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Abstract

In Swaziland, where one in four adults is HIV positive, identifying and addressing barriers to a strong referral system is critical to ensure continuity of care for HIV positive individuals. This study examines the referral system from the perspectives of health providers, community health workers, traditional healers, clients seeking facility-based care, and managers of private health organizations. Structured and semi-structured questionnaires were administered to 52 senior providers, 161 providers, and 307 clients in 52 health facilities. In 82 randomly selected communities, 81 traditional healers and 247 CHWs also participated. Staff from private health agencies providing HIV-related care were also interviewed.

Referral is commonly understood as sending clients to seek care at higher level facilities and is an individualized process dependent on various factors. Providers sending clients rarely hear back on any regular basis about those clients. Referrals and linkages for certain services are particularly weak including nutrition support, psychosocial support, palliative care and home-based care. Many providers recommended that referral protocols with improved communication tools are needed and said referred clients should be given priority at referral-receiving sites. Policy recommendations include: referral form redesign; formalizing or reforming the referral protocol; strengthening communication and linkages between community- and facility-based providers; and improving patient-flow at referral sites.

KEYWORDS: referral, HIV and AIDS, treatment and care, barriers

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Introduction

Appropriate and timely referral is an essential part of a functioning health system (Hensher, Price, and Adomakoh 2006; Rohde et al. 2008). Regrettably, it is often one of the weakest components of a health system (English et al. 2006; Macintyre, Lochigan, and Letipila 2003; Macintyre et al. 1999). As treatment and care for HIV and AIDS as a chronic illness becomes possible in parts of Sub-Saharan Africa, issues relating to referral become even more urgent (WHO 2005; Harling, Orrell, and Wood 2007; UNAIDS 2007; Hardon et al. 2007). These concerns include: what referral should look like; how to improve existing systems; which providers must be responsible for referral; treatment at referral sites; and referral uptake (Mshana et al. 2006; Wagner, Ryna, and Taylor 2007; Posse et al. 2008). These issues are highly relevant in the Sub-Saharan African nation of Swaziland, where adult HIV prevalence is 26.1% (CSO and ORC Macro 2008).

This study is part of a larger initiative in Swaziland to look at issues around referral and access from the community level to referral hospitals in the context of HIV treatment and care (MOHSW/WHO 2006). This paper focuses on findings from the first stage of the project, and seeks to show how referral is *understood* from multiple perspectives. We present perceptions of the main barriers to referral as seen or experienced by key groups: facility-based providers, traditional healers, community health workers (CHWs), clients seeking care at health facilities, and staff working in nongovernmental organizations (NGOs) providing HIV and AIDS services. These groups let us answer questions such as: How is referral understood? How are decisions to advise or accept referral made? What are the main barriers to referral?

While this study had its origins examining referral around HIV, it transpired that referral could not be studied without taking into account the whole of the health system. This paper maintains this focus on the perceptions of the health workers and clients to the HIV/AIDS continuum of care, but the results are generalizable beyond this. We investigate barriers from many perspectives along the continuum of care in a country with a high HIV burden and offer recommendations as to how those barriers may be overcome.

Background

Demand for HIV care and treatment services in Sub-Saharan Africa (SSA) is expected to increase given the continued roll-out of antiretroviral therapy (ART) (Hardon et al. 2007), which began in 2003. Effective roll-out requires an efficient healthcare delivery system that offers appropriate care at many levels (Posse et al.

2008). Services include counseling and testing; information for positive living; nutritional and psychosocial support; prophylaxis and treatment for opportunistic infections (OI); regular monitoring of health status and CD4 count; initiation/maintenance of ART including monitoring of adverse reactions, adherence, and resistance; prevention of mother-to-child transmission of HIV (PMTCT); palliative care; and home-based care. Given this array of services, comprehensive care means accessing services from a number of sites including at community level (e.g., CHWs, traditional healers), clinics, health centers, hospitals, and the interaction of many governmental, mission, and NGO facilities. In any pluralist system (and most health systems in SSA are pluralist), quality care is dependent on how various components of the system communicate and coordinate care. This, however, is far from easy to achieve (Mukherjee and Eustache 2007).

Referral in the context of a health system is defined as a process that a patient moves through the system to ensure they receive the best care at the most appropriate level (Hensher, Price, and Adomakoh 2006; Macintyre et al. 1999; Low et al. 2001). Providers use referral when they identify a patient needs a level of care (equipment, drugs, or personnel) that they are unable to provide. *Self-referral* is when patients select the referral site themselves based on factors such as severity of illness, perceived services available, cost of transport or other costs, and their personal experience of the health system (Akin and Hutchinson 1999; Bapna et al. 1991). Referral is also applied to the situations when community-based providers see the need for a higher level of care than they are able to provide (Escott and Walley 2005; Suri, Gan, and Carpenter 2007).

A *referral system* is dynamic and links an individual seeking care and support to a variety of services. The ideal arrangement occurs when clients receive the most appropriate care at the *lowest* level possible in the system, as lower-level care needs fewer human and financial resources (Macintyre and Hotchkiss 1999; English et al. 2006). In theory, referral networks are designed to move clients "up" through a pyramid-shaped structure (see Figure 1), with entry points at the base through primary care clinics, or through a community health worker (CHW). Clients move up to higher levels of care at a regional or district hospital, or private facility, dictated by illness and availability of service. At higher-level service-delivery sites, such as regional hospitals, clients are referred between departments. As acute conditions are resolved, the client is referred back to lower levels of care for management. Referral down the pyramid is called reverse referral (Rohde et al. 2008).

Referral for HIV and AIDS Care and Treatment

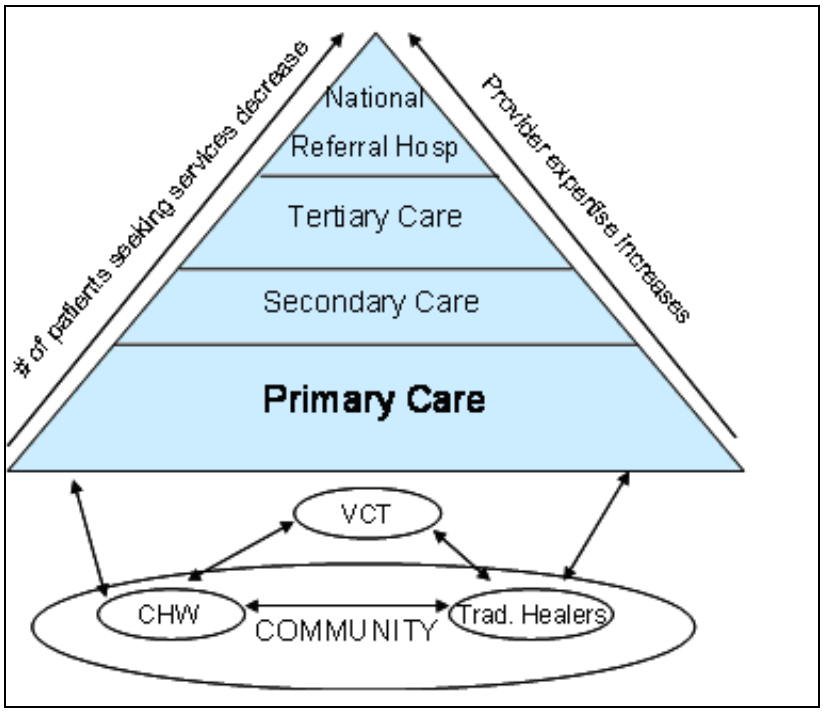
Community-based services for HIV and AIDS care are viewed as essential for ensuring clients access to care and treatment and maintaining social, physical, and mental health (Mukherjee and Eustache 2007; Schneider, Hlophe, and van Rensburg 2008). Equally important are clinical treatment and referrals, which are necessary to manage acute illnesses including opportunistic infections; initiate ART treatment; provide AIDS care and treatment services including ART; manage complications; address treatment failure; and make diagnoses (WHO 2005; GOS 2006; Mshana et al. 2006).

Although referral is often referenced in national health plans, HIV programs often lack guidelines giving referral procedures among health facilities and between the health system and the community. The HIV and AIDS continuum of care requires feedback provided to the provider (CHW or traditional healer) that referred the patient; however, the structure underpinning health system referral is largely hierarchical. In theory, these networks are designed so that clients move through the pyramid (Figure 1); however, the interface with services provided in the community is particularly important for HIV care. There are many gaps in our understanding of these interfaces, including what are the barriers to the relationships and why do linkages often fail.

Barriers to Referral

Barriers to referral are usually couched in typologies using frameworks such as one developed by Macintyre and Hotchkiss (1999). Barriers can be grouped in levels. For example, at the household level, barriers can include financial constraints (i.e., not enough money for transport, supplementary food, drugs, hospital fees, cost of family traveling with the patient) or time or opportunity costs of not working while going to the clinic or hospital to take up a referral, or costs related to having to find and pay others to look after children (English et al. 2006; Atkinson et al. 1999; Low et al. 2001). Personal factors that may prevent referral are prior poor experience with the system (e.g., long waiting times), idea that providers are too busy, or the hospital is an impersonal space or has no drugs; and fear of staff attitudes (rudeness or they demand money or are openly stigmatizing) (Meiberg et al. 2008; Posse et al. 2008).

Figure 1 The ideal referral pyramid



While few studies examine referral from the community, available data point to barriers and perceptions that influence whether a referral is recommended by providers at community level (WHO 2006; Escott and Walley 2005; Mshana et al. 2006). Perceptions at the receiving site may be influenced by prior experience and ideas of whether resources are available to the patient and to the providers, and stigma or discrimination that may meet clients at the receiving centers (Suri, Gan, and Carpenter 2007; Meiberg et al. 2008).

In the health system itself, several constraints challenge the referral system. Constraints include copious, complex paperwork, and underpaid and unmotivated staff who may lack technical resources to do their job (Hensher, Price, and Adomakoh 2006; Orimadegun et al. 2008). Providers may fail to refer patients because they perceive patients as unable to take up a referral because of poverty or lack of transportation, or due to severity of illness, i.e., a patient is too ill to access referral (Simba et al. 2008; Mkhabela, Mavundla, and Sukati 2008).

Study Site

The Kingdom of Swaziland is landlocked bordered by South Africa on three sides and Mozambique in the east. With a land area of 17,300 km^2, the country has four regions. About 77% of Swazi's 1.23 million population are rural,

deriving their main income from various forms of agriculture. Nearly half of the population are below 15 years. Life expectancy is now only 33 years and infant mortality rate is 71.85 deaths/1,000 births. In 2007, the estimated per capita gross domestic product (GDP) was $4,500, with a growth rate of 1.8%, and unemployment was 44%. Nearly 70% of the population live below the poverty line (CSO and MACRO 2008).

HIV and AIDS in Swaziland

The first case of AIDS was reported in 1987, and HIV/AIDS was declared a national disaster in 1999 (MOHSW 2006). By 2007, Swaziland had the highest HIV prevalence in the world. A sentinel surveillance system, monitoring the proportion of pregnant women attending ANC clinics infected with HIV, was based on the 90% of pregnant women who attend an ANC clinic at least once per pregnancy. HIV sero-prevalence in pregnant women rose from 3.0% in 1992 to 42.6% in 2004 (MOHSW 2006). Current prevalence for *all adults* (15–49) is about 26.2% (CSO and Macro 2008).

By 2008 there were an estimated 190,000 Swazis living with AIDS or HIV (PLHA) in the country; of those, approximately 25,000 had been put on ART as they were defined as being eligible for the therapy based on WHO criteria of having their CD4 count below 200 cells per cubic millimeter (MOHSW/SNAP 2008). The roll-out of a new medical protocol is complex in any setting, but in many of the healthcare settings in SSA it is both complicated and risky, with many components of the systems too weak, understaffed, underresourced, and undersupervised to be able to supply these new treatment protocols for the numbers of patients that need them. The pace of the roll-out is dictated by these constraints of the system, which are compounded by poor patient education, lack of access, misunderstandings, and weak communication systems (WHO/UNAIDS/MOH, 2010 2010). So while the recent report from WHO in 2010 says that an estimated 85% of PLHA in need of ART are now receiving it, this is followed by a statement saying that more than a third of those who begin ART are lost to follow-up within 12 months, owing to “centralized services, ineffective adherence support and poor patient monitoring” (WHO/UNAIDS/MOH 2010).

The Healthcare System in Swaziland

The formal health system is divided into primary care (clinic), secondary care (public health unit (PHU) and health center), and tertiary care (hospital) and

includes public, mission, and private facilities (see Table 1). The system is relatively accessible with 80% of the population living within 8 km of a healthcare unit and over 60% able to access a healthcare unit within an hour. To date, Swaziland has lacked a formal national protocol for referral. Forms have been developed, but their use had not been evaluated up to 2008.

Study Design and Methods

To define the main barriers to referral the research team used a cross section design involving individual questionnaires to reach a nationally representative sample of providers at health facilities and within communities across the country.

Sample Selection and Data Collection

From a list of facilities, a random selection of providers and clients were selected to provide as broad a spectrum of views as possible. Nearly all ART facilities nationwide were included, and a sample of non-ART-providing facilities was randomly selected from a list of all facilities in each region based on distance from the regional referral hospital using the 2006 Service Availability Maps (MOHSW/WHO 2006). Up to three providers in non-ART facilities and six providers in ART-providing facilities were recruited. They were taken from a list of all providers at each selected facility and randomly selected on the day of interview. About 30 clients in the hospitals that provided ART and 10 clients in other facilities participated. All interviews conducted at a given facility were completed during one visit on one day.

We sampled 20 communities per region using systematic sampling to select census enumeration areas (GOS 2006). In selected enumeration areas, a listing of CHWs was obtained from a CHW informant; these included CHWs trained by both government and nongovernmental organizations. From this list, three CHWs were invited to participate. Utilizing CHWs as informants, a list of traditional healers was generated and one per community was invited to participate. CHWs and traditional healers selected from a given community were interviewed on one day; three to four communities were visited per day.

While many perceptions of referral were gathered using this sampling plan, we recognize that the one group we did not have the resources to reach were the community members or PLHA clients who were *not* at facilities. Of particular importance is the group who either did not or refused to follow referral advice and who simply stayed in the community. The only way we could try to understand their attitudes was through the perceptions of the providers who served them. This is a limitation described below.

Ethics Review and Consent

All individuals gave voluntary consent for the interview based on the protocol and informed consent procedures approved by the two ethics committees of the Swazi MOH and the U.S.-based Tulane University Human Subjects Review Board.

Six questionnaires were created where the content focused on experiences with referral and with accessing/proving health services in the context of referral. Basic facility and respondent demographic information was collected. These instruments were translated into Siswati. Piloting and revisions occurred during interviewer training. Data were collected by 12 research assistants over two months who had been thoroughly trained in the research and ethical protocols. After data collection, the data were double entered and validated using Microsoft Access and Stata 9.2 © was used for analysis. Tabulations assessed referral practices and barriers across the providers, clients, CHWs, and traditional healers. Chi-square tests were used to examine differences in practices and barriers across facility types. The measures used were standard measures of provider and client perceptions and behaviors, usually just simply constructed from the questions as proportions based on total responses for each question. Missing data were rare as the trained interviewers were competent in their work. Complex scales were avoided as these often require more sophisticated questioning that we felt this study needed.

Tables 1 and 2 summarize characteristics of the facility-based samples. Participants were drawn from 52 health facilities. Most facilities included in the study are government (54%) or mission facilities (27%), including the national referral hospital, three regional referral hospitals, two sub-regional referral hospitals, a private hospital, six private clinics, public clinics (31), two private health centers, five public health centers, and a public health unit. Eighteen of the facilities were providing ART.

Participants included 161 attending providers with responsibilities for referral; 22% providers were doctors, 66% nurses, 12% nursing assistants, and 7% counselors. At each facility an interview focused on policies and procedures was conducted with a senior medical officer or senior nurse (n=52). Exit interviews were done with clients only within the sub-sample of facilities that were providing ART. Three hundred and seven clients seeking either general outpatient services, TB treatment, PMTCT, Voluntary Counseling and Testing (VCT), or other AIDS care participated in the study. More than 60% of clients interviewed were seeking care at a hospital. Clients were mentally and physically fit enough to complete a brief interview, and were at least 18 years of age. Clients ranged in age from 18 to 78 with a mean age of 35. More than half were female (66%). Clients were interviewed at facilities in each of the four regions, although nearly a third of the

sample came from Hhoho region due to a larger number of facilities providing ART in that region, including the national referral hospital.

Table 1 Swaziland Healthcare Delivery System

Facility Type	Healthcare Unit	Staff	Capacity	Number
Clinic	Primary	Nurses	Outpatient services	162
Public health units	Secondary	Nurses	Health promotion Prevention	8
Health centers	Secondary	Regional medical officers Nurses Midwives	In-client services (24–42 beds) Minor surgery Prevention Curative outpatient services	12
Hospitals	Tertiary	Specialist Professionals	Health promotion Prevention Curative Rehabilitation Outpatient services	7

Source: MOHSW et al. (2006); USAID (2004); MEASURE Evaluation (2006).

Community-based Sample

A total of 247 CHWs were interviewed from 84 communities divided equally across four regions. The majority of the CHWs (86%) had received training from the government. Most were women, and to participate in the study each CHW had to have been working in the community for at least a year. The mean number of years as a CHW among the sample was 11 years. On average, CHWs were serving 34 households and seeing seven clients per week. In addition, 81 traditional healers from 73 communities participated in the study. Most were male (72%) and they self-identified as herbalists (47%), Zionist herbalists (30%),[1] Zionist *sangoma* (diviner) herbalists (12%), traditional birth attendants (10%), and one was a *bogobela*[2] trainer. To participate, healers had to have been practicing for at least a year. The mean years in practice was 24.

[1] A Zionist herbalist is a healer who aligns themselves with one of the many Zionist African Churches that are common in southern Africa, and who typically and actively do not follow western medicine as part of their belief system.

[2] A *bogobela* is usually a senior diviner/*sangoma*, so this was someone who was training other healers.

NGO Sample

Interviews were conducted with key informants from seven NGOs working in HIV and AIDS prevention, care, and/or treatment. These NGOs were all U.S. government (USG) partners (i.e., they had received from the USG). The individuals who participated were program staff working in either service or management of medical services for HIV and AIDS care.

Results 1: Referral Practices

Facility-based Providers.

Table 3 summarizes provider reports of facility service provision and referral for specific services showing that referral for most services is common. However, referrals are not generally made for services not provided by that facility. According to these data, referral is commonly made for a service provided by the facility in certain cases where the provider/facility cannot serve the particular patient with that service (e.g., due to complications requiring higher-level care, referral for clients to access care closer to home and/or at a lower level, and/or lack of supplies). For example, in the case of diagnosing concurrent infections, 19% say the facility provides this service and does not refer, while 73% say the facility provides this service but still refers some clients elsewhere. Only 8% say the facility does not provide the service and therefore refers. This pattern of high frequency of provision of service, as well as high frequency of referral for that service, occurs for several items, e.g. HIV counseling, medical follow-up and concurrent infections. For nutrition and psychosocial support, palliative care, home-based care, and family planning services, there is a greater frequency of provider reports not providing the service and either referring or not referring.

Referral practices differ for several services, depending on the type of facility. Table 4 presents referral practices for treatment services across facility types. For many of these services, most clinic providers are more likely to not provide a service and refer for it as compared with hospital and health center providers that often both provide and refer for the service. For example, with respect to ART, 63% of clinic providers do not provide ART and instead refer. Just over half of both hospital and health center providers report that the facility provides ART and does not refer.

Table 2 Characteristics of Facility-Based Samples

	% Facilities	(*n*)	% Providers	(*n*)	% Clients	(*n*)
Facility type						
National referral hospital	1.92	(1)	3.73	(6)	12.05	(37)
Regional referral hospital	5.77	(3)	11.18	(18)	31.27	(96)
Sub-regional referral hospital	3.85	(2)	8.07	(13)	14.98	(46)
Private hospital	1.92	(1)	3.73	(6)	3.91	(12)
Private clinic	11.54	(6)	6.21	(10)	2.28	(7)
Public clinic	59.62	(31)	40.99	(66)	8.47	(26)
Private health center	3.85	(2)	4.35	(7)	3.91	(12)
Public health center	9.62	(5)	18.63	(30)	19.22	(59)
Public health unit	1.92	(1)	3.11	(5)	3.91	(12)
Facility ownership						
Government	53.85	(28)	59.01	(95)	60.59	(186)
Mission	26.92	(14)	21.74	(35)	20.85	(64)
Industry	7.69	(4)	9.94	(16)	7.82	(24)
Private for profit	7.69	(4)	3.73	(6)	2.28	(7)
Nonprofit	3.85	(2)	5.59	(9)	8.47	(26)
ART provision						
Facility provides ART	34.62	(18)	55.28	(89)	100.00	(307)
Region						
Hhohho	21.15	(11)	24.84	(40)	30.07	(92)
Manzini	34.62	(18)	28.57	(46)	29.41	(90)
Lubombo	21.15	(11)	23.60	(38)	22.22	(68)
Shiselweni	23.08	(12)	22.98	(37)	18.30	(56)
Respondent designation						
Medical doctor	—	—	13.66	(22)	—	—
Matron	—	—	0.62	(1)	—	—
Nurse*	—	—	65.84	(106)	—	—
Nursing assistant	—	—	12.42	(20)	—	—
Counselor	—	—	7.45	(12)	—	—
Client characteristics						
Female					66.34	(203)
Mean age (SD)					35.22	(12.31)
Age range					18–78	—
Total	100%	(52)	100%	(161)	100%	(307)

*Nurse includes nurse practitioner, nursing sister, senior nurse, registered nurse, and enrolled nurse.

Senior medical officers and nurses gave information on common reasons for referral of clients testing positive for specific HIV and AIDS services. The referrals most frequently cited for people who test HIV positive were ART (50%), lab work/CD4 count (44%), TB (35%), and concurrent infections (25%). Significantly higher rates of referral were found among clinics in comparison with hospitals and health centers for ART (58%) as compared with health centers (43%) and hospitals (14%) (χ^2=4.66, p<0.00). This pattern was also found for referrals for lab work/CD4 count; 55% of clinics refer for this service as compared with 14% of health centers and 14% of hospitals (χ^2=6.96, p<0.05). Finally, while a third of hospitals said they never refer clients that test positive for HIV, none of the health centers and 3% of clinics reported never referring these clients (χ^2=7.81, p<0.05).

Providers were asked to list all referral sites used for specific health services. Examining these data across facility type, we found that for many services there is a great deal of referral to hospitals by clinic providers and health center providers. So rather than referral to health centers (middle link in the referral chain), instead clinics are more often referring directly to hospitals. Health centers and specialized clinics are the second most frequent site for referral from clinics. Hospital providers report most frequently referring to other hospitals or to specialized clinics. Very few providers reported referral from the hospital to a health center or to a lower-level facility including counseling about HIV and AIDS (9% to health centers, 18% to clinics); and medical follow-up (4% to health centers, 13% to clinics).

Although never the most frequently cited referral site for any one particular service, referral to NGOs was cited by providers for palliative care (35%), home-based care (22%), psychosocial support (15%), HTC/VCT (10%), nutrition services (14%), and family planning (18%). Referral to the community was cited for home-based care (72%), psychosocial support (25%), palliative care (21%), and nutrition support (17%).

Table 3 Proportion of providers referring to other facilities for services provided and not provided by the provider's facility

	% Provides Service				% Does Not Provide Service					
	Refers for Service	(*n*)	Does not Refer	(*n*)	Refers for Service	(*n*)	Does not Refer	(*n*)	Total	(*n*)
Counseling about HIV and AIDS	28.13	(45)	70.63	(113)	1.25	(2)	0.00	(0)	100.00	(160)
HIV Testing and Counseling (HTC)/VCT	35.00	(56)	61.88	(99)	2.50	(4)	0.63	(1)	100.00	(160)
Medical follow-up	66.25	(106)	27.50	(44)	3.75	(6)	2.50	(4)	100.00	(160)
Concurrent infections diagnosis	72.78	(115)	18.99	(30)	7.59	(12)	0.63	(1)	100.00	(158)
Concurrent infections treatment	72.15	(114)	19.62	(31)	8.23	(13)	0.00	(0)	100.00	(158)
TB diagnosis	39.13	(63)	22.98	(37)	37.89	(61)	0.00	(0)	100.00	(161)
TB treatment	47.20	(76)	21.12	(34)	31.68	(51)	0.00	(0)	100.00	(161)
Counseling on PMCTC	31.68	(51)	63.98	(103)	4.35	(7)	0.00	(0)	100.00	(161)
PMTCT treatment	38.51	(62)	52.80	(85)	8.70	(14)	0.00	(0)	100.00	(161)
Nutrition support services	28.93	(46)	49.06	(78)	10.69	(17)	11.32	(18)	100.00	(159)
Palliative care	42.14	(67)	26.42	(42)	26.42	(42)	5.03	(8)	100.00	(159)
Home-based care	43.40	(69)	22.01	(35)	23.90	(38)	10.69	(17)	100.00	(159)
ART	31.25	(50)	35.63	(57)	33.13	(53)	0.00	(0)	100.00	(160)
STI counseling and testing	39.62	(63)	54.72	(87)	5.66	(9)	0.00	(0)	100.00	(159)
STI treatment	51.25	(82)	45.00	(72)	3.75	(6)	0.00	(0)	100.00	(160)
Psychosocial support	45.00	(72)	39.38	(63)	10.63	(17)	5.00	(8)	100.00	(160)
Family planning	34.59	(55)	51.57	(82)	13.21	(21)	0.63	(1)	100.00	(159)

Table 4 Proportion of providers referring to other facilities for services provided and not provided by the provider's facility across facility type

	% Provides Service				% Does Not Provide Service					
	Refers for Service	(*n*)	Does not Refer	(*n*)	Refers for Service	(*n*)	Does not Refer	(*n*)	Total	(*n*)
Concurrent infections treatment**										
Hospital providers	61.90	(26)	35.71	(15)	2.38	(1)	0.00	(0)	100.00	(42)
Health center providers	74.29	(26)	25.71	(9)	0.00	(0)	0.00	(0)	100.00	(35)
Clinic and PHU providers	76.54	(62)	8.64	(7)	14.81	(12)	0.00	(0)	100.00	(81)
TB treatment**										
Hospital providers	48.84	(21)	39.53	(17)	11.63	(5)	0.00	(0)	100.00	(43)
Health center providers	64.86	(24)	32.42	(12)	2.70	(1)	0.00	(0)	100.00	(37)
Clinic and PHU providers	38.27	(31)	6.17	(5)	55.56	(45)	0.00	(0)	100.00	(81)
PMTCT treatment**										
Hospital providers	32.56	(14)	62.79	(27)	4.65	(2)	0.00	(0)	100.00	(43)
Health center providers	18.92	(7)	78.38	(29)	2.70	(1)	0.00	(0)	100.00	(37)
Clinic and PHU providers	50.62	(41)	35.80	(29)	13.58	(11)	0.00	(0)	100.00	(81)
Palliative care*										
Hospital providers	41.86	(18)	44.19	(19)	13.95	(6)	0.00	(0)	100.00	(43)
Health center providers	37.14	(13)	34.29	(12)	20.00	(7)	8.57	(3)	100.00	(35)
Clinic and PHU providers	44.44	(36)	13.58	(11)	35.80	(29)	6.17	(5)	100.00	(81)
ART**										
Hospital providers	44.19	(19)	53.49	(23)	2.33	(1)	0.00	(0)	100.00	(43)
Health center providers	44.44	(16)	52.78	(19)	2.78	(1)	0.00	(0)	100.00	(36)
Clinic and PHU providers	18.52	(15)	18.52	(15)	62.96	(51)	0.00	(0)	100.00	(81)
STI treatment**										
Hospital providers	25.58	(11)	67.44	(29)	6.98	(3)	0.00	(0)	100.00	(43)
Health center providers	44.44	(16)	55.56	(20)	0.00	(0)	0.00	(0)	100.00	(36)
Clinic and PHU providers	67.90	(55)	28.40	(33)	3.70	(3)	0.00	(0)	100.00	(81)

*Facility χ^2 $p<0.01$.
**Facility χ^2 $p<0.001$.

Referral Sites.
Referral Procedures.
The majority reported using a referral form to refer clients to another facility, but only 73% of providers could produce a sample referral form. Further, many versions of referral forms were found to be in use. In total, the team collected nearly 50 different forms spread across the country. And while 78% of facilities reported using a record keeping system to track referrals, only 61% of those could show the system to the research team. Common tracking systems included use of the Outpatient Morbidity Register (the OPD register) which has check-box columns for "referred in" and "referred out." Some used the column entitled "treatment outcome" to note referrals. Other less reported systems used tally sheets or exercise books. When asked to think about the last client that they referred for HIV/AIDS services, only half knew whether or not the client actually followed the referral.

Clients.
From the client perspective, referral practices were considered in the context of the client's current visit to the health facility. Only 16% of all clients seeking care at the health facility had received a referral from another facility; this frequency of referral did not differ significantly across facility type. Few clients said they had been referred from the community level. Clients were asked if they had received a referral on the day of their visit; only 8% of clients indicated having received a referral from a health provider.

CHW and Traditional Healer Practices.
CHWs and traditional healers reported specific reasons for referring clients affected by HIV or AIDS to a health facility. The most commonly cited by both CHWs and traditional healers were HIV testing (67% of CHWS, 80% of traditional healers), HIV and AIDS counseling (45% of CHWs, 37% of traditional healers), and ART (37% of CHWs, 21% of traditional healers). Infrequently mentioned were referrals for TB diagnosis (5% of CHWs, 13% of traditional healers) or treatment (6% of CHWs, 4% of traditional healers) or opportunistic infection treatment (2% of CHWs, 3% of traditional healers).

Nearly all health workers attempted to get feedback on the referred clients. Most said this feedback comes from the clients themselves (81% of CHWs, 59% of healers) or less frequently from the client's family (15% of CHWs, 31% of healers). Few got feedback on referred clients from staff at the referral site (5% of CHWs, 6% of traditional healers). When asked if they "ever feel reluctant to give a client a referral," only a few indicated reluctance to refer. CHWs reported often referring clients to a clinic (72%), hospital (69%), or health center (19%). Healers

reported referring clients to hospitals (69%), clinics (45%), other healers (34%), or health centers (19%).

NGO Practices.

NGOs both refer and receive referrals. Staff noted receiving referrals from health facilities for services including hospice care, palliative care, and home-based care. Staff reported referring clients from their clinics, support programs (e.g., HBC, support groups), and/or mobile VCT programs to government and mission facilities for general outpatient services, ART, CD4 count, TB diagnosis and treatment, and pediatric services. They also refer to other NGOs and community-based care for support services. NGO providers reported that referral formalized by a written form and characterized by feedback is not common, as illustrated by the following comment made by one NGO staff member:

> *Right now the referral that is happening is mostly verbal only. When it is only verbal, you don't know if the referral is working or not. For example, when we refer people from the community to a facility by verbal only, we don't know the result. If referral was written and more formal, we could follow the clients. We could track where patients are.*—Local NGO staff

Results 2: Barriers to Referral

Provider Perspectives.

Across facilities, providers most often cited poverty (67%) and lack of transport (47%) as barriers (see Table 5). A higher proportion of clinic and PHU providers (79%) cited client poverty as a barrier compared with hospital and health center providers (χ^2=10.61, p<0.01). Across facility type, providers also cited quality of care issues as barriers to referral. These include long lines/congestion at the referral site (27%), client perception of poor care (25%), lack of good communication in the system (18%), and lack of providers at the referral site (11%). Providers at clinics and PHUs were also more likely to cite long waiting lines at referral sites compared with hospital and health center providers (χ^2=11.22, p<0.01). Lack of client understanding was reported by 15% of providers. Also noted were barriers related to stigma and fear including client fear (14%); and lack of confidentiality and/or fear of stigma (4%).

Providers were asked to explain reasons behind client failure to follow referral advice when it is given. Most gave poverty (71%), with clinic and PHU providers more likely to cite this barrier (81%) compared with the other providers (χ^2=9.77, p<0.01). Another common barrier cited was client perception of poor quality of care and lack of transportation. While 20% of clinic and PHU providers cited client preference for traditional healers as a reason that clients do not follow

referral, few other formal system providers cited this reason (χ^2=6.51, p<0.05). Other reasons included stigma, fear of the next stage, not thinking they will improve, and denial.

For clients that follow referral advice, providers noted most often that this is because the client perceives benefit—they believe that they will improve if they follow the referral advice (60%). More clinic and PHU providers (68%) gave this reason for following referral compared with others (χ^2=7.92, p<0.05). Many also noted that clients take up referral advice because the provider "said so" (40%) and because the client is feeling sick (29%). Providers also cited client perception of good care and/or medicines being available (23%). Only a few providers cited ability to pay and availability of transport as reasons that clients who follow referral were willing or able to do so.

Qualitative Results.

In discussing how the referral system can be improved, providers identified several barriers. Some said the lack of a referral system with a clear protocol is a serious barrier. One provider explained:

> *There is no national referral system. There needs to be one in place. There must be a system for referral within facilities and between facilities. There should be a system in place so that not just anyone can walk into the regional referral hospitals.*—Senior medical officer, Referral hospital

Others explained that without a formal protocol, clients seek care wherever they can. As a result, referral hospitals become highly congested as they serve referred and self-referred clients. They noted that many self-referred clients should be served at the first level. But with no protocol there is no guidance on communication or feedback procedures between providers. Providers often talked about this with respect to failure to receive information from referral sites on patients that were sent there. They noted that communication is hindered by a lack of reliable, known communication channels. While health facilities have phones, they often don't work.

Several providers identified the need for a fast-tracking system to deal with referred patients. Referred clients often wait in line (for a second time), complete the registration process, and are reevaluated as though they had arrived without a referral. This contributes to congestion, reducing the quality of care. These delays and reevaluations reportedly deter some clients from following referral advice.

In addition to gaps in linkages between health facilities, providers acknowledged particularly weak linkages with community-based services. A lack

of community resources or, at the very least, a lack of provider linkages with community resources was evident. As one provider explained:

> *When we refer for HBC, we basically refer to "the community." But we don't actually know if there are any structures in place to care for the patients.*—Senior medical officer, referral hospital

Providers gave inadequate infrastructure as a barrier. Services such as ART and CD4 count are provided in a limited number of facilities by a limited number of providers, and in those facilities, provision is restricted to certain weekdays. Providers noted that referring for these services is often frustrating because clients face challenges, including long waiting times, lack of comprehensive services, and lack of services offered daily. Thus clients can be turned back without being served. Finally, providers often identified transport as a barrier and said addressing the transportation barrier would be an important step to improving the referral system. With respect to HIV care, they noted that following referral advice for services such as CD4 is critical, but without transport they simply don't access the service.

CHW and Traditional Healer Perspectives.

Table 6 presents barriers to referral reported by CHWs and traditional healers. The most commonly cited barrier to referral was client lack of money (78% of CHWs, 59% of healers) followed by fear (32% of CHWs, 30% of healers). CHWs said transport (20%) and distance (13%) were barriers while healers noted client perception of care (15%) followed by transport (11%) as main barriers to referral.

These community providers identified reasons that referred clients who follow referral advice are willing to do so because either they are feeling very sick or because the client thinks that they will improve or because they are following advice of someone they trust. While nearly a third of traditional healers said that clients follow referral because they know that the traditional healer cannot treat them, only a few CHWs cited this reason. When asked for reasons that clients don't follow referral advice, most said the main reason was lack of money (48% of CHWs, 22% of healers). Also commonly cited were issues of stigma and fear, including fear of the next stage . Both types of providers noted that quality of care issues, including client perception of poor care and that they will not improve, were important reasons for not going. Preference for traditional medicine was given by 22% of CHWs and, interestingly, by only 12% of traditional healers.

Table 5 Facility-based provider reports of barriers to referral across facility type

	% Hospital Providers		% Health Center Providers	(*n*)	% Clinic and PHU Providers	(*n*)	% All Providers	(*n*)
Clients do not have money*	53.49	(23)	56.76	(21)	79.01	(64)	67.08	(108)
Clients do not have transport	41.86	(18)	51.35	(19)	48.15	(29)	47.20	(76)
Referral site has long lines/congestion*	23.26	(10)	8.11	(3)	37.04	(30)	26.71	(43)
Clients think care is better here/do not want to be sent to another place	20.93	(9)	29.73	(11)	25.93	(21)	25.47	(41)
System lacks good communication	16.28	(7)	18.92	(7)	18.52	(15)	18.01	(29)
Clients do not understand/do not understand reason for referral	16.28	(7)	18.92	(7)	12.35	(10)	14.91	(24)
Clients have fear	18.60	(8)	5.41	(2)	14.81	(12)	13.66	(22)
System lacks enough providers	9.30	(4)	16.22	(6)	8.64	(7)	10.56	(17)
Clients are affected by outside influence	9.30	(4)	2.70	(1)	4.94	(4)	5.59	(9)
Clients lack confidentiality at the referral site/fear stigmatization by other clients at the referral site	4.65	(2)	0.00	(0)	6.17	(5)	2.48	(4)
Providers lack coordination/do not follow up	4.65	(2)	2.70	(1)	1.23	(1)	2.48	(4)
Clients do not have family support	2.33	(1)	2.70	(1)	2.47	(2)	2.48	(4)
Providers think there is no need to refer	0.00	(0)	0.00	(0)	1.23	(0)	0.62	(1)
No barriers	4.65	(2)	2.70	(1)	0.00	(0)	1.86	(3)
Other‡	13.95	(6)	13.51	(5)	18.52	(15)	16.15	(26)
Total	—	(43)	—	(37)	—	(81)	—	(161)

*Facility-type χ^2 $p<0.01$.

‡Other: clients do not care (*n*=2); cultural beliefs (*n*=1); client denial of HIV status (*n*=1); client loss of hope (*n*=2); clients are too sick (*n*=1); clients don't want to be admitted (*n*=2); client preference for traditional healers (*n*=1); clients refuse HBC (*n*=1); conflicting advice from medical workers (*n*=1); difficult to know where to send someone (*n*=1); doctors at referral site tell us to treat here (*n*=1); health staff attitude (*n*=1); lack of drugs (*n*=1); lack of infrastructure at referral hospital (*n*=1); lack of proper care at referral site (*n*=1); lack of referral forms (*n*=2); shortage of medical equipment (*n*=1); referral site does not treat referring providers well (*n*=1); treatment at referral site same as referring site (*n*=1); lack of national guidelines/policy on referral (*n*=2).

While CHWs did not mention client fear of mixing traditional with western medicine, 20% of healers cited this as a reason for not following advice. Very few mentioned transport and distance as reasons why referred clients failed to follow referral advice.

Table 6 Proportion of CHWs and traditional healers reporting specific barriers to referral

	% CHWs	(*n*)	% Traditional Healers	(*n*)
Clients do not have money	78.37	(192)	5946	(44)
Clients are frightened	31.84	(78)	29.73	(22)
Clients do not have transport	19.59	(48)	10.81	(8)
Distance—referral site is too far	13.06	(32)	4.05	(3)
Clients think the care is better elsewhere	12.24	(30)	14.86	(11)
Facilities are too overburdened to take new clients	7.35	(18)	2.70	(2)
Clients prefer traditional healers	4.49	(11)	4.05	(3)
Client doesn't believe me	4.08	(10)	8.11	(6)
It is too complicated for most clients	3.67	(9)	0.00	(0)
Clients fear HIV testing	1.22	(3)	0.00	(0)
Clients do not like hospitals	0.41	(1)	5.41	(4)
No barriers	0.41	(1)	0.00	(0)
Other*	3.27	(8)	4.05	(3)
Total	—	(245)	—	(74)

*CHW other: ARV side-effects (*n*=1); fear of disclosure in the community (*n*=1); lack of family support (*n*=1); ignorance (*n*=1); clients don't care (*n*=1); lack of caregiver (*n*=1); poverty (*n*=1); client doesn't want to take medicines (*n*=1); clients are very sick (*n*=1). Traditional healer other: partner does not allow going to facilities (*n*=1); don't want clients to go with money to other providers (*n*=1); medication not effective (*n*=1).

Qualitative Results.

The local providers described weak links between community- and facility-based providers as barriers to referral. They expressed feeling that their work with clients in the community is not acknowledged, valued, or respected by the formal health system providers and noted a lack of communication with nurses and doctors about their work. CHWs said that they are able to offer a great deal of information about clients referred to the facility, yet when they accompany clients to a facility, nurses and doctors often dismiss CHWs as sources of information, and at times can be intimidating and/or dismissive. As one explained:

> *The majority of the providers in the health facilities have pride. They look down upon us as CHWs and that makes us feel inferior and scared to go to health facilities.*

CHWs and traditional healers want to strengthen communication with the health system providers. They suggest greater collaboration with facility-based providers through increasing formalized referral both to facilities and from the facility back to community-based providers for follow-up and continued care.

NGO Perspectives.

NGO staff described weak referral structures between NGO services/facilities and other health facilities often marked by a lack of communication and feedback. Many suggested that a formalized protocol for referral is needed to improve procedures and communication. They explained that the lack of communication is particularly a problem at referral sites, where client history and need are not known:

> *There is no information that is sent with the patient when they are referred to us and so we have no idea of the history or what has been done.*—International NGO, staff nurse

Lack of communication affects the continuum of care. As one explained, where providers do not communicate, clients are "moving on their own without support from the providers who referred them." This contributes to frustration and confusion, and leads to people refusing to access care.

Like the local providers, the NGO staff also said linkages between community- and facility-based providers were weak. With almost no specific information about clients coming to a referral site or returning from a referral, the client often gets duplicated care or inappropriate care at the community level.

Providers described the limited capacity of lower-level facilities to provide care and treatment services. Referring PLHA to higher-level facilities that are overburdened can mean that clients will not follow advice and may not receive the care that they need on time. This builds distrust. Providers suggested greater decentralization and strengthening clinic capacity to service clients. As one NGO staff member explained:

> *Capacity at clinic level needs to be built up. We have challenges managing at tertiary institutions, because there are too many patients and at the same time, at clinics there is no one there accessing care. So if we can build this capacity at clinic level—like ART management, management of PLHA, management of symptoms like diarrhea, collecting sputum, refills of ART—these things if done at clinics would relieve the larger facilities.*—National NGO, staff member

NGO providers often seemed to take on the perspective of their clients when talking about barriers to referral. They believed that fear and stigma are major barriers. Clients develop a trusting relationship with a provider at a particular facility and when they are referred to another, it is difficult to trust that the new provider will respect confidentiality. Also, when clients are referred for ART, they may be reluctant to follow that advice for fear that accessing such services identifies them as HIV positive and will lead to stigmatization. Finally, clients are reluctant to follow referral advice because of quality of care, which is either described in terms of poor provider behavior at referral sites and fear of mis- or maltreatment or they think there might be inadequate staff or services available, that the waiting times may be long and in the end they may be turned back without service anyway. Finally, NGO providers described problems of client poverty and transport as barriers to referral.

Discussion

This study provides evidence that referral is common among both facility- and community-based providers, and is largely understood as sending clients to seek care at higher-level healthcare facilities, most notably hospitals. These practices were true for providers at all facilities as well as among community providers; each most frequently cited hospitals as the main referral site with the exception of CHWs who said they often referred clients to clinics as well as hospitals. Reverse referral from hospitals down to health centers or clinics was low, except for home-based care, psychosocial support, and palliative care. While NGOs reported both receiving and making referrals to the health facilities, NGOs were rarely cited by the government providers for specific services such as palliative care, home-based care, psychosocial support, nutrition support services, and counseling.

Results suggest that referral is an individualized and flexible process that depends on various factors. It is most often made for cases where the provider cannot serve the patient with a required service. Factors such as complications requiring higher-level care, referral for clients to access care closer to home or at a lower level, and lack of supplies are also reasons for these types of referral. In addition, around a quarter of the providers reported using more than one referral site, indicating that different circumstances call for sending clients in need of the same service to different referral sites.

The study suggests that referrals and linkages for certain services are particularly weak. These services are those mainly given by community providers such as nutrition and psychosocial support, palliative care, and complications in the context of home-based care. Yes, several providers said that when referring to

"the community," formal structures or linkages don't exist; instead clients are left to search for care alone. CHWs echoed this in expressing a lack of communication with facility-based providers. The qualitative data supported these findings, and all noted that stronger community systems and better communication would improve client care and reduce the burden on facilities.

Accepting Referral: Client Behavior

Like other studies of referral refusals and perceptions in Africa, different factors emerged to explain why some clients followed and others failed to follow referral advice (Simba et al. 2008; Low et al. 2001). Nearly all providers said that taking up a referral occurs for those who think they will improve, because they trust the provider's advice and because they are feeling sick. They emphasized lack of transport and perceptions of poor care at the referral site as factors that influence client behavior. A few also cited fear of discrimination at the next stage, of not improving, and of death as factors at work when clients fail to follow referral, although when asked about specific problems that PLHA face when seeking care and in following referral, most providers and NGO staff cited poor quality of care as well as stigma. In contrast, the community-level providers emphasized issues of stigma and fear of the next stage over quality of care or transport issues (see also Suri, Gan, and Carpenter 2007, in South Africa). In addition, it was these local providers that noted preference for traditional medicine and/or fear of mixing traditional and western medicines as factors that influence client behavior. These differing and even disagreeing perspectives are not unusual in studies of referral, but they need to be taken account of in any reforms (Meiberg et al. 2008; Posse et al. 2008; Rohde et al. 2008).

Barriers to Referral

A common barrier to referral noted by all provider groups was the cost of care, and this barrier is reported elsewhere in Africa (e.g., Posse et al. 2008; Mshana et al. 2006). But while Swazi facility-based providers placed importance on transport, the community-level providers did not overemphasize this. The latter group tended to cite client fear and quality of care issues over transport. Although this study did not gather data on barriers to referral from clients who *did not* follow referral advice, from those that were interviewed at health facilities, we know that on average they'd traveled one hour and paid E/R 20 ($2.50). While this time and cost may be manageable, providers noted that other costs such as facility fees, medication, food, and accommodation may be the real barriers. The issue of transport and cost of seeking care deserves more analysis to understand all factors involved; merely adding more ambulances, as was suggested by many

facility-based providers, may be an expensive and insufficient way of dealing with the issue, especially if the issue is the opportunity costs rather than the transport costs per se.

Communication is a constant theme emphasized by many providers for its role in ensuring that clients receive necessary care in a timely manner and that feedback is given to ensure proper follow-up. About half of the providers said they knew what happened with the last client they referred for HIV treatment, while nearly all CHWs and most traditional healers reported trying and failing to get feedback on referrals made. Feedback is not provided through formalized communication channels with facilities but instead often comes from clients or their families. We found almost no reports of patients bringing home written advice, nor were there reports of phone calls made as reports to sending providers.

Improving the Referral System

Nearly all providers recommended that a referral protocol be put in place with strong communication tools, most notably a common referral form that includes sections for detailed history as well as feedback to be returned to the referring provider. While formal providers most often emphasized the need for better communication between facilities, community-based providers consistently emphasized the need for better linkages between themselves and facilities. This was found in one of the only other recent studies in Swaziland that focused on traditional healers in the context of AIDS (Peltzer, Mngqundaniso, and Petros 2006).

CHWs and facility-based providers alike described that priority should be given to referred clients upon arrival at the referral site. They also expressed a desire to strengthen the quality of care. CHWs said they needed equipment, training, and support from health facilities to minimize the need for referrals when care can be provided in the community. NGO staff also spoke of the need to improve community-based services. Many providers said that comprehensive care should be given to PLHA at the lowest levels possible to obviate the frequent need for referral.

Limitations

Due to resources, it was not feasible to interview members of communities who were *not* already clients within the system. So, participants were those who had managed to reach a facility. This study can only understand the perspectives of those clients who are *unsuccessful* through the reports of providers and staff. Reporting bias, or socially acceptable responses, is always a potential problem in

surveys but perhaps especially here where providers may have suspected an element of monitoring. Also, respondents may have perceived the potential of receiving something if they gave "acceptable" responses.

Interviewer bias may be an issue as it emerged during the fieldwork that there were still levels of denial and misunderstanding around HIV even in this well-educated group. One challenge emerged in interviewing ART/VCT clients in comparison with general OPD clients. With VCT clients, many were eager to leave the facility after testing, even if, before going for their results, they had told the interviewer they would participate. In the case of ART, where clients wanted only a drug refill and did not need to queue in outpatient clinics, many were eager to leave immediately. These constraints meant that interviewers doing client interviews preferred the OPD.

It must be kept in mind when interpreting these results that referral is understood in different ways by different providers. Some understand referral to be the process of transferring clients to another facility, sometimes actually physically transporting them in ambulances. Others, particularly in larger facilities, include in their understanding of referral sending clients to other departments in the same facility. Further, when interpreting the perspectives on referral of providers at specific facilities, we noted that there are discrepancies in provider reports of referral practices that occur in the same site (e.g., referral practices for ART). Multiple providers were interviewed at each facility, and they at times provided different responses on referral practices due to their location in different departments.

Finally, reports indicated that some providers were clearly frustrated with the questionnaire, noting that it did not capture the true picture of procedures and provider behavior. Everything *depends*, and neither behavior nor procedures are as straightforward as the line of questioning appeared to make them. This is a valid criticism and is part of what makes referral so challenging to study. Providers often say referral depends on many factors, and yet health systems require that a certain amount of protocol be followed for efficiency and quality of care. The tension between protocol and flexibility in practice will persist; however, addressing discrepancy between these dimensions will be an important challenge for many countries to address in order to improve patient care at reasonable cost.

Conclusions

This study sought to understand referral from various perspectives to inform decision makers on ways to reform the referral system in Swaziland. Although there was an initial focus on the referral needs around the ART system and for

HIV treatment and care, the study is applicable to referral for many different diagnoses and issues (acute or chronic).

Improvement of the system could come through policy-level efforts to standardize referral protocols, procedures, and practices. However, improving the referral system also inevitably includes reforms of the healthcare system itself. These reforms include addressing client access to appropriate and timely services, including hours of operation, distribution of services, and human resources at the different levels. Results point towards specific areas where the system is overburdened or lacks capacity, but these problems are not uniform. As such, discrete short-term reforms may alleviate some of the burdens on the system. Other reforms will be more costly in terms of time and resources necessary for change.

Short-Term Recommendations

- Re-train on existing referral forms
- Emphasize the feedback portion of referral forms
- Revisit supply of forms (may be more of an issue at particular facilities)
- Wide dissemination of the national *HTC/VCT Referral Directory and Guide*.
- Develop a simple reporting system for facilities to track patients referred internally
- Ensure community-based providers are involved in regional meetings
- Develop mentoring/communication programs between providers and CHWs
- Extend current hours of operation in health centers
- Improve access to CD4 count by increasing days of operation, staff, and machines nationally.

Long-Term Recommendations

- Develop a standard referral form with more space for observations and client history and a substantial feedback section to be sent to the referring site
- Train on and disseminate widely the referral protocol at all levels—include all stakeholders
- Develop a protocol for referral between facilities, and between communities and facilities
- Revisit the triage system at referral sites so that they become more focused on referral rather than operating as a general health facility

- Appoint referral officers at each referral receiving site
- Continue to improve service provision for all HIV services at the lower levels to reduce burden on upper levels and reduce need for some of the referrals
- Computerize referrals made for clients on ART to properly track them through the system
- Use SMS to communicate regarding referred patients
- Continue to address issues related to stigma and discrimination in the healthcare delivery settings.

While transport was mentioned often, perhaps transport—most frequently recommended were "more ambulances"—will not guarantee a better situation if other factors are also not addressed. For example, if a referred patient arrives by ambulance but has to wait for treatment, or has to begin the registration and diagnosis process again, then it may not have done much good to bring them in by ambulance (see also Leonard, Mliga, and Mariam (2002) for discussion of this problem).

While it is an essential component of a health system, referral is not well understood. It is a complex phenomenon, interpreted by different actors in various ways. It is hard to measure and challenging to train providers. This study has begun to address information gaps and points towards some reforms that, if implemented, could improve collaboration and communication which are essential components of referral. The execution of a reformed referral system will require resources and political will. Solitary reforms will not fix all problems. What is possible, however, is that with a more efficient referral system, confidence in the whole system from all perspectives may rise. A system in which workers and clients are not confident is not a well-functioning system. Referral may be hard to do well, but it is an essential part of any good healthcare system and deserves more attention.

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