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Geographical, Health Systems' and Sociocultural Patterns of Tb/Hiv Co-Infected Patients' Health Seeking Behavior in a Conflict Affected Setting: The Case of Eastern Democratic Republic of Congo

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Abstract

Background: The Democratic Republic of Congo (DRC) is one of the high burden TB countries. The country has been affected by a political conflict for more than 15 years now. HIV prevalence has been increasing in the country too. Detection and care of TB/HIV co-infected cases is a major problem in the country.

Aim: This study aimed at describing patterns of health seeking behaviors among patients with TB/HIV regarding their choice of health facilities for integrated TB/HIV care in the Goma and surrounding health districts.

Methods: The methods used included a cross-sectional descriptive survey with TB/HIV co-infected patients and qualitative interviews of health workers.

Results: The study found that geographical residence did not play a major role in choice of facility for care by patients infected with TB and HIV. Many patients shun facilities which are close and seek care relatively far away. Instead of geographical proximity, availability of drugs and welcoming attitudes determined the choice of integrated care facilities. Also, fear for discrimination and stigmatization in the community result into patients in this area concealing their infection; rather, they claim being victim of empoisoning.

Conclusion: Sustained decentralization of integrated TB/HIV services through better programs' coordination and community involvement to address misconceptions about TB and HIV and stigmatization are essential to promote uptake of TB/HIV services and retain patients in treatment.

Keywords: TB; HIV; Co-infection; Cultural patterns; Health behavior; Health systems

Introduction

The Democratic Republic of Congo (DRC) is one of twenty the high-burden Tuberculosis (TB) countries that together account for 80% of the global disease burden [1]. DRC occupies the 11th position among these countries, with an incidence of more than 325 cases per 100,000 people per year [1]. All health districts in this country are virtually affected, and the epidemic continues to thrive due to worsening poverty across communities and the spread of HIV/AIDS. As to HIV, DRC is a high prevalence country with a prevalence of about 2.5% among the general population [2]. According to WHO estimates, up to 27% of adults with TB are also positive for HIV [1]. This co-infection challenge is even complicated by increasingly prevalent multi-resistant TB, due to poor treatment adherence.

Besides poverty and constant forced displacements by the population due to war, significant numbers of TB and HIV cases can be attributed to poor access to quality diagnosis and treatment, the use of inadequate and non-standardized treatment regimens, weak supervision, data management and monitoring of patients under treatment. The development of Directly Observed Treatment Short course (DOTS) both at facility and community levels remains the best alternative to ensure better detection and better management of cases. In DRC, current guidelines for HIV/TB co-infection recommends that, in addition to antiretroviral treatment, HIV patients are offered co-trimoxazole treatment to prevent TB; whereas TB patients are provided with ART if they fulfill the required CD-4 counts criteria [3].

We recently conducted a study in the city of Goma and its surroundings to explore the challenges and responses to integrated TB and HIV services. The study showed that the prevalence of HIV among TB patients was estimated at 9% on average; that 22 HIV tests were performed per month (the month that preceded the survey) on average; that on average 7 cases of HIV were diagnosed per facility and that the capacity for HIV screening per facility was per month about 19 cases [4]. The study showed that (1) HIV and TB services are not widely available in the area; (2) that the services available are largely underutilized and (3) that the level of integration of services to address TB/HIV co-infection is unsatisfactory [4].

The preceding findings indicated a need for better understanding of the ways health facilities are engaging communities in their catchment areas to promote TB and HIV testing and treatment. Also, the extent to which geographical proximity determines or not the choice of facility by TB and HIV patients appeared to be an interesting question to investigate.

There are several difficulties associated with TB/HIV management, including clinical, health systems and sociocultural. Clinically, diagnosis of TB in HIV-infected individuals can be challenging as HIV patients have higher rates of sputum smear-negative disease [5]. This is a challenge since radiography and culture are of limited availability

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as diagnosis techniques in most poor-resource settings. The literature dealing with issues of access to TB and HIV services or of retention of patients to treatment programs is abundant. [6,7]. Constraints -related to transport to and from health facilities have always been portrayed as being the major causes for poor uptake of health services and non-compliance, including for TB and HIV treatment services [8,9]. This implies that the health service organization should be such that all TB and HIV patients may take an HIV or TB test in the health facilities closest to their place of residence, and perhaps be transferred only to distant facilities when necessary.

To our knowledge, no study has been conducted in this area and focusing on reasons for choosing or not a facility by co-infected patients. The underlying causes of the low detection rate of TB and HIV in such areas of high levels of risk and vulnerability are poorly elucidated, both in people living near centers of integrated care and those located far from them.

In conducting this study, we intended to generate some initial evidence that would allow planners within TB and HIV control programs to be able to develop strategies that could address issues of low uptake of TB and HIV services primarily limit by-passing of health facilities by patients.

Aim

To describe patterns of health seeking behaviors among TB/HIV patients with regards to centers of integrated TB/HIV care in the Goma and surrounding health districts. This will facilitate understanding of the root causes of the low detection rate of TB and HIV co-infection in the concerned areas.

Methods

Design and study population

This study adopted a descriptive cross-sectional design, combining both qualitative and quantitative methods. The data collection tools used included a structured questionnaire targeting TB/HIV co-infected patients as well as qualitative interviews allowing collection of detailed additional information from health workers (physicians, nurses and lab technicians) employed in health facilities providing TB/HIV care.

Sampling

A sample size calculation was performed to determine the optimal number of respondents to the quantitative questionnaire. Based on the demographic information that estimates the population in the concerned districts at 586 250 persons (or 99 521 households) [10], a sample size calculation based on a 4.4% HIV prevalence in Nord-Kivu [11] indicated that a target sample of 379 patients (representing 398 households) would be needed (with a standard error of 0,05 and a 95%-confidence interval). When considering the TB incidence of 325 TB cases per 100 000 inhabitants (i.e. 1 803 TB incident cases estimated), the study would require a sample of 317 subjects. The research team aimed therefore at achieving a minimum of 317 respondents.

Data collection

The research team established a list of all facilities providing TB, HIV and TB/HIV co-infection related services. In order to ensure access to patients with TB and HIV, the team requested information from the concerned facilities regarding consultation days for TB and HIV services.

On the days of the appointments, the interviewers were given a room at the facilities where the interviews were to take place. When a patient had been given the care needed from the nurse or the physician, the staff explained to the patient about the research project and interviewer's request of interviewing the patient. If the patient agreed, the staff member advised the interviewers by phone. The patient was then taken to the interview room and presented to the interviewer, who then introduced themselves, the reason for their presence (the objective of the study) and asked for patients' consent before the interview could start. In some cases where patients had been transferred to the hospital, the interviews obtained the addresses and other details from the health professionals and went to look for them and interview them in case they agreed. As to the qualitative interviews, they took place the same day with the available health care professionals working with TB and HIV care.

All the interviews were conducted by a team of twelve trained research assistants (interviewers). The criteria for their selection included: a minimum of 25 years of age, good knowledge of French and local language (essentially Swahili), having a qualification in health sciences or development studies, have a good knowledge of TB and HIV. The research assistants underwent a two-days training to understand the objective of the work and their role as well as to pre-test the data collection tools.

Data analysis

The collected data were coded and entered and analyzed in SPSS. The results were presented in tables for a better interpretation. Descriptive statistics (frequencies and percentages) were used to summarize the results. Chi-square and t-test were used to assess statistical differences, with significance level determined at α=0.05 and 95%- confidence interval. The qualitative data was analyzed using a manifest content analysis approach. The data were searched to identify categories that corresponded to the main topics that emerged in the quantitative data, in order for the qualitative information to be used to substantiate, contrast or enrich quantitative findings.

Ethical considerations

The respondents were informed from the onset that their participation in the survey and the qualitative interview was entirely voluntary, and that they could refuse to participate or withdraw at any time without their decision affecting their future care. The interview setting was appropriately chosen, guaranteeing total privacy. Confidentiality was the rule; all respondents were assured that the information they would provide will not be used for other purposes than research, and that participants' names were not listed on the questionnaire. Before administering the questions to the respondent, the interviewer first obtained verbal consent. Moreover, the survey protocol prior was submitted to the Provincial Health Inspection for approval.

Results

Patients' background data

Of the 398 targeted patients, 335 (86%) responded to the questionnaire. The mean age of the respondents was 36 years with a standard deviation of 10.7 and a range of 15 to 74 years. Most respondents were between the age of 20 and 54 years (94.3%). Women were slightly in majority (53.7%) as compared to men. More than one third of the respondents had completed high school (37.6%), one quarter of them (25.7%) had primary level education and 15.5% had university level education (Table 1). Concerning health workers

Background variables	Frequencies (%)
Sex	
Male	155 (46,3)
Female	180 (53,7)
Total	**335 (100,0)**
Education level	
Primary	86 (25,7)
Secondary	126 (37,6)
Tertiary	52 (15,5)
No level completed	15 (4,5)
Illiterate	56 (16,7)
Total	**335 (100,0)**
Marital status	
Single	61 (18,2)
Married	141 (42,1)
Widow/widower	63 (18,8)
Divorced	32 (9,6)
Living in partnerships	38 (11,3)
Total	335 (100,0)

Table 1: Patients' socio-demographics.

Health districts (HD)	HD of residence	HD of care		
	Total	Karisimbi (n, %)	Goma (n, %)	Kirotshe (n, %)
Karisimbi	226 (67,5%)	103 (30,7%)	81 (24,2%)	42 (12,5%)
Goma	97 (29,0%)	22 (6,6%)	68 (20,3%)	7 (2,1%)
Kirotshe	6 (1,8%)	2 (0,6%)	3 (0,9%)	1 (0,3%)
Outsiders	6 (1,8%)	4 (1,2%)	2 (0,6%)	0 (0,0%)
Total	**335 (100,0%)**	**131 (39,1%)**	**154 (46,0%)**	**50 (14,9%)**

A chi-square test to check for the difference between the proportions of patients received and sent out per health district indicated a statistically significant difference (X2=34,688, p=0.000)

Table 2: Place of residence versus place of care.

qualitative interviews, a total of twenty six interviews were completed.

Patterns in choice of treatment facilities: places of care versus place of residence

The health workers were asked information as to the residence of the co-infected patients that they care for. It was found that patients do not always seek care in facilities located in their geographic place of residence. For instance, for the Karisimbi health district, only 103 of 226 patients (i.e. 45%) of respondents living in the district consulted in health facilities within the same district, as compared to 112 of 226 patients (54%) who live in the same district but seek care in the Kirotshe and Goma health districts. In Goma district, 68 of 97 patients living in the district (70%) seek care within the district. Overall, the results of this study showed that more than half of the patients received in health facilities came from areas outside of the concerned health districts. This distribution was found to be statistically significant, as shown in Table 2 above.

These places of care were contrasted with the places of residence (where the patients ideally should seek care), and differences (called here "differences in frequentation") were calculated per health district. A negative difference would indicate that the concerned health district lost in patient frequentation, i.e. patients living in that specific district tended proportionally to seek care more from facilities located in other health districts as compared to patients from other districts coming for care in the district into question (Tables 2 and 3). As it appears below, the major loser is Karisimbi whose residents were found more in Goma and in Kirotshe.

Patients' perceived distance to health facilities

The patients were asked to estimate the distance separating their residences with the facilities where they turn for TB/HIV care. It appeared from the results that distances were not so long, as only less than 30% of patients lived more than 5 km from the health facilities, as shown in Table 4. In addition, 53% of patients considered the distance to the health facility they patronized as being at normal distance, as compared to 47% who thought it was too far.

Factors determining choice of health facilities Reasons for patronizing a health facility

A general question on factors that play role in the patients choice of health facility revealed that availability of drugs was the principal reason behind patients' choice (77%), followed by staff welcoming attitude (65%) and by geographic location (51%) (Table 5).

The role of income

Although meager income could be considered as reason behind low frequentation of health facilities and therefore of TB/HIV detection, it was only mentioned by half of the patients (51%) as being a constraint. The health professionals shared the same opinion of relatively limited influence of economic purchasing power, as one explained:

"*Finance is not in itself a determining factor of the low detection rate of co-infection of TB and HIV/AIDS. Treatment is free. If one can say that care is expensive, it may be because patients are supposed to*

Health districts	(a) Respondents' places of care (Interview districts)	(b) Respondents' places of residence (Home districts)	Differences in frequentation
	Frequencies (%)	Frequencies (%)	(a)-(b) %
Karisimbi	131 (39,1)	226 (67,4)	-28,3
Goma	154 (46,0)	97 (29,0)	17
Kirotshe	50 (14,9)	6 (1,8)	13,1
Outside districts	-	6 (1,8)	-1,8
Total	**335 (100)**	**335 (100)**	**0**

Table 3: Differences in frequentation per health district.

Distance between residence and TB/ HIV care center	Frequencies (%)
<1 km	62 (18,5)
1-2 km	82 (24,5)
3-5 km	100 (29,9)
>5 km	91 (27,2)
Total	**335 (100)**

Table 4: Estimated distances from residence to health facilities.

Factors influencing choice of health facility	Yes (%)	No (%)
Geographical location	171 (51,0)	164 (49,0)
State of the buildings/premises	41 (12,2)	294 (87,8)
Availability of medical equipment	129 (38,5)	206 (61,5)
Accessibility of health workers	157 (46,9)	178 (53,1)
Availability of drugs	259 (77,3)	76 (22,7)
Confidentiality	194 (57,9)	141 (42,1)
Welcoming attitude	217 (64,8)	118 (35,2)
Food supplies	165 (49,3)	170 (50,7)

(More than one response was allowed per respondent)

Table 5: Factors determining the choice of health facilities for TB/HIV care.

pay for treatment of certain types of diseases such as malaria and other opportunistic infections; and as the income level of people is low, we could admit that economic factors would influence the low detection co-infection of TB and HIV / AIDS. Sometimes we see patients coming to the treatment center to collect the drugs and the only complaint they would report of is the lack of food".

Other social and health systems constraints

Patients were asked to provide their opinions on why TB/HIV co-infection was so poorly detected. Poor knowledge of the pathologies and too few number of health facilities with integrated care were mostly mentioned. Their responses are summarized in Table 6.

Health professionals' views corroborated those of patients. They recognized that their facilities are not always supplied with the necessary drugs, and that this could not motivate patients to seek care, as treatment was not guaranteed even after knowledge of the TB and HIV status.

"*The lack of medicines, lack of an effective program involving the community and community volunteers as well as ourselves as health care providers we are the primary factors that I can consider to be related to health systems. In the course of the year, we experience shortage of drugs and this discourages patients. Others prefer to change health facility turning to places where drugs are available throughout the year as in Rwanda, for example. Home visits are not regular, yet they could help us to strengthen our relationships with our patients, and secondly, the number of trained staff is insufficient, which makes people neglect the treatment*".

In addition, stigmatization remains extremely pronounced. People infected with HIV and/or TB prefer therefore either avoiding taking test in order to hide their condition or when this is no longer possible, they pretend being victims of sorcery or poisoning or the like rather disclosing their HIV or TB status.

"*The problem of HIV/AIDS and TB are still considered in some communities as diseases of shame, and people do not like to talk, we prefer to say, for example, that the person has been poisoned by the neighbors to cover the true diagnosis.*

In some families in the city of Goma and around the first symptoms of the disease have different names, such as "pesse", "bad luck". People prefer to treat traditionally. In this matter, fear is a typical attitude at HIV or TB testing. By knowing his condition, there is a risk of suicide or of accelerating the progression of the disease, and sometimes discordant couples divorce. People prefer rather not going to the center for screening".

The patients themselves reported of several negative attitudes from the community members that influence patients' attitudes towards disclosing their TB/HIV status or even to accept taking the test. The

Perceived constraints	Yes (%)	No (%)
Limited access to services	160 (47,8)	175 (52,2)
Poor knowledge of their pathologies	176 (52,5)	159 (47,5)
Low DOTS coverage in facilities and communities	119 (35,5)	216 (64,5)
Low number of health providers trained in TB/HIV	112 (33,4)	223 (66,6)
Too few number of health facilities with integrated services	176 (52,5)	159 (47,5)
Absence of effective health communication program on behavior change	164 (49)	171 (51)
Insufficient involvement of old patients in mobilizing others	187 (55,8)	148 (44,2)

(More than one response was allowed per respondent)

Table 6: Low TB/HIV detection- reasons according to patients.

Community attitudes	Yes (%)	No (%)
Discrimination	205 (61,2)	130 (38,8)
Stigmatization	196 (58,5)	139 (41,5)
Isolation	191 (57)	144 (43)
Disrespect	166 (49,6)	169 (50,4)
Negligence	9 (2,7)	326 (97,3)

(More than one response was allowed per respondent)

Table 7: Community attitudes towards TB/HIV hindering disclosure and uptake of TB/HIV care.

Table 7 presents a summary of these attitudes.

Discussion

This study highlights some characteristics of health seeking of TB and HIV co-infected patients in one of the world's worst conflict-ridden areas. Experiences of TB/HIV co-infection in such settings are very scarce in the published literature. One pattern emerging from this study seems to indicate TB/HIV co-infected patients' health seeking behavior has not much to do with the geographical distribution of integrated care facilities. Some districts receive proportionally more patients from other districts than they send out. This pattern can have several explanations. One reason can be that some districts are more residential while others have higher concentration of health facilities. This is the case for the Karisimbi health district which traditionally is a residential district, as compared to the Goma district where businesses are concentrated, including health businesses (i.e. facilities).

However, if such a trend is persistent even after years of significant demographic growth and the tremendous geographic expansion of the city and its surrounding areas, it points to poor decentralization of health services. The services are not adapting to demographic mutations. Indeed, areas of high density should be endowed with equivalent number of health facilities. This requirement is even more critical in such a setting with constantly numerous internally displaced people (IDPs) and refugees. These people need adequate health services, including TB/HIV services, as close their sites as possible. There are examples from other settings of success in TB treatment even among these categories of patients [12].

Also, previous lessons from Antiretroviral Treatment (ART) programs indicated that increased decentralization of the ART services from the hospital to health centers that are closer to home and communities would be an essential step towards reducing the overall cost and burden of travel [8]. This is even more important in this particular setting where significant proportion of the population are internally displaced and therefore unsettled people who are more likely to experience difficulties in finding resources to pay for transport fares. A review suggested that IDPs in non-camp settings are often dependent on local government health services, and they experience limited access to TB care because of discrimination and fear of identification, and legal or financial barrier, which could also result in higher risks of mortality and morbidity [13].

There is strong evidence on the association between costs of transport or perceived distance and uptake or interruption of HIV antiretroviral treatment by patients [8,9]. Even if cost of transport has not been found to be a major issue to most patients one of these studies, short distances in physical terms can be experienced or perceived as being long in areas where insecurity prevails. This is the case for Goma areas where mobility is constrained by security issues (such as at nights, early morning and early evenings). In such settings, it is imperative that health services planners adapt policies that allow patients to access care in safe conditions, either in adapting opening hours or setting up

appropriate outreach services. This suggests the necessity of providing really integrated care by improving coordination and collaboration between TB and HIV control programs and services in response to context-specific constraints [14]. Health workers interviewed reported problems of shortage of human resources, infrastructure and drug supplies. Similar aspects have been found elsewhere as hindering effective collaboration between TB and HIV services [15,16].

Beyond above mentioned factors which are more linked to the wider context, it is critical to pay attention to motivations behind individual patients' choice of specific treatment facilities. In this study, the majority of respondents indicated availability of drugs as their primary criteria for choosing which facility to go to. This raises the critical issue for both TB and HIV control programs. They need to properly equip all integrated care facilities; otherwise they will not be patronized by patients. Positive attitude by caring personnel was also valued high by patients, as usually reported in HIV and TB perceptions or experience of quality care [17].

The policy of providing HIV and TB treatment and care free of charge is current in DRC. This would imply that even the poorest of the patients access treatment. However, this is always not the case given the importance of other costs such as the consultation fee, laboratory fee, costs for other infections associated with TB and HIV. The health workers who participated in this study recognized that these costs are a constraining factor, together with the general poverty issues indicated by lack of enough food. This area is invaded by a multitude of humanitarian organizations providing assistance to vulnerable people, internally displaced or not. Teamwork among healthcare workers and other key stakeholders in the community involved in TB/HIV prevention and control might be used as a strategy to improve joint service delivery and patients' uptake of services [15,18]. A substantial group of actors that need to be part of this teamwork are the social workers from diverse humanitarian organizations whose work is significant in mitigating disease impact among vulnerable groups in this area.

According to patients who responded, low detection of TB/HIV in the concerned area is due to insufficient involvement of old TB/HIV patients in community mobilization efforts, limited number of facilities with integrated services, poor knowledge of the pathologies by the communities and lack of effective health communication program. These dimensions point to failure by the disease control programs to reaching out to the communities.

Other cultural and patient-specific challenges associated with the delivery of TB/HIV care have been shown to be important [19]. A study from Malawi found that progression through the HIV care pathway, including TB care for co-infected patients, was strongly influenced by socio-cultural norms [20]. Among these norms is particularly the need for the patient to remain respected despite one's declining health. This norm is related to pervasive discrimination, stigmatization, isolation, disrespect and similar social norms. There are always local context-specific interpretations or ways of describing or hiding diseases. It has been found that concerns about stigma are associated with reductions in test and treatment-seeking behavior, disclosure of HIV status, the level of social support solicited and received as well as personal identity and esteem [21,22]. Secrecy is therefore critical in community where HIV or TB till suffer social stigmatization [23]. In our study area, it was found that patients shun their testing and treatment facilities by fear for being discriminated against if they are labeled as infected with TB/HIV. As the disease progresses and health declines in a way that the disease becomes difficult to conceal, affected persons in this area claim they have been empoisoned. It has been reported that at least 30 percent of those testing positive for TB in eastern DRC health centers initially assumed that they had been poisoned [24]. This is phenomenon is known in the area as "the karuho phobia" – karuho being the name of the feared poison that people get from their social enemies. Such perceptions are pervasive and entrenched in settings with longstanding social conflicts and affect dangerously the health seeking behaviors.

In Kenya, it has been found reported time from initial symptoms to TB diagnosis ranged from 3 weeks to 9 years, and among the reasons for this delay is misinterpretation of early symptoms [6]. It can be argued that it is even more unfortunate if the misinterpretation reflects not simply lack of knowledge but it is used as a way of concealing one's condition. Robust health communication programs, targeting the wider community and even patients' families [25], are required in such settings to address such social issues on a constant basis.

It can be argued that in a context such as our study area, attracting patients to treatment or retaining those under treatment can also entail serious challenges, given the intertwined social, economic, political and health systems-related factors. Such settings require context-specific and highly dynamic policy measures to improve uptake of TB and HIV co-infection services and to retain patients. Integrated services defined as just adding on HIV or TB services to facilities that previously lacked them, is not enough. It have been found in South Africa that co-location of services alone is insufficient to permit timely initiation of antiretroviral treatment for instance among TB patients [26]. Recent data from Malawi highlight the importance of intensified patient education and health workers training, in addition to providing integrated care [27]. Measures that recognize the role of geography, people mobility patterns, social norms, community involvement and broader health systems need to be carefully considered in order to facilitate TB/HIV integrated treatment.

Conclusion

This study shows that patients co-infected with TB and HIV in the Goma areas tend to seek care outside of their geographical residential districts. Factors that justify patients' choices of treatment facilities are drugs availability, health workers' welcoming attitude, but also the need for concealing their diseases for fear of discrimination and stigmatization. In such an unstable setting, proximity of integrated facilities through decentralization of services as a strategy to promote retention of patients, as well as community involvement are critical to improve TB/HIV care.

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