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Title

Evaluating the role of primary care physicians in the treatment of latent tuberculosis: a population study.

Permalink

<https://escholarship.org/uc/item/5kd444wh>

Journal

The International Journal of Tuberculosis and Lung Disease, 18(12)

ISSN

1027-3719

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Rubinowicz, A
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Publication Date

2014-12-01

DOI

10.5588/ijtld.14.0166

Peer reviewed



Published in final edited form as:

Int J Tuberc Lung Dis. 2015 August ; 19(8): 912–917. doi:10.5588/ijtld.14.0166.

Pathways and costs of care for patients with tuberculosis symptoms in rural Uganda

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SUMMARY

SETTING: Six district-level government health centers in rural Uganda and the surrounding communities.

OBJECTIVE: To determine pathways to care and associated costs for patients with chronic cough referred for tuberculosis (TB) evaluation in Uganda.

DESIGN: We conducted a cross-sectional study, surveying 64 patients presenting with chronic cough and undergoing first-time sputum evaluation at government clinics. We also surveyed a random sample of 114 individuals with chronic cough in surrounding communities. We collected information on previous health visits for the cough as well as costs associated with the current visit.

RESULTS: Eighty per cent of clinic patients had previously sought care for their cough, with a median of three previous visits (range 0–32, interquartile range [IQR] 2–5). Most ($n = 203$, 88%) visits were to a health facility that did not provide TB microscopy services, and the majority occurred in the private sector. The cost of seeking care for the current visit alone represented 28.8% (IQR 9.1–109.5) of the patients' median monthly household income.

CONCLUSION: Most patients seek health care for chronic cough, but do so first in the private sector. Engagement of the private sector and streamlining TB diagnostic evaluation are critical for improving case detection and meeting global TB elimination targets.

RESUME

L'étude a eu lieu dans six centres de santé gouvernementaux situés au niveau des districts dans une zone rurale d'Ouganda et dans les communautés des alentours.

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Conflicts of interest: none declared.

Déterminer les parcours des patients vers les soins et les coûts associés pour les patients ayant une toux chronique, référés pour évaluation de tuberculose (TB) en Ouganda.

Nous avons conduit une étude transversale sur 64 patients présentant une toux chronique et bénéficiant d'un premier examen de crachats dans un centre de santé; public. Nous avons également enquêté sur un échantillon aléatoire de 114 individus présentant une toux chronique dans les communautés des alentours. Nous avons recueilli des informations sur les consultations précédentes pour toux ainsi que sur les coûts associés à la consultation actuelle.

Quatre-vingt pour cent des patients de la consultation avaient précédemment sollicité des soins pour leur toux, avec une médiane de 3 (fourchette 0–32, IQR 2–5) consultations préalables. La plupart des consultations ($n = 203$, 88%) avaient eu lieu dans un centre de santé qui ne disposait pas de services de microscopie de TB et en majorité dans le secteur privé. Le coût de la recherche de soins pour la consultation actuelle représentait à lui seul 28,8% (IQR 9,1–109,5) du revenu mensuel médian du foyer des patients.

La majorité des patients sollicitent des soins de santé pour une toux chronique, mais le font en premier lieu dans le secteur privé. L'évaluation de l'engagement du secteur privé; et la rationalisation du diagnostic de la TB sont cruciaux pour améliorer la détection des cas et atteindre les objectifs d'élimination mondiale de la TB.

RESUMEN

El presente estudio tuvo lugar en seis centros de salud distritales del sector público, en una zona rural de Uganda y en las comunidades circundantes.

Determinar la trayectoria de búsqueda de atención y los costos conexos asumidos por los pacientes con tos crónica, remitidos con el fin de investigar el diagnóstico de tuberculosis (TB) en Uganda.

Se llevó a cabo un estudio cruzado de seguimiento de 64 pacientes que presentaban tos crónica y acudían por primera vez a un consultorio del sector público para examen del esputo. Se practicó también el seguimiento de una muestra aleatoria de 114 personas con tos crónica en las comunidades circundantes. Se recogió información sobre las consultas médicas anteriores por tos y los costos asociados con la consulta actual.

El 80% de los pacientes del consultorio había buscado atención por causa de la tos, con una mediana de tres consultas anteriores (entre 0 y 32; intervalo intercuartil [IQR] 2–5). La mayoría de los pacientes consultaron centros que no ofrecían servicios de microscopía de TB ($n = 203$; 88%) y centros del sector privado. Los costos de la búsqueda de atención en la consulta actual representaron 28,8% de la mediana del ingreso mensual del hogar de los pacientes (IQR 9,1–109,5).

La mayoría de los pacientes con tos crónica busca atención médica, pero se dirige inicialmente al sector privado. La vinculación del sector privado y una mayor eficacia de la evaluación diagnóstica de la TB constituyen elementos fundamentales en el mejoramiento de la detección de los casos y el cumplimiento de las metas mundiales de eliminación de esta enfermedad.

Keywords

cough; cost; diagnosis; delay; care seeking

ACCORDING TO THE WORLD HEALTH Organization (WHO), only 66% of the estimated 9 million incident cases of active tuberculosis (TB) in 2014 were notified to public health authorities.¹ Although there are many reasons for the failure to notify incident cases, at least some of this gap may be attributed to the barrier imposed by the high costs incurred by patients with symptoms and the circuitous paths they follow when attempting to access TB diagnostic and treatment services.

Previous studies on cost of care have focused mainly on patients being treated for TB in the public sector. In general, these studies have shown that patients incur significant direct and indirect costs when accessing TB care, leading to delays in TB diagnosis and losses to follow-up both before and after initiation of anti-tuberculosis treatment.² A recent systematic review of studies from low- and middle-income countries described these costs as catastrophic, with patients suffering significant lost income and total costs approaching 40% of household income.³ However, studies to date have focused on patients who are diagnosed with and initiate treatment for TB rather than the much larger population seeking care for TB symptoms such as chronic cough.

There are far fewer studies on the pathways by which patients with TB symptoms seek care. In India, detailed mapping of the pathways to care of TB patients revealed that most initiated care for TB symptoms in the private sector and consulted two to four providers before reaching a public sector TB diagnostic unit.⁴ However, few studies assessing pathways to care have been conducted in sub-Saharan Africa,⁵⁻⁷ where the contribution of the private sector in providing TB care is less well described.

In the present study, we focus on both pathways and costs associated with the evaluation of chronic cough, a recommended entry point into the TB diagnostic pathway in high-burden countries.⁸ Our objectives were to determine the sequence and types of providers visited by patients with chronic cough in rural Uganda and to estimate the direct and indirect costs associated with seeking care for chronic cough throughout this diagnostic pathway.

METHODS

Study setting

This cross-sectional study was conducted at six geographically dispersed district-level (Level IV) government health centers in rural Uganda.^{9,10} Level IV health centers are the lowest level of the health system, where TB diagnostic (microscopy) and treatment services are made available free of charge through the National Tuberculosis and Leprosy Programme (NTLP). Each Level IV health center serves a population of approximately 100 000.

Participants

We surveyed all consenting adults undergoing sputum smear evaluation for TB diagnosis during 1-day site visits to six Level IV health centers between November 2011 and September 2012. We administered surveys immediately after patients submitted sputum specimens to the laboratory. In addition, we surveyed a sample of adults living in the sub-

counties served by three of the health centers for the presence of chronic cough. For the community survey, we used household coordinates on regional maps to randomly select 50 households per health center (150 households in total), and screened one adult per household (starting with the head of household) for any episode of cough of at least 2 weeks' duration within the past year for which care had been sought.⁸⁻¹⁰ The findings from this sample did not differ significantly from the clinic population and are therefore presented in the Appendix.*

Surveys

We administered all surveys in the participant's local language, with translation services provided by a local health worker when needed. To map pathways of care, we collected information on up to five health care visits for the current episode of chronic cough (clinic sample) or for any episode of chronic cough within the past year (community sample). Data included the type of health care facility visited and the costs associated with seeking care in that setting. Cost data collection was based on the Tool to Estimate Patient Costs (Stop TB Partnership, Geneva, Switzerland) and included participants' demographic information, household size, monthly personal and household income, and round-trip transport time from their home to the health center.¹¹ We asked patients to estimate total direct (e.g., clinic, laboratory or pharmacy fees) and indirect (e.g., transport, missed work, child care) costs associated with seeking care for each visit. In addition, we asked patients seeking care in Level IV health centers to estimate each individual component cost for the current visit. We report costs both as 2012 US dollars (converted from Ugandan shillings using the nominal exchange rate) and as a proportion of median reported monthly household income.

Data analysis

We described patient characteristics, costs, and time required for care-seeking visits using proportions with 95% confidence intervals (CIs) for dichotomous outcomes and either medians with ranges and interquartile ranges (IQRs) or means with standard deviations (SDs) for continuous outcomes. We performed analysis of variance to assess statistical differences in costs and time of visits across different health-care settings. We performed all analyses using Stata, version 13 (StataCorp, College Station, TX, USA).

The study protocol was approved by the institutional review boards at the University of California San Francisco (San Francisco, CA, USA) and Makerere University (Kampala, Uganda) and by the Uganda National Council for Science and Technology (Kampala, Uganda).

RESULTS

Participants

Among patients submitting sputum for TB evaluation in Level IV health centers, 64/67 (96%) agreed to participate in the survey. Of these, 34 (53%) were female and the median

*The appendix is available in the online version of this article, at <http://www.ingentaconnect.com/content/iatld/ijtld/2015/00000019/00000008/art00009>

age was 45 years (IQR 35–58). Patients had a median household size of 5 members (IQR 3–8) and median monthly household income equivalent to US\$16 (IQR 4–40). Patients had cough for a median duration of 6 weeks (IQR 2–12) prior to the current visit to the Level IV health center, and 49 (77%) reported at least one other TB symptom.

Pathways to care

Of the 64 patients, 51 (80%) had sought care previously for chronic cough, and their pathways to care were complex (Figure 1). These 51 patients made a median of three visits (IQR 2–5) to health facilities to seek care for their current cough episode. Repeated visits to the same type of health facility were common, accounting for 60% of all second visits, 66% of all third visits, 38% of all fourth visits, 65% of all fifth visits and 27% of all sixth visits (Figure 2). Most patients who had previously sought care first visited a health facility that did not provide TB microscopy services ($n = 40$, 78%), including lower-level government health posts ($n = 7$, 18% of non-microscopy facility first visits), private clinics ($n = 13$, 33%), herbalists ($n = 5$, 13%), and pharmacies ($n = 15$, 38%) (Figure 2). Among the 23 patients who first visited a TB microscopy unit (Level IV health center or district hospital), nearly half ($n = 11$, 48%) made at least two visits and one quarter ($n = 6$, 26%) made at least three visits before being referred for sputum microscopy.

Total time for a provider visit, including transit and waiting time, ranged from a median of 1 h (IQR 0–5) for a visit to a herbalist to a median of 11 h (IQR 10–12) for a district hospital visit (Table 1). Significantly more time was required to visit Level IV health centers or district hospitals that provided TB microscopy services (median 7 h, IQR 5.5–9.0) than to visit health-care settings that did not provide TB microscopy services (median 2 h, IQR 1–5), ($P < 0.001$).

Costs associated with seeking care

Patients spent a median of US\$4.60 (IQR 1.46–17.52) seeking care for their current episode of cough, representing 28.8% (IQR 9.1–109.5) of their monthly household income. The median cost per patient per visit ranged from US\$1.14 (IQR 0.80–2.40) to visit a government health post to US\$8.00 (IQR 6.00–9.20) to visit a district hospital (Table 1). These costs represented 15.2% (IQR 4.0–20.0) to 100% (IQR 57.5–53.8) of the monthly household income. The median cost was similar to visit health facilities that did (US\$2.00, IQR 0–6.00) and did not (US\$1.80, IQR 0.80–4.00) offer microscopy services ($P = 0.90$).

The largest contributors to cost of the current visit to the Level IV health center were transportation (mean 35% of total) and lost wages (mean 33% of total) (Table 2). No patients reported having to pay for clinical or laboratory services. More than a quarter of patients ($n = 17$, 27%) reported selling a possession to pay for their visit.

DISCUSSION

Pathways to care in Uganda are complex, with most visits occurring in the private sector. The costs of a single visit to any health care setting often represent a quarter or more of the monthly household income, and multiple visits are generally required for TB patients to reach a microscopy center, have sputum requested, complete sputum smear evaluation, and

initiate treatment if smear-positive. Even more visits may be required for symptomatic patients with negative sputum smears. Furthermore, we found that the burden of high costs and complex pathways affects not only patients eventually found to have TB, but all those who initiate diagnostic evaluation for TB, the vast majority of whom will not be diagnosed with TB. To reach the 'missing 3 million', TB diagnostic and treatment services must be offered in a more patient-centered manner.

Our findings are consistent with the small number of previous studies describing patient pathways to accessing TB care in other high-burden settings. As in South Asia, the majority of patients accessing care for chronic cough in Uganda initially contact the diverse private sector, including herbalists, pharmacists, informal providers, and private physicians. Notably, the cost to patients of public sector and private sector care is similar, although public services are often touted as being 'free'; this may reflect the longer distance patients have to travel to public clinics. Patient care seeking is complex, with the average patient making two to three visits to various providers and several repeat visits before being tested for TB. According to previous studies, such complex pathways often result in diagnostic delay as patients seek care with repeated visits to providers in facilities without diagnostic services. This delay may contribute to worsening patient morbidity and mortality and ongoing transmission.^{8,11,12} Even for those patients who reach a TB microscopy unit, repeated visits are common before there is a referral for sputum smear microscopy. This supports our previous findings that few patients with chronic cough actually receive care adherent to the International Standards of Tuberculosis Care (ISTC), including referral for sputum examination, reporting of results, and treatment initiation.^{1,8,10}

Our findings are consistent with previous studies presented in systematic reviews of the economic consequences and impact of TB diagnosis on patients and households in Africa. Few studies reported pre-diagnostic costs, but of those that did, costs for patients ranged between US\$36 and US\$196, representing between 10% and 35% of the annual household income.^{2,13} Although our results report lower costs than this, our setting is rural Uganda, where incomes are also much lower. However, when comparing the median monthly household income our results are consistent with those reported in other settings. Worldwide, half of total costs are thought to be pre-treatment initiation costs, and overall these costs disproportionately affect the poor.³ A recent large systematic review demonstrated that total TB care costs in Africa, even in settings with free diagnosis and treatment, were catastrophic, representing >10% of the annual household income.^{4,14} The same and even worse is true in rural Uganda, where pre-diagnosis costs alone are often catastrophic and may be a barrier for patients seeking TB care.

Our study confirms the hypothesis that patients with symptoms suggestive of TB are seeking the majority of their care at facilities that do not offer microbiological TB testing. High rates of patient utilization of private providers, particularly pharmacies, confirm the importance of understanding the private sector when considering patient pathways to care in sub-Saharan Africa. In Uganda, the majority of health care is provided by the private sector, while all anti-tuberculosis treatment resources are within the public sector (Health Center IV and hospitals).^{5-7,15} A survey of health facilities in rural Uganda found that 96% of facilities were private, which underlines the importance of understanding the role of private providers

in patient pathways to care.^{8,16} Interventions that better incorporate the private sector into TB care are worth exploring. For example, expanding sputum microscopy services to private sector providers through public-private partnerships, or simply strengthening referral systems for private providers to triage patients with symptoms suggestive of TB, may help streamline pathways to care. However, more studies are needed to identify the most effective ways of engaging the private sector.

There are several limitations to this study. First, although we present patient costing information, we could not collect diagnostic and therapeutic outcomes in this cross-sectional study, and thus cannot report cost-effectiveness from a patient perspective. However, our focus is on patient costs, and as such cost-effectiveness analysis may not be necessary to describe patient barriers to care. Our methodology is also vulnerable to recall bias in the costing information provided by the patients surveyed. Although this bias will be lowest for questions regarding the current visit, questions about previous visits are more susceptible to bias. Moreover, we only enrolled patients who were seeking care at a Level IV health center; this patient population may not be generalizable to those treated in hospitals or entirely in the private sector. However, the results were consistent with those from our population-based sample taken from communities surrounding the targeted health centers (see Appendix).

Despite these limitations, the study does present important insights into the care-seeking behaviors of patients with chronic cough, and illuminates some barriers to TB diagnosis that can be addressed. First, improved engagement with private sector facilities is needed to encourage rapid referral of patients with chronic cough to TB diagnostic units. Second, incorporating same-day microscopy services, which have been shown to be as accurate as the traditional multiday sputum microscopy process, may substantially reduce patient costs.^{9,10,17} Further gains can be made by investing in infrastructure, such as systems to transport specimens from both public and private sector facilities to TB diagnostic units and from smear-negative patients to the increasing number of facilities with rapid molecular diagnostics.^{8-10,18} In addition, mobile technologies to report results back to patients via text messages may prove helpful in linking patients to treatment when indicated.^{11,19,20} The costs and impact of such health system interventions, from a societal and health system perspective, require urgent evaluation.

CONCLUSION

Reducing both direct and indirect costs incurred by patients seeking care for chronic cough may improve the speed of TB diagnosis and mitigate the financial impact on the patient and his/her family. The WHO emphasizes the need to pursue pro-poor approaches as a means of increasing case detection rates.^{8,11,12} In rural Uganda, current systems of TB diagnosis may severely burden already vulnerable populations. It is important to recognize the economic impact not only on TB patients, but also on those who have symptoms that may have been caused by TB. Improved TB care and control requires developing strategies to improve patient-centered TB diagnosis and mitigate key barriers to accessing care.

Acknowledgements

The authors would like to thank the patients and community members who participated in the surveys and the staff of the Uganda Tuberculosis and Malaria Surveillance Projects, Kampala, Uganda, for enabling the study. The study was funded by the US National Institutes of Health, Bethesda, MD, USA (R21 AI096158).

APPENDIX

RESULTS OF COMMUNITY SAMPLE

Participants

The community sample included 119/150 (79%) randomly selected households for which there was at least one adult present during a study visit. Of these, 55 (48%) had experienced cough of ≥ 2 weeks' duration within the last year, and 49/55 (89%) had sought care for their cough. There were no significant demographic differences between participants with cough who did and those who did not seek care (data not shown). The reasons for not seeking care included lack of money ($n = 2$), not feeling ill enough ($n = 2$), and long distance and/or travel time to the nearest health center ($n = 2$). Of the 49 participants who sought care, 30 (61%) were female; the median age was 42 years (interquartile range [IQR] 30–60), the median household size was 6 (IQR 4–7) and the median monthly household income was US \$12 (IQR 6–40). The average duration of cough was 4 weeks (IQR 2–9) (Table A.1).

Pathways to care

The 49 participants who sought care for their cough made a median of 2 (IQR 1–3) visits to a health care provider. Similar to the clinic sample, repeated visits to the same type of health care provider were common. Most participants ($n = 35$, 71%) first visited a health facility that did not provide TB microscopy services, including lower-level government health posts ($n = 11$, 31% of visits to services without microscopy), private clinics ($n = 11$, 31%), herbalists ($n = 4$, 11%), and pharmacies ($n = 9$, 26%). Twenty-one (43%) participants visited a health facility that provided tuberculosis (TB) microscopy services. Only 10 of the total participants seeking care (20%) underwent sputum examination. Of these, only three (30%) reported having received their sputum examination results.

Table A.1

Patients surveyed on costs of care seeking in community samples

	Community sample	
	Total ($n = 114$) Median [IQR]	Persons seeking care for cough ($n = 49$) Median [IQR]
Female sex, n (%)	73 (64.0)	30 (61.2)
Age, years	40 [28–56]	42 [30–60]
Household size	5 [3–7]	6 [4–7]
Monthly household income, US\$	20 [8–40]	12 [6–40]
Cough duration, weeks *	—	4.3 [2–8.6]

* Measured to time of household visit in community patients.

IQR = interquartile range.

Participants spent a median of 7 h (IQR 3–15) seeking care for their cough. Total time spent seeking care, including transit and waiting time, ranged from a median of 0.5 h to visit a pharmacy (IQR 0.4–2.5) to 48 h for a single visit to a district hospital (Table A.2). Similar to the clinic sample, significantly more time was required to visit Level IV health centers or district hospitals that provided TB microscopy services (median 8 h, IQR 7–10) than to visit health care settings that did not provide TB microscopy services (median 2 h, IQR 1–5, $P < 0.001$).

Costs associated with seeking care

Patients spent a median of US\$4.00 (IQR 1.60–9.84) seeking care for their current episode of cough, which represented 37% (IQR 7–91) of their monthly household income. Total costs per visit ranged from US\$0.80 (IQR 0–1.20) or 3% (IQR 0–100) of the monthly household income to visit a herbalist to US\$12.80 or 21% of their monthly household income to visit a district hospital (Table A.2). The median cost was similar for visiting health facilities that did (US\$3.20, IQR 0.80–4.40) and did not (US\$1.80, IQR 0.48–4.00) provide TB microscopy services ($P = 0.83$).

Table A.2

Costs and time associated with health care visits: community sample

	<i>n</i> (%)	Cost of visit/patient median US\$ [IQR]	Cost/visit as % of MHHI median % [IQR]	Time/visit median h [IQR]
Visits to facilities without TB microscopy services				
Level I-III health post	25 (16)	2.00 [0.40–3.20]	6.7 [1.5–90.0]	6 [5–7]
Herbalist	13 (9)	0.8 [0–1.2]	3.0 [0–100]	1 [0.5–2.0]
Pharmacy	19 (37)	2.00 [1.60–4]	33.3 [2.5–40.0]	0.5 [0.2–2.0]
Private clinic	39 (26)	4.00 [1.60–10.00]	25.8 [13.3–338]	3 [2–4]
Visits to facilities with TB microscopy services				
Level IV health center	56 (37)	4.00 [1.00–6.00]	27.3 [6.5–50.0]	8.5 [7–10.5]
District hospital	1 (<1)	12.80*	21.3	48

IQR = interquartile range; MHHI = median monthly household income; TB = tuberculosis.

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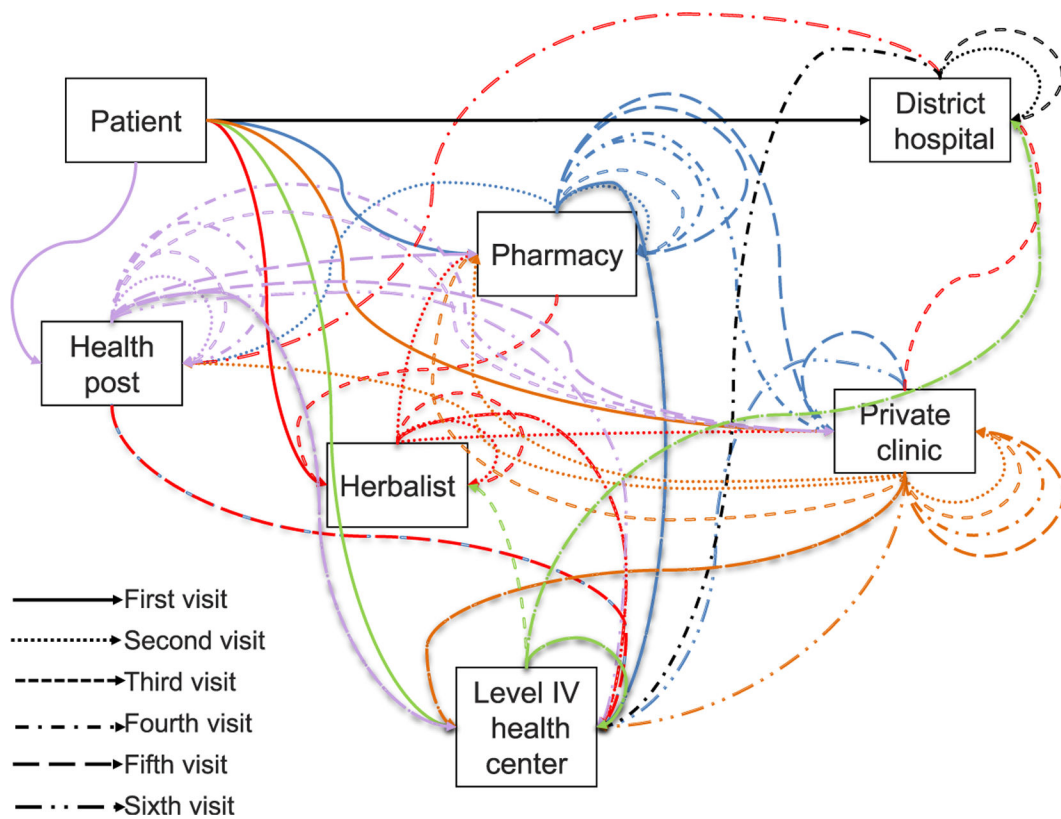


Figure 1.

Pathways to care for patients with chronic cough in rural Uganda, seeking care for symptoms consistent with TB. Colors correspond to the health facility where patients started seeking care and the different arrows represent successive care-seeking visits. While complex, the pathways analysis demonstrates that patients first seek care in diverse settings and most often at facilities that do not provide sputum smear microscopy services. Excluding the current visit to the Level IV health center, the most common setting for the remaining 229 visits was pharmacies ($n = 59$, 26%), private clinics ($n = 57$, 25%), lower level health posts ($n = 45$, 20%), Level IV health center ($n = 28$, 12%), district hospital ($n = 17$, 7%), and traditional healers ($n = 2$, <1%). This image can be viewed online in color at <http://www.ingentaconnect.com/content/iatld/ijtld/2015/00000019/00000008/art00009>

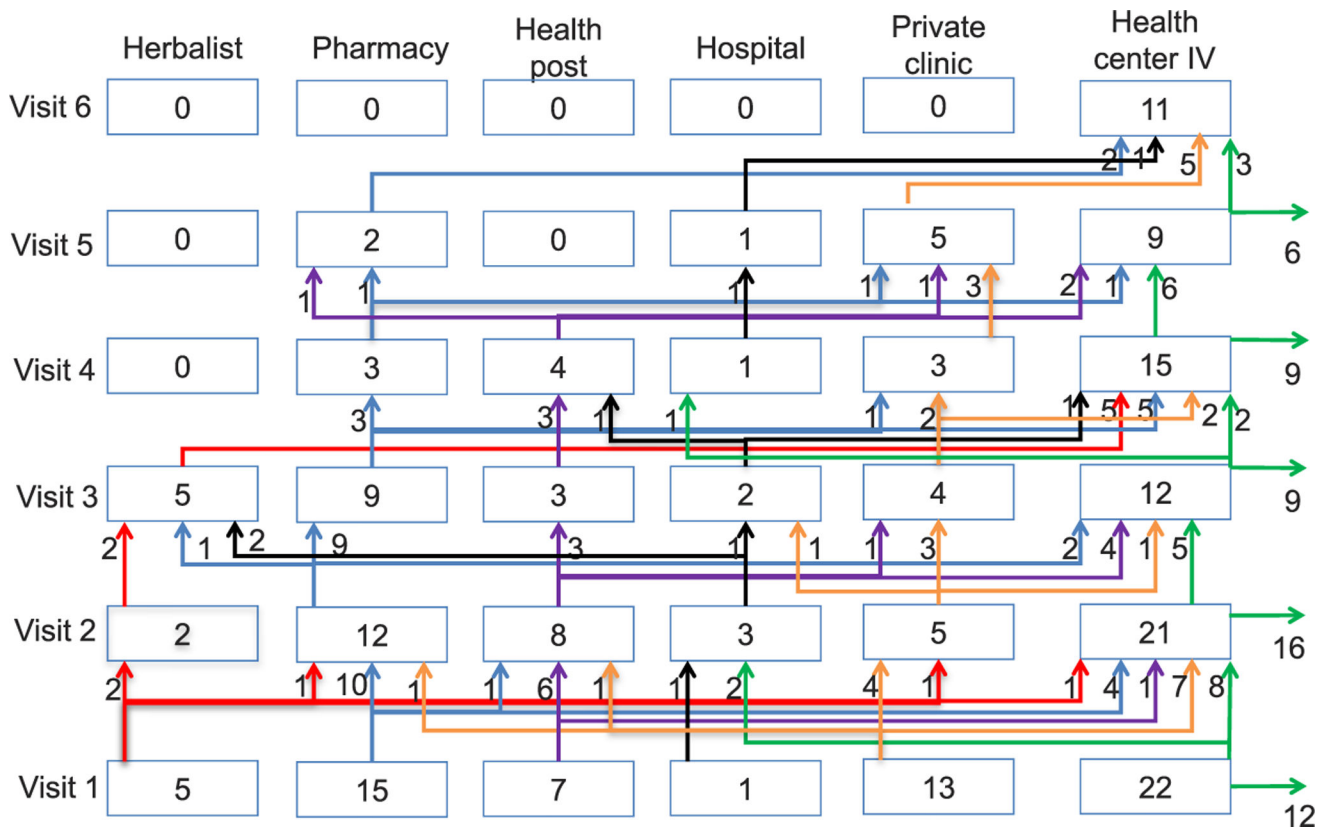


Figure 2. Frequency and type of health provider visited sequentially by patients seeking care for chronic cough in rural Uganda. Colors correspond to the health facility where patients started seeking care. Arrows on the right-hand side indicate the current visit to the Level IV health center. Of the five patients who started seeking care from a herbalist, two made a second and third visit to the same setting. Overall, repeated visits to the same type of health facility were common, accounting for 60% of all second visits, 66% of all third visits, 38% of all fourth visits, 65% of all fifth visits and 27% of all sixth visits. This image can be viewed online in colour at <http://www.ingentaconnect.com/content/iatld/ijtld/2015/00000019/00000008/art00009>

Table 1

Costs and time associated with health care visits

	Total visits to that facility (% of total visits) (n = 229) n (%)	Cost of a visit/patient US\$	Cost of visit/patient as % of MMHI median [IQR]	Time/visit, h median [IQR]
Visits to facilities without TB microscopy services				
Level I-III health post	45 (20)	1.14 (0.80–1.84)	15.2 (4.0–20.0)	4 [3–6]
Pharmacy	59 (26)	1.60 (0.96–2.00)	5.6 (2.5–15.0)	1.5 [0.5–3.0]
Private clinic	57 (25)	3.60 (1.68–7.20)	12.4 (7.1–26.7)	2.5 [1.5–9]
Herbalist	12 (5)	4 (0–8)	16.7 (0–71.0)	1 [0–5]
Visits to facilities with TB microscopy services				
Level IV health center	28 (12)	2.00 (0.24–5.00)	10.8 (1.0–25.0)	8.5 [6.5–10]
District hospital	17 (7)	8.00 (6.00–9.20)	100 (57.5–300)	11 [10–12]

MMHI = median monthly household income; IQR = interquartile range; TB = tuberculosis.

Table 2

Cost of current visit to the Level IV health center for the clinic sample

Component of cost	Cost US\$ mean \pm SD	Mean cost as % of total current visit costs %
Transport	21.29 \pm 2.51	35
Medicine	0.16 \pm 1.02	5
Food	0.34 \pm 0.91	10
Family care	0.50 \pm 1.39	15
Lost wages	1.13 \pm 2.02	33
Total visit costs	3.42 \pm 4.42	100

SD = standard deviation.

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