.

The literature on social networks in East Africa suggests on the one hand that extended family resources are critical during times of crisis (e.g., Ankrah, 1994; Kilbride and Kilbride, 1990, 1997; McGrath, et al., 1994; Weisner, 1997). On the other hand, researchers indicate that extended family networks may be stretched thin by the ongoing AIDS epidemic (Barnett and Blaikie, 1992; Cattell, 1997), or are being supplemented, if not replaced, by less supportive non-kin associations (e.g., Watts, et al. 1989). These findings support the argument that non-kin ties are sources of support, but for this study’s sample of successful treatment-seekers, extended family members provide the majority of assistance. Further research is needed to determine if greater numbers of non-kin ties characterize the networks of unsuccessful treatment seekers. In addition, as will be discussed below, there is little evidence that participants are isolated because of their
illness, however, it is also possible that participants' friendships have decreased and their need for kin assistance has increased as a result of the infection.

**Social isolation and stigmatization**

While findings elsewhere suggested that TB patients experience some level of social isolation, particularly when a patient or his or her family members wish to marry (e.g., Liefooghe, et al., 1995; for a review of the data, see Rubel and Garro, 1992), others indicated that the disease is not necessarily stigmatized (e.g., Menegoni, 1996; Steen and Mazonde, 1999). Prior research from Uganda is inconsistent on whether patients are isolated; there is also concern that the disease's ties to HIV/AIDS may increase any existing stigmas (Odongo-Aginya, 1985; Saunderson, 1995; Wamai, 1993).

This study found, as described above, that social network members provide critical treatment seeking and nursing support. The participants in this study clearly were not shunned. Indeed, they remained socially integrated. It is also important to note that the majority of these female participants have not hidden their illness, although they may be discrete about who they tell. In addition, the participants who have known others with TB report that people generally were not unkind to this person. Finally, while a few participants express that others have questioned their HIV-status or recommended that the participant obtain an HIV test, such comments are not associated with increased reports of isolation or stigma.

In summary, the majority of participants do not report experiencing overt social isolation as a result of their TB and/or its association with HIV. It is possible, however, that this clinic-based sample is biased towards successful treatment seekers who remain connected to their social networks, while those who have been shunned by their families...
are not able to seek treatment. Further research is needed to confirm whether there is variation in patients' isolation experiences.

Public Health Recommendations

Along with their anthropological significance regarding the links between female patients' health beliefs, economic barriers, and social networks, these findings also lead to a number of public health recommendations regarding TB treatment. First, it is clear that an increased and consistent TB information campaign is needed across the country. The community-at-large needs more information on how to identify the initial symptoms of TB and how to determine the first choice for care. Indeed, female TB patients' high levels of satisfaction with the NTLP clinics can be used as a selling point for choosing government care. Such a campaign would ideally lead TB patients to recognize the early symptoms of TB and reduce the number of treatments utilized before a diagnosis is sought from the TB clinic. This would also reduce pre-TB clinic treatment expenditures, possibly leaving more funds to support TB clinic treatment seeking.

This campaign should also target private and traditional practitioners. Regardless of their motivation, by not diagnosing or referring TB patients during their early stages of TB, these providers unwittingly encourage the spread of the disease. In connection with education on the warning signs of TB infection, an incentive to refer patients to the TB clinic could increase referral practices.

TB patients likewise are in need of additional education. It is clear that patients both comprehend and attempt to implement the information they receive at the clinic, e.g., many do not share their dishes and cups, and they agonize that their children who do not understand this separation will utilize their utensils. Thus, staff must reinforce that
patients also limit the disease’s transmission through treatment. Such a message could both reduce patients’ anxiety and help motivate continued treatment seeking.

In addition, increased training among staff on the concept of “explanatory models” and the importance of developing rapport could lead to improved communication and adherence. Patients are not necessarily convinced that the TB clinic has the cure for their illness; instead, they have tried all other options and none have worked. Rather than berating patients for using traditional or alternative therapies, staff need to determine the patient’s understanding of his or her illness and then explain biomedicine’s conceptualization of TB. As staff begin to understand that patients develop explanatory models, they can start to address patients’ understandings that limit TB treatment-seeking behaviors.

Finally, the NTLP programs may wish to encourage patients to talk with each other or meet as informal or formal support groups while they are waiting for their prescription to be filled each week and/or month. Patients in the later stages of treatment seeking can provide advice on what to expect from the medication and how they dealt with difficulties. Patients who have felt an improvement from the medication may also be a source of encouragement for sick patients. The findings here indicate that non-kin ties are important sources of information and advice. Thus, it would be culturally appropriate for staff to encourage formal or informal peer support relationships among patients.
Summary

This study on Baganda women’s TB treatment seeking reveals a number of key points regarding the treatment seeking process, participants’ health beliefs, and the role of their social networks. It also clarifies participants’ perceptions of the relationship between HIV/AIDS and TB, and the impact of such an association on treatment seeking.

First, regarding participants’ health beliefs, it is clear from this research that Kleinman’s (1980) concept of the “explanatory model” remains a useful tool for understanding the range of potentially conflicting ideas and experiences which merge into a patient’s personal illness conceptualization. Such models truly “steer” patient treatment seeking.

At the same time, however, the role of explanatory models as an influence on treatment decisions should not be overstated. Additional factors, including the costs of treatment seeking, impact whether patients will consult a doctor. In the case of TB treatment, even if medications are free, travel, lost work time, and diagnostic testing costs may be prohibitively expensive. Furthermore, whether participants adhere to treatments may depend on such mundane practicalities as whether there is an appropriate drink or food to take with the tablets or whether the rainy season has spoiled the month’s pill supply. Thus, to truly understand the determinants of treatment seeking, it is important to consider a participant’s health beliefs, the social and economic context, and the logistical requirements of the treatments and treatment seeking.

Second, although it is important to recognize the inclusion of friends in both urban and rural social networks, extended family networks still play a critical role during times of illness. Siblings and parents, in particular, carry much of the responsibility of
nursing an ill female patient, managing her household responsibilities, and ensuring that she obtains treatment. This continues even though TB is known to be contagious. It is critical for follow-up studies to determine whether treatment defaulters have lower levels of social support and/or experience greater social isolation because of their illness. The results here clearly indicate that social network support facilitates much of the treatment-seeking process.

Third, it must be stressed that these female TB patients are not socially isolated, nor is there a large amount of concern over TB’s link with HIV. It is likely that TB is now viewed as one of the many diseases that occurs with HIV, and that it is nonetheless curable.

Ultimately, this research suggests that explorations into participants’ health beliefs and explanatory models should continue to be pursued in connection with studies on the social and economic context of treatment seeking. A patient’s health beliefs may determine whether a symptom is evaluated as requiring treatment and then direct treatment-seeking preferences. However, the expense of seeking treatment and a patient’s resources may dictate whether treatment is actually sought. Treatment seeking, itself, even for a contagious and potentially stigmatized disease like TB, is a social process, with social network members playing a pivotal role. This is especially true for Baganda women with limited resources.
Appendix A

Initial Help Seeking and Health Beliefs Questionnaire

Hello. My name is ... I am working on a project for Case Western Reserve University in the U.S. that is interested in talking to women like yourself who are seeking treatment for tuberculosis. We would like to learn from you about your treatment seeking and your relationship with your family and how you feel about the TB treatments. We are looking for women who would be willing to talk to us for about 20 minutes here, and then we could make an appointment to talk longer on another day. You will not lose your place in line – the nurse will call you.

I also want you to know that your participation is completely voluntary. You do not have to answer questions if you don’t want to – it will not influence the treatment you receive at this clinic. You should also know that I am not a doctor and I will not be able to provide any medical care.

If subject is interested:

The first thing we need to know is how long have you lived in Kampala? ________
(If less than 6 months, thank subject and explain that you need to interview subjects who have lived in Kampala for a longer time)

If 6 months or greater, give subject a copy of the consent form and read it to her, ask her to mark it with an “x” or her initials to signal that she understands the study.

We would like to ask you some questions about tuberculosis and how you have treated it. Remember -- all you of your answers are private and will not be revealed to anyone. None of the doctors or nurses here will find out what you say.

Explanatory Model
1. What disease do the doctors say that you have?

2a. Tell me about your illness?

2b. After subject responds, when did it begin (how long ago did you first experience your TB symptoms)?

2c. What symptoms did you have first?

2d. Did you try any treatments for those symptoms? (if yes go to 7e; if no go to 7g)
2e. If yes, what did you try? (if tablets, ask where they got the tablets)

2f. Did it help?

2g. Did the symptoms change?
2h. If yes, how did they change?

2i. What did you do when you got those other symptoms?

2j. What other treatments have you tried?

3. Do you think you have any other illness? (if yes, what illness?)

4. Can you describe what happens to your body when you are infected with tuberculosis?
   4a. Are any of these symptoms of TB?

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fever</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wasting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Night Sweats</td>
<td></td>
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<tr>
<td>Rash</td>
<td></td>
<td></td>
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<tr>
<td>General weakness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Backache</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chest Pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diarrhea</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sores/Blisters</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thin appearance</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4b. Are there any other symptoms of TB?

5. How did you get your disease?

5a. Are there other ways that you can get it?

5b. After subject responds, can you get it from: (if subject mentions item above, you do not have to ask about it)

   5b1. using the eating utensils of someone with TB   y   n
   5b2. having sexual relations with someone with TB   y   n
   5b3. having sexual relations without a condom      y   n
   5b4. talking to others with TB                      y   n
   5b5. living in a dirty house                       y   n
   5b6. breathing dusty air                           y   n
   5b7. working too hard                              y   n
   5b8. not getting enough sleep                      y   n
   5b9. drinking alcohol too much                     y   n
   5b10. poor nutrition                               y   n
   5b11. smoking                                      y   n
   5b12. contacting the blood of someone with TB      y   n

6. Where did you hear this information about TB?

7. Are you worried that someone might catch your TB from you? Why or why not?
8. What treatments are available for TB?

8a. *After subject responds*, are there any home remedies? (if yes, go to 13b)

8b. If yes, what are they?
8c. Can a traditional healer treat TB?

8d. What treatments are at the hospital?

8e. What treatments are available outside the hospital?

9. How long have you been coming to this clinic for your TB?

10. Why did you come to this clinic?

11. How do you get to the clinic?

11a. *if not on foot*, how much does this cost?

11b. *if not on foot* how do you usually get the money for this?

12. How long does it take to get from where you are staying to the clinic?

13. Have you had TB before? (if yes, go to 18a) ___________
13a. If yes, how long ago did you have it? ____________
13b. What did you do to treat it?

14. For the next few questions, I’m going to read a statement and ask whether you agree or disagree with it:
   a. I have told my household that I have TB agree disagree
   b. I have told my relatives that I have TB agree disagree
   c. I feel I must hide the fact that I have TB from my neighbors agree disagree
   f. My partner agrees with my decisions on treating my disease agree disagree
   g. My partner has not been a source of support during my illness agree disagree
   h. This TB clinic is too far away from me agree disagree

Demographic information
15. How old are you?

16. Where were you born?

17. Are you married? _________________
17a. If yes, does your husband live with you? ________

18. Who else lives in your household?
19. What ethnic group do you belong to?

20. How many children do you have?

Those are all the questions I/we have for today, but I/We’d like to talk to you some more about your experience with this disease and trying to find a cure. Could we come to your house in a couple days to talk more? Will you have time on .... (suggest day and time)

What is your name?

Do you have a nickname or name they know you by in your village?

Could you give us directions to your house?

Directions to subject’s house:

Or Directions to Subject’s work place:

Subject’s Phone Number (if available) ______________________
Name of village ______________________
Name of Zone _______________________

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Appendix B

Date __________________________ ID Number ______
Start time: ______________ Stop time: ______________

Follow-up Social Networks and Health Beliefs Questionnaire

Treatment-seeking behavior

Illness history
We would like to learn more about what you have tried to treat your tuberculosis. We know that sometimes people try to treat their symptoms themselves, or they talk to their family to find a treatment, or to a local healer. You told us a little bit about your symptoms and treatments last time, but we'd like to know a little more.

1. How did you realize that you were very sick?

2. At first, what made you decide to seek treatment?

Probe for details on self care:
3. Did you try to treat your symptoms at home? __________(if yes -> a; if no ->4)
   a. What did you do?
   b. How did you hear about this treatment? (if relative, specify relationship)
   c. Did it help?
   d. Are you still using these treatments?
   e. How much do these treatments cost?
   f. Where did you get the money? (if relative, specify relationship)

4. Has anyone recommended that you try an herbal remedy? _____
   (if yes ->a; if no-> 5)
   a. Who? (if relative, specify relationship)
   b. Did you try it? __________ c. If yes, did it work?

Probe for details on traditional healer if not mentioned above:
5. Do people sometimes go to a traditional healer for TB?
5a. Have you tried a traditional healer? ________ Why or why not? (if yes->b; if no->6)
   b. If yes, what did the traditional healer say was wrong with you?
   c. What treatment did they advise?
   d. Did it help?
   e. Are you still going to a traditional healer? ________ Why or why not?
   f. How much did it cost to see a traditional healer?

   g. Is this big or small compared to “scientific treatment” [Luganda phrase encapsulating clinics/doctors/biomedicine]?
5h. Where did you get the money to pay?
i. Why did you decide to consult a traditional healer?

6. Are there any other illnesses or symptoms that you would take to a traditional healer? _____ a. if yes, What illnesses?

7. Does anyone in your family ever go to a traditional healer? ______ If yes, for what illness?

8. Some people like traditional healers more than doctors, others like doctors better, some say there are good and bad parts of each. What do you think?

Other clinics
9. Have you visited any other doctors, clinics, hospitals, or pharmacies before you came to Mulago/Hospital ‘x’? ________ If yes, what did you do? (specify location of clinic, pharmacy e.g., clinic in their village)

9a. Did it help?

9b. Are you still doing this? ________________ If no longer doing this, why not?

9c. How much did this cost?
9d. Where did you get the money to pay? (if relative, specify relationship)

Probe, unless mentioned above:
10. How long do you have to wait to see a doctor at this clinic?

11. How often are you supposed to go back to the clinic?

12. Are you able to come back then? _______________ If no or not always, why not?

13. Do you ever give the nurses or doctors tips? ____________ (if yes ->a; if no->b)

13.b. If no, have you ever heard of anyone giving a tip? __________ How much would they give? __________ How often? __________ Why did they give a tip?

TB medication
14. How many drugs does the doctor say that you have to take? (number of different types)

15. How often do you have to take them? ______________ Are you able to take them as instructed?

16. How often do they have the drugs at the clinic?
17. How often do you have to buy them at the pharmacy?

17a. If you ever have to buy them, how much do the drugs cost?

17. Where do you usually get the money when you have to buy them?

18. For how long do you have to use the drugs? [length of time] ______________

19. Do you have any problems [i.e. side effects] using these drugs? __________

a. If yes, what problems?

b. What did you do about these problems?

c. Did these problems influence whether you continued taking the medication? ______

If yes, how?

20. Have you been able to take all the drugs you have been given? ______ Why or why not?

21. Are you doing any other things to treat your TB? (Probe for changes to diet, sleep)

Utility of treatment
22. How do you like how the drugs are working?

23. Has there been any change for the better since you’ve been taking treatment? ______

23a. If yes, how long did it take?

23b. If no, how long do you think it will take for the treatment to make you feel better?

24. Who has the most effective treatment for TB? (what type of healer/medicine)

25. Does this treatment work for everyone?

25a. If no, who does it not help?

26. Do you have any other illnesses besides the TB? (Probe: what illnesses, how long had them, what treatments)

Household decision-making, incl. treatment-seeking decisions
27. Sometimes if you have to ask people for money to pay for medicine, people want to tell you what medicine you should buy or where you should go. Has this happened to you? (probe for what happened)

28. Do you have enough money to buy the treatments that you would like? (probe: if no, if you had money, what would you like to do for treatment?)

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29. Does seeking treatment require you or your family to go without other things that you need? ________________ If yes, what things?

30. Do your friends and family think that it is important to seek treatment for TB? _____ Why do you say this?

31. If you wish to purchase something, do you consult with anyone about spending the money? ________________ If yes, who?

32. Who decides how much money can be used to see the doctor?

33. Who usually decides what food to buy? ________________ Who pays for the food?

Concept: Subject's Health Beliefs;
Now I'd like to ask you about your beliefs and experience having TB.

34. Is it possible for someone to prevent getting TB? ________________ If yes, how?

35. Does being pregnant make you susceptible to TB? ________________

35a. Does TB change in pregnant women?
   b. Do pregnant women who have TB seek different treatments than women who aren't pregnant?
   c. Are you pregnant now? (if yes go to d; if no go to e) __________
   d. If yes, have you changed the treatment for TB you have been with?
   e. If no, would you change your treatment seeking if you became pregnant?

36. Does having AIDS change the way TB occurs in a person? ________________ If yes, how?

37. Does having AIDS change a person's ability to treat their TB? ________________ If yes, how does it change?

38. Is it easy for people with TB to get AIDS? __________ Why or why not?

39. Is it easy for people with AIDS to get TB? __________ Why or why not?

Social network advice/social stigma
40. Who do you talk to about your illness? [if family, specify relationship]

41. What do you talk about?

42. Has anyone given you advice on how to treat your symptoms? ______ (if no—>
   43)
42a. If yes, who? (if relative, specify relationship)
42b. What did they say?

42c. How have they influenced how you have treated your symptoms?

43. Does anyone know that you have been diagnosed with TB? [if no, skip to 45]

44. If yes, has their interaction with you changed since you told them? ____________
a. if yes, how has it changed?
b. Do they fear they may catch your illness from you?
c. Do you regret that you told them?
d. Do they help you with treatment for your illness? ____________ If yes, how?
e. Do they help you or did they help you do things that you cannot or could not do because of your illness? ________________ (if yes->44f; no->g)

f. If yes, what do they do?

g. Are you going to tell anyone else? Why or why not? [Go to 46]

45. If no, [people don’t know it is tb]
a. Why haven’t you told people about your illness?

b. Do you expect their behavior would change if you told them? ____________

45b1. if yes, in what ways would you expect their behavior to change?

c. Do you expect they would fear catching your illness from you?

46. Does anyone talk to you about their health or illnesses? ____________ If yes, who [specify relationship]

Social Network Members’ Health Beliefs

47. Skip – duplicated 49

48. Do you ever hear people talk about anyone who has TB? ____________ 48a. If yes, what do people say about this person?

49. Do you know anyone else with TB? ________________ (If yes->a: if no->social networks)
a. If yes, who?

b. Do you think people treat this person in a special way because he/she is sick?

50. Are they unkind to this person?

51. Do they avoid this person?
Social Networks
For the next set of questions, we would like to know more about the people who are important in your life. Think over the last few months, what people have been important to you? They may have been people you saw, talked with, or wrote letters to. This includes people who made you feel good, people who made you feel bad, and others who just played a part in your life. They may be people who had an influence on the way you made decisions during this time. They may also be people who live far away, but who are still important to you. There are no right or wrong answers, just list the people you think of. For each person you mention, we will place their first name on a card.

[interviewer will have small index cards with spaces for network member’s name and blanks to record the following characteristics; cards will then be used to sort network members into piles]

Probes: [this may be adjusted after pretesting]

52. First, think of people in your household or compound, whom does that include? Fill in category on map

53. Now, going around the map, what other family members would you include in your network? Fill in map

54. How about people from your neighborhood, the RC1 or 2, or even people from the market?

55. Is there anyone from your place of birth that you would include?

56. How about people that you know from your work or from school?

57. Is there anyone from church?

58. Is there anyone that you know from a social club, association, or meetings (like wedding meetings) that you would list?

59. Is there anyone from the hospital, clinic, or local healer that you would include?

60. Look over your network. Are these the people you would consider important in your life over the past few months? (Should we add any names or take any names off?)

61. Who would be available to help you out in concrete ways – for example, if you need help making a repair in your house, or assistance getting somewhere, or needed money for an emergency? Divide your cards into three piles – those people you can hardly ever rely on for this help, those you can rely on sometimes, and those you’d almost always rely on for this type of help.

62. Who would be available to give you emotional support – for example, to comfort you if you were upset, to be there for you in a stressful situation, or to listen to you talk about
your problems? Again, divide your cards into three piles – those people you can hardly ever rely on for emotional support, those you can rely on sometimes, and those you almost always can rely on for this type of help.

63. Finally whom do you rely on for advice – for example, who would give you information on how to do something, or help you make a big decision, or teach you how to do something? Divide your cards into three piles – hardly ever, sometimes, and almost always – for this type of support.

64. Look through your cards and this time select those people, if any, in your network who you feel are critical of you -- either critical of you, or your lifestyle, (or if subject has kids – of you as a parent). By “critical,” I mean people who make you feel bad or inadequate. Divide the cards into three piles, those people who are hardly ever critical of you, sometimes critical of you, and almost always critical of you.

65. Now look over your cards and think about the direction of help. Divide your cards into three piles, those people with whom help goes both ways (you help them as much as they help you), those whom you help more, and those who help you more.

66. Now think about how close you are to the people in your network. Divide the cards into three piles – those people you are not very close to, those you are sort of close to, and those you are very close to.

67. Now we would like to know more about each of these people you have listed. (For each person ask:) [About each subject ask the following questions:]

68. a. How old is _______? (approximate)

   c. How much time does it take to get from your house to where _______ stays?

   d. Do you know if _______ has been to school? How long did they study?

69. (If not mentioned above and a relative), what is their relationship to you?

70. How long have you known ______________?

71. Before you got sick, how often do you see _______? (daily, weekly, monthly, yearly)

72. Has this changed? _______________Why?

***Does this person know about your illness? ______________ If yes, what does he/she know?

***Have any of these people given you advice about your symptoms? (although social networks may not know subject has TB, they may still suggest treatments for the cough)
73. If you were to estimate about how wealthy or how much money each of these people has or earns, could you put these cards in order from who is the wealthiest to who has the least amount of money? (mark cards)...where in this order would you put yourself?

74. Have the relatives or friends in your life changed in the last year? _____
If yes, ________
   a. how has it changed?
   b. what was the impact on your life?

Now, I want to ask you about specific examples of if something were to happen who you would go to. You can name the people on these cards, or anyone else who fits.

Social support network
Tangible support
(if subject has children->75; if no->78)
75. What do you do with your children when you go to the doctors?

75a. Do you ever pay someone to watch them? ________ If yes, how much do you pay? ________ How often? ________

76. If you temporarily could not take care of your children, who could help you look after them? (probe for people nearby and far away)

77. Are your children in school? ________ If yes, how do you get the school fees?

78. Sometimes people make arrangements with their family or friends for matoke, beans, or other food. Do you receive food from anyone? ________ (if yes->a; if no-> 79)
   a. If yes, who gives you food? (specify relationship)
   b. What kind of food?
   c. How often does this happen?
   d. Do you give anything in return for this food?

79. Is there anyone to whom you give food? ________ If yes, who?

80. As you have been sick, has anyone helped you take care of your household? _____
   (if yes->a; if no->81)
   a. Who? (specify relationship)
   b. What did they do?

81. Has anyone helped you take care of yourself while you have been sick? _____
   (if yes->a; if no->82)
a. If yes, who? (specify relationship)

b. What did they do?

82. Has anyone helped you obtain any of the drugs the doctors prescribed? _____
   (if yes->a; if no->83)
   a. If yes, who? (specify relationship)
   b. What did they do?

83. Has anyone helped you with transportation to the doctor or other places for treatment?
   (if yes-> a; if no-> 84)
   a. If yes, who? (specify relationship)
   b. What did they do?

Emotional support
84. Who can you talk to about your problems? (Probe for partner, other family, friends)

85. Do people ever come to you to talk about their own worries? _________ If yes, who?

86. Who can you talk to about your concerns about your children? (probe for partner,
family, friends)

87. Do people ever come to you to talk about their own children? _______ If yes, who?

88. Who can you talk to about your concerns about your partner? [if subject doesn't
have a partner, ask who she has talked to in the past about problems with her
partner]

89. Do people ever come to you to talk about their partner? Who?

Informational support
90. Who do you get advice from when making important decisions?

91. Who comes to you for advice?
91a. How often do they come to you?

92. Who do you talk to concerning jobs?

93. Does anyone come to you for this information? _____________ a. If yes, who?
   b. How often do they come to you?
94. Who do you talk to for information about doctors or medicine?

95. Does anyone come to you for this information? _________ If yes, who?

96. Look over who is mentioned as providing support. If same person or a few select people are repeatedly mentioned, ask: you have mentioned _______ many times as a source of support. Why is he/she an important source of support?

97. Is there anyone outside of Kampala/village ‘x’ who can assist you? _________
   a. If yes, who?
   b. when would you ask them for help?

Meaning/impt. of network members
98. Who is more important to you, friends or relatives? _________ Why do you say this?

99. Who do you rely more on when you are in need, your relatives or your friends? _______ Why do you say this?

Subjects’ economic contributions
For questions 100-103, ask subject to think of the time prior to being ill with TB
100. Before you got sick, what things did you do to earn money?
   a. how much would you earn at each of these jobs (e.g., on a day or each week or month)?
   b. how did you usually spend the money?

101. What were your major expenses? (probe for rent, food, school fees)
   a. whose money paid most of the bills?
   b. Did you usually have enough money to pay these expenses? _________ If no, how would you get the money?

102. Would you ever give money to your partner to use? _________ If yes, how often would you give him money?

103. Would you give money to other family members? _________ If yes, how often would you give them money?

For questions 104-109, ask subject to think of the time while they’ve been sick
104. Since you have gotten sick, have the things that you do to earn money changed? ______ If yes, what has changed?

105. How much money do you make now?
106. Does anyone else contribute money to your household? (If not mentioned, probe for partner’s contributions, other family members’ contributions)

107. Are you able to pay all your bills? ________________

108. Has needing to go to the clinic had an impact on your business or job? (If just starting treatment, ask if subject thinks coming to the clinic for treatment will impact her business or job) ________________ If yes, how has it had an impact?

109. Have you borrowed money from someone else? _________ (if yes->a; if no->110)

   a. If yes, who?

   b. How much did you borrow?

   c. what did you use it for? (If not mentioned, probe: have you asked anyone for money in order to seek treatment or to pay your medical bills?)

Demographic Information

110. If subject has moved from place of birth, why did you move?

111. Did you ever study? [i.e. go to school?] ____________ If yes, how many years?

112. Do you rent or own your house?

   Do you have any animals (cows, goats, chickens)? ________________ If yes, what and how many?

   Do you have a garden? __________________________ (if yes->a; if no->end)

   Is yes, what do you grow? __________________________

   Do you supplement what you grow? ____________ If yes, how much do you spend (and how often)?
End of interview

Location of interview: ________________________________________________
(geographical location and site – e.g., subject’s house in Kalarwe or take away in Ntinda)

SES
Observe the following:
Does subject’s house have a (circle if present): radio TV electricity
  telephone refrigerator cooker (stove) bicycle Car
Describe construction of subject’s house: (building material, roof, windows, # of rooms, overall upkeep)

Describe interior of subject’s house (if seen): (amount and type of furniture, size of room, upkeep)

Other comments:
Appendix C

Social Networks and Health Beliefs
Additional Follow-up questions (third interview)

8. How have you been feeling the past month?

Treatment-seeking
1. In the past month, have you been to the ________ clinic?
   If yes->a; if no->c

   1a. how many times
   1b. Reason for going? (ask about each visit—if regular appointment, please note) go to 2

   1c. If not been back, were you supposed to go back? ____________ If yes, why didn’t you go?

2. Are you still taking treatment from __________________? If no, why not?
3. Have you taken any other treatments for your cough this past month? ____________
   a. If yes, what treatments? B. hear about treatment

4. Have you had any illnesses in the past month? ____________
   4a. If yes, for each how did you treat them?

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5. How satisfied were you with how the treatments worked (for the other illnesses)?

6. Have you visited any other clinic in the last month?
   If yes, which clinic(s) ________ How many times ____________ Reason(s) for going

Satisfaction
13. Now that you have been going to Mulago/Kawolo hospital for some time, how satisfied are you with the doctors?
   a. The nurses?
   b. The clinic overall?
14. deleted [question on if you could change anything about TB drugs – difficult to answer]

15. If you could change anything about the TB clinic, what would you change?

16. Is there anything that could be done to make it easier to obtain the TB drugs?

17. Is there anything that could be done to make it easier to take all the medicine? (each day or 6 month course of treatment??)

17a. What is the biggest problem you have had with taking the TB medicine [not side effects, more problems with keeping the regime or taking medication]

9. Have you been able to take your drugs everyday? If no, why not?

10. Have you been able to take all your drugs this month? If no, why not?

11. Have you had any problems obtaining the drugs at the clinic? If yes, what?

12. Have you had any side effects from the drugs the past month? If yes, what?

18. What could be done to get people to come to TB clinic sooner after their cough develops?

19. Has the clinic staff answered all your questions about your illness or the medications? If no, what questions do you have?

20. duplicate deleted

20a. Has any of the advice or treatment you have received from people you know or from doctors/nurses conflicted with other advice or treatment you have received (e.g., one says to take this tablet or do this, and another person says no, don’t do that do this…)

If yes describe the situation

20b. Thinking about all the advice that you have received about your illness, have you ever disagreed with any of the advice or treatment that you received from people you know or doctors? If yes, describe situation

Health Beliefs

21. What is TB?

22. What causes TB?

23. duplicate deleted
25. What different types of cough are there?

26. What are the things that you or other people do to treat each of these coughs?

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<th>Types</th>
<th>What causes each type of cough?</th>
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27. duplicate deleted

24. Is it possible to tell the difference between TB and other coughs? If yes, what is the difference? If no, why not?

28. In children, how do you know if a cough is TB or caused by something else?

Scientists are interested in finding more about the number of different types of healing methods and medicine that people use (herbs or local medicine that are used for all illnesses, not just TB). Sometimes plants or local medicines have the ability to heal illnesses or reduce symptoms. We would like to find out what you know about plant medicines and local treatments.

29. duplicate deleted

30. What herbs or plants that can be used to treat or reduce an illness?

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<th>Herb record Luganda</th>
<th>Illness record Luganda</th>
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30a. Have you ever used any of these herbs? If yes, what was used/when did you use it? (prev 29)

31. Can witchcraft cause TB? Why or why not?

32. Can witchcraft cause other coughs? Why or why not?
   a. if yes, describe

33. What did they tell you about TB at Mulago/Kawolo?

34. Have other clinics/doctor told you anything? If yes, what?

35. Is there a clinic in your village? _____________
   a. If yes, how often do you use it?

   if EVER used it -> b; if not used -> d

   b. If ever used it, how do you like the care you receive there?
c. If ever used it, how do you like the care you receive there compared to the Mulago/Kawolo clinic?  
   Go to 36; skip d

d. If never use it, why not?

37. Is there a traditional healer in your village?
37a. If yes, have you ever visited this healer for treatment?

38. Is there someone who sells traditional herbs or medicine in your village?
38a. If yes, have you ever used herbs or medicine from this person?

39. Are there ever times that you are unable to travel to Mulago/Kawolo or other clinics for medical help because you don’t have the money  
   If yes, how often?

   Describe the last time this happened

40. If you could tell the doctors anything, what would you want to tell them? (based on your experience having TB and seeking treatment for the illness)
Appendix D

Case Western Reserve University – Makerere University
Social Networks and Health Beliefs
Informed Consent Letter

I understand that the purpose of this study is to examine Baganda women’s health beliefs about their illness, how they decide to treat their illness, and the involvement of their friends and/or family in treatment-seeking.

I understand that the project investigator, Sarah Chard, or her field assistant, Grace, will interview me two times at a time and location convenient to me. The first interview should last about 15 minutes; the second will last two hours. I will be asked questions concerning my beliefs about my illness and my treatment actions. I will also be asked about my friends and family and whether they know or help with my illness. I will additionally be asked about how I contribute to my household and how decisions about spending money are made in my home, especially concerning paying for health treatments. After the second interview, if I am willing, the interviewer will visit me again for a final one hour interview. I also give this project permission to read my medical records to find the names of the drugs I have been taking, how long I have been taking them, how often I come to the TB clinic, the doctor’s diagnosis, and the outcome of my treatment.

I can refuse to answer any question and stop the interview at any time. All of my answers will be confidential. No one will know my name or my responses, and my care at the health clinic will not be influenced by participation in this study. There are no costs or direct benefits to me for participating in this research.

I have read or have been read this statement and I understand it. If I have any questions or concerns regarding this study I can contact Sarah Chard in Kampala at 534-262 or at the Dept of Anthropology, Case Western Reserve University, 10900 Euclid Ave., Cleveland, OH, 44106, U.S.A.

Subject’s Initials ___________________________________ Date __________________________

Interviewer Sign ____________________________________________________________________
Appendix E: Description of Kampala recruitment clinic site

Kampala, Uganda’s capital, is the largest city in the country. It is governed as its own administrative district, and includes a business and industrial city center and surrounding suburbs. The district’s area covers 238 square kilometers and has a total population of 774,241. All of the residents of the district are classified as “urban dwelling” (Rwabwoogo, 1997), although residents may tend gardens for both subsistence and informal sale.

The Mulago TB clinic is housed a series of largely unattached, single story buildings scattered down a hillside, at the bottom of which is the modern, multi-storied hospital (New Mulago), built by the British in the 1960s.

The Old Mulago complex is reached by either unpaved footpaths that cut across the back of the hill, or by a road which is only partly paved. At the TB clinic, there is neither pavement nor a sidewalk. Visitors, including sick patients, often must walk up the steep hill to reach the clinic, as most Matatu taxi-buses stop at New Mulago. The few Matatus that continue to old Mulago take a circuitous route through the surrounding neighborhood which may add over 30 minutes to patients’ travel time. Along with the TB treatment facility, Old Mulago contains Uganda’s National Cancer Institute, the dental clinic, the antenatal and maternity clinics, and Case Western Reserve University’s and Johns Hopkins University’s research offices. Thus, although lacking a well-serviced road, a number of important clinics lie within the Old Mulago complex.

The TB clinic itself is found in Wards 5 and 6 of Old Mulago, two buildings at the top of Mulago hill. The clinic has both inpatient and outpatient services, although, as
described in chapter two, only the sickest of patients are hospitalized\(^1\). For those who are hospitalized, there are separate sections within the wards for men and women. Each section consists of a long, narrow room, with glass-less windows and metal bedframes running the length of both sides of the room.

Upon diagnosis, outpatients are given a registration card, medication, and instructions on when to return for their next injection or tablets. The TB clinic is typically open on Wednesdays and Thursdays of each week for drug distribution. When patients return for their prescription refills, they do not see a doctor unless they are experiencing medical problems such as medication side effects. Instead, patients report to the rear window of the clinic where the pharmacist collects their clinic registration cards, evaluates their treatment statuses (i.e., whether additional sputum or x-rays are needed), and the next phase of treatment. He then typically supplies them with a month’s worth of TB drugs.

Because a large number of patients report for drugs each week, patients may have to wait long periods for their prescriptions. Patients must stand at the window or sit on mats on the ground outside the ward while waiting for their name to be called from the pharmacist’s window. The pharmacist and his assistant may spend the entire morning and into the afternoon preparing medication packets and distributing them to the patients.

\(^1\) Along with the NTLP’s policy of treating the majority of TB patients as outpatients, patients themselves may delay or refuse hospitalization if there is no one who can take care of them in the hospital or their children at home. The majority of in-patient hospital care (e.g., preparing meals, washing linen and clothing, and bathing the patient) is supplied by patients’ relatives.
Appendix F: Description of Mukono recruitment clinic sites

Mukono district lies directly to the east of Kampala, its southern edge running alongside Lake Victoria. The district has an area of 14,242 km, and according to the 1991 census, a population of 824,604. Twelve percent of this population is urban dwelling; the remaining 88% are classified as “rural” (Rwabwoogo, 1997). The district’s economic activities center on agricultural production, dairy farming, and fishing. The food crops produced include cassava, plantains, sweet potatoes, yams, and ground nuts. The primary cash crops are tea, coffee, sugar cane, and cotton. The district houses some facilities for processing these crops, along with a small number of furniture, metal, and textile workshops. On the most eastern edge of the district lies one of the country’s most popular breweries, Nile Breweries (Ibid.).

The first research site, Kawolo hospital, is located on the outskirts of the Lugazi trading center in Mukono district. Lugazi is 44.8 km east of Kampala, and 43.2 km west of the town of Jinja (Kalyegira, 1997). While tourists often drive from Kampala to Jinja to visit the source of the Nile River on Lake Victoria or Bujagali Falls, they rarely stop in Lugazi. The area’s trading center once may have been sizable, but now many of the shops are boarded up, and no new tourist industry has developed. This contrasts with other trading centers along the road to Jinja, which attract tourists with fresh produce, roasted chicken or bananas, and crafts.

Lugazi is surrounded by rolling hills of sugar cane and the area is primarily known for its sugar cane processing plant. The population size of Lugazi is unknown. There are a few housing structures located near the trading center as most of the area’s inhabitants reside on small compounds that are scattered throughout the hillsides, far
from the main road. The only access to many of these homes is on secondary dirt roads and foot paths.

Kawolo hospital, one of four government hospitals in Mukono district, is a ten minute walk from the Lugazi trading center. The hospital consists of a series of single story wards, which are connected via covered sidewalks. Along with the administration building and the outpatient services building, which holds the TB clinic, there are separate inpatient structures for men, women, and children, and an antenatal clinic. As with many hospitals in Uganda and other developing nations, Kawolo's technological resources are limited. The TB clinic itself is manned by a single medical officer and at times, a nurse assistant. The medical officer works under the supervision of the National Tuberculosis and Leprosy Control Program and is responsible for seeing patients each week on the clinic day (Tuesday), evaluating symptoms, prescribing medications, and administering injections. Unlike Mulago, patients return to the clinic every one to two weeks for the next week's medication. If a patient fails to return as scheduled, the medical officer has been known to conduct home visits to determine the reason and to distribute the medication.

The second Mukono site, The Mukono Health Centre, is located on the main Kampala-Jinja road, on the western edge of the Mukono town trading center. Mukono is 20.8 km east of Kampala, and 24.8 miles west of Lugazi. Larger, more prosperous, and closer to Kampala than Lugazi, the town is the administration headquarters of the district. Despite the busy trading center, a modern hotel, and light industry, the areas off the main road are largely agricultural. Again, due to the lack of census data, the exact size of the population and their distribution is unknown.
Unlike the hospitals described above, the health center is much smaller, consisting of one primary building with a central waiting room, and two clinic rooms. The waiting room is bare except for wooden benches alongside each wall and a desk for the medical officer. There is no inpatient ward. On clinic days, the medical officer sits at the waiting room desk, conversing softly with patients about their condition and dispensing medication. Of the three sites, this is the smallest, both in terms of the facility and the number of patients. It is an important TB clinic, however, because it minimizes the amount of traveling required by local TB patients. Without it, patients would have to travel 30 to 45 minutes from Mukono town to Kawolo hospital or up to two hours to Mulago hospital to obtain their medications.
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</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

70. How long known

71. How often see:
   0 never
   1 yearly
   2 monthly
   3 weekly
   4 daily

72. Change in frequency of seeing since illness:

72a. Know about illness

72b. Offer advice about symptoms

73. Order of wealth (1 = wealthiest; number from wealthiest down)*
   - closest to subj

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## Table E-1 Number of participants reporting symptom as characteristic of TB by district

<table>
<thead>
<tr>
<th></th>
<th>Kampala</th>
<th>Mukono</th>
<th></th>
<th></th>
<th>X²</th>
<th>V</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>N (%)</td>
<td>No</td>
<td>N (%)</td>
<td>Don't Know</td>
<td>N (%)</td>
</tr>
<tr>
<td>Breathing Difficulty</td>
<td>13  (20.3)</td>
<td>51  (79.7)</td>
<td>0</td>
<td>0</td>
<td>25  (100.0)</td>
<td>0</td>
</tr>
<tr>
<td>Weakness</td>
<td>59  (92.2)</td>
<td>5   (7.8)</td>
<td>0</td>
<td>23  (92.0)</td>
<td>0</td>
<td>2   (8.0)</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>10  (15.6)</td>
<td>53  (82.8)</td>
<td>1</td>
<td>5   (20.0)</td>
<td>16  (64.0)</td>
<td>4   (16.0)</td>
</tr>
<tr>
<td>Dementia</td>
<td>2   (3.1)</td>
<td>62  (96.9)</td>
<td>0</td>
<td>1   (4.0)</td>
<td>21  (84.0)</td>
<td>3   (12.0)</td>
</tr>
<tr>
<td>Sores</td>
<td>4   (6.3)</td>
<td>60  (93.8)</td>
<td>0</td>
<td>2   (8.0)</td>
<td>21  (84.0)</td>
<td>2   (8.0)</td>
</tr>
</tbody>
</table>

## Table E-2 Number of subjects reporting activity as a route of TB transmission

<table>
<thead>
<tr>
<th></th>
<th>Kampala</th>
<th>Mukono</th>
<th></th>
<th></th>
<th></th>
<th>V</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes/ sometimes</td>
<td>No</td>
<td>Don't Know</td>
<td>Yes/ sometimes</td>
<td>No</td>
<td>Don't Know</td>
</tr>
<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Sex with TB patient</td>
<td>31   (48.4)</td>
<td>17  (26.6)</td>
<td>16  (25.0)</td>
<td>15  (60.0)</td>
<td>0</td>
<td>10  (40.0)</td>
</tr>
<tr>
<td>Sex without a condom</td>
<td>18   (28.1)</td>
<td>32  (50.0)</td>
<td>14  (21.9)</td>
<td>14  (56.0)</td>
<td>0</td>
<td>11  (44.0)</td>
</tr>
<tr>
<td>Blood of TB Patient</td>
<td>39   (61.9)</td>
<td>14  (22.2)</td>
<td>10  (15.9)</td>
<td>17  (68.0)</td>
<td>0</td>
<td>8   (32.0)</td>
</tr>
</tbody>
</table>
## Appendix I Patient Satisfaction

### Table I-1 Patient satisfaction with the clinic staff and the TB clinic overall* (N=40)

<table>
<thead>
<tr>
<th>Satisfaction with doctors</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors “handle” patients well/are good to patients</td>
<td>25 (62.5)</td>
</tr>
<tr>
<td>Doctors treat patients</td>
<td>13 (32.5)</td>
</tr>
<tr>
<td>Doctors examine patients</td>
<td>6 (15.0)</td>
</tr>
<tr>
<td>Doctors are polite or kind</td>
<td>5 (12.5)</td>
</tr>
<tr>
<td>Drugs are free</td>
<td>2 (5.0)</td>
</tr>
<tr>
<td>Other positive responses (systematic service; explain illness, answer questions; listens; follow up if miss appointments; ask how feeling)</td>
<td>11 (27.5)</td>
</tr>
</tbody>
</table>

### Satisfaction with nurses

#### Positive comments

| Handle patients well/are good to the patients | 26 (65.0) |
| Systematic service/distribute drugs systematically | 5 (12.5) |
| Other (let participants sit; helped participant with drugs) | 2 (5.0) |

#### Negative or neutral comments

| Can be rude or shout at patients/bad directions | 8 (20.0) |
| Don’t know/no contact with nurses | 7 (17.5) |

*participants could give more than one response

### Table I-2 Satisfaction with clinic overall* (N=40)

<table>
<thead>
<tr>
<th>Positive comments</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good/not bad/handle patients well</td>
<td>18 (45.0)</td>
</tr>
<tr>
<td>Good – have drugs</td>
<td>8 (20.0)</td>
</tr>
<tr>
<td>Good – drugs are free/staff don’t ask for money</td>
<td>5 (12.5)</td>
</tr>
<tr>
<td>Clinic/hospital is clean/cleanliness improved</td>
<td>5 (12.5)</td>
</tr>
<tr>
<td>Treat all patients/always treat patients</td>
<td>3 (7.5)</td>
</tr>
<tr>
<td>Nothing/nothing to say</td>
<td>2 (5.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Negative comments</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinic/hospital lacks furniture/patients must stand</td>
<td>2 (5.0)</td>
</tr>
<tr>
<td>Too many patients</td>
<td>2 (5.0)</td>
</tr>
<tr>
<td>Wait is too long/delays obtaining drugs</td>
<td>2 (5.0)</td>
</tr>
<tr>
<td>Other (expensive, dirty, care is not systematically provided)</td>
<td>3 (7.5)</td>
</tr>
</tbody>
</table>

*participants could give more than one response
**Appendix J  Social Network Support**

### Table J-1. Who can you talk to about your concerns about your children (N=50)*

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister(s) and/or Brother(s)</td>
<td>12 (37.5)</td>
<td>6 (33.3)</td>
<td>18 (36.0)</td>
</tr>
<tr>
<td>Mother and/or Father</td>
<td>10 (31.2)</td>
<td>3 (16.7)</td>
<td>13 (26.0)</td>
</tr>
<tr>
<td>Other relatives (cousins; aunts; grandparents; children)</td>
<td>8 (25.0)</td>
<td>1 (5.6)</td>
<td>9 (18.0)</td>
</tr>
<tr>
<td>Husband/boyfriend/father of children</td>
<td>4 (12.5)</td>
<td>1 (5.6)</td>
<td>6 (12.0)</td>
</tr>
<tr>
<td>Friends/coworkers/neighbors/church friends</td>
<td>6 (18.8)</td>
<td>4 (12.5)</td>
<td>10 (20.0)</td>
</tr>
<tr>
<td>Medical personnel (doctors, nurses, counselors)</td>
<td>1 (3.1)</td>
<td>0</td>
<td>1 (2.0)</td>
</tr>
<tr>
<td>Talk to no one</td>
<td>1 (3.1)</td>
<td>7 (38.9)</td>
<td>8 (16.0)</td>
</tr>
</tbody>
</table>

*subjects could give more than one response; 8 Kampala subjects and 2 Mukono subjects who had no children are not included

### Table J-2 Who comes to subject with their worries/problems (N=60)*

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister(s) and/or Brother(s)</td>
<td>7 (17.5)</td>
<td>2 (10.0)</td>
<td>9 (15.0)</td>
</tr>
<tr>
<td>Other relatives (cousins; aunts; grandparents; children)</td>
<td>6 (15.0)</td>
<td>1 (5.0)</td>
<td>7 (11.7)</td>
</tr>
<tr>
<td>Friends/coworkers/neighbors/church friends</td>
<td>15 (37.5)</td>
<td>2 (10.0)</td>
<td>17 (28.3)</td>
</tr>
<tr>
<td>No one</td>
<td>18 (45.0)</td>
<td>15 (75.0)</td>
<td>33 (55.0)</td>
</tr>
</tbody>
</table>

*subjects could give more than one response

### Table J-3: Who comes to subject to talk about their children (N=59)*

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister(s) and/or Brother(s)</td>
<td>7 (17.9)</td>
<td>0</td>
<td>7 (11.9)</td>
</tr>
<tr>
<td>Mother and/or Father</td>
<td>1 (2.6)</td>
<td>0</td>
<td>1 (1.7)</td>
</tr>
<tr>
<td>Other relatives (cousins; aunts; grandparents; children)</td>
<td>6 (15.4)</td>
<td>1 (5.0)</td>
<td>7 (11.9)</td>
</tr>
<tr>
<td>Friends/coworkers/neighbors/church friends</td>
<td>10 (25.6)</td>
<td>2 (10)</td>
<td>12 (20.3)</td>
</tr>
<tr>
<td>Talk to no one</td>
<td>19 (48.7)</td>
<td>17 (85.0)</td>
<td>36 (61.0)</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

*subjects could give more than one response

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### Table J-4: Who do subjects talk to concerning jobs? (N=58)*

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister(s) and/or Brother(s)</td>
<td>8 (20.5)</td>
<td>2 (10.5)</td>
<td>10 (17.2)</td>
</tr>
<tr>
<td>Mother and/or Father</td>
<td>2 (5.1)</td>
<td>0</td>
<td>2 (3.4)</td>
</tr>
<tr>
<td>Other relatives (cousins; aunts; grandparents; children)</td>
<td>5 (12.8)</td>
<td>0</td>
<td>5 (8.6)</td>
</tr>
<tr>
<td>Husband/boyfriend/father of children</td>
<td>3 (7.7)</td>
<td>1 (5.3)</td>
<td>4 (6.9)</td>
</tr>
<tr>
<td>Friends/coworkers/neighbors/church friends</td>
<td>13 (33.3)</td>
<td>5 (26.3)</td>
<td>18 (31.0)</td>
</tr>
<tr>
<td>Talk to no one</td>
<td>13 (33.3)</td>
<td>11 (57.9)</td>
<td>24 (41.4)</td>
</tr>
<tr>
<td>Missing/Not specified</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

*N subjects could give more than one response

### Table J-5: Who comes to subject for information about jobs (N=60)*

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister(s) and/or Brother(s)</td>
<td>6 (15.0)</td>
<td>0</td>
<td>6 (10.0)</td>
</tr>
<tr>
<td>Husband/boyfriend/father of children</td>
<td>1 (2.5)</td>
<td>0</td>
<td>1 (1.7)</td>
</tr>
<tr>
<td>Friends/coworkers/neighbors/church friends</td>
<td>11 (27.5)</td>
<td>6 (30.0)</td>
<td>17 (28.3)</td>
</tr>
<tr>
<td>Talk to no one</td>
<td>23 (57.5)</td>
<td>14 (70.0)</td>
<td>37 (61.7)</td>
</tr>
</tbody>
</table>

*N subjects could give more than one response

### Table J-6: Who comes to subject to talk about their partner (N=60)*

<table>
<thead>
<tr>
<th></th>
<th>Kampala N (%)</th>
<th>Mukono N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sister(s) and/or Brother(s)</td>
<td>9 (22.5)</td>
<td>1 (5.0)</td>
<td>10 (16.7)</td>
</tr>
<tr>
<td>Other relatives (cousins; aunts; grandparents; children)</td>
<td>2 (5.0)</td>
<td>0</td>
<td>2 (3.3)</td>
</tr>
<tr>
<td>Friends/coworkers/neighbors/church friends</td>
<td>10 (25.0)</td>
<td>3 (15.0)</td>
<td>13 (21.7)</td>
</tr>
<tr>
<td>Talk to no one</td>
<td>24 (60.0)</td>
<td>16 (80.0)</td>
<td>40 (66.7)</td>
</tr>
</tbody>
</table>

*N subjects could give more than one response
Bibliography


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O'Reilly, P. (1988). Methodological issues in social support and social network research. *Social Science and Medicine, 26*(8), 863-873.


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