Diagnosed with TB in the era of COVID-19: patient perspectives in Zambia

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<http://dx.doi.org/10.5588/pha.20.0053>

Introduction: Delayed TB diagnosis and treatment perpetuate the high burden of TB-related morbidity and mortality in resource-constrained settings. We explored the potential of COVID-19 to further compromise TB care engagement in Zambia.

Methods: From April to May 2020, we purposefully selected 17 adults newly diagnosed with TB from three public health facilities in Lusaka, Zambia, for in-depth phone interviews. We conducted thematic analyses using a hybrid approach.

Results: The majority of participants were highly concerned about the impact of lockdowns on their financial security. Most were not worried about being diagnosed with COVID-19 when seeking care for their illness because they felt unwell prior to the outbreak; however, they were very worried about contracting COVID-19 during clinic visits. COVID-19 was perceived as a greater threat than TB as it is highly transmittable and there is no treatment for it, which provoked fear of social isolation and of death among participants in case they contracted it. Nonetheless, participants reported willingness to continue with TB medication and the clinic visits required to improve their health.

Conclusion: The COVID-19 pandemic did not appear to deter care-seeking for TB by patients. However, messaging on TB in the era of COVID-19 must encourage timely care-seeking by informing people of infection control measures taken at health facilities.

The COVID-19 pandemic is predicted to greatly undermine the global TB response^{1–3} and result in an additional 6 million TB cases and 1.4 million TB-related deaths over the next 5 years.⁴ Since early 2020, the diversion of infrastructure and resources from TB to the global COVID-19 pandemic response has threatened to erase hard-won gains in TB control in high TB burden settings.^{5,6} COVID-19-related restrictions and the fear of contracting COVID-19 may further delay engagement in TB care and disrupt preventive and curative TB measures. This disruption could have far-reaching consequences, as the COVID-19 pandemic is estimated to increase the number of people living in poverty by up to half a billion,⁷ substantially increasing the number of individuals at greater risk of acquiring and developing TB.⁸

While COVID-19 represents a new threat to Zambia, TB is a leading cause of morbidity and mortality in the country much like in the rest of southern Africa.^{5,9} After the first two COVID-19 cases were re-

corded in the capital, Lusaka, on 18 March 2020, Zambia implemented several measures to limit the spread of COVID-19. These included business closures, travel restrictions and limiting public gatherings to <50 people.¹⁰ While many of these restrictions have since been eased, strict social distancing and infection control policies remain in place. As of 1 October 2020, Zambia has reported 14802 COVID-19 cases and 333 related deaths.¹¹

Before COVID-19, Zambians faced substantial barriers to TB care engagement, with nearly a third of individuals taking more than 8 weeks to initiate TB treatment after symptom onset.¹² Thus, there was a strong concern that COVID-19 could worsen healthcare-seeking behaviors, resulting in fewer TB cases diagnosed and worsened outcomes—as observed during the West African Ebola epidemic.^{13–15} Therefore, we adapted an ongoing qualitative study among newly diagnosed TB patients in Zambia to explore how COVID-19 may have influenced healthcare-seeking for TB during the early months of the COVID-19 pandemic in order to inform decision-making by the Zambian Ministry of Health (MOH) on maintaining effective TB services throughout the COVID-19 pandemic.

METHODS

Setting and participants

The present study was nested within a larger, ongoing qualitative study to understand TB patients' barriers and facilitators to care engagement. Enrolment for the study was started on 26 March 2020 and in-depth interviews containing COVID-19 related questions were completed between 7 April and 7 May 2020. Study sites included three public health facilities in Lusaka, Zambia—Kanyama and Matero first-level hospitals, which run busy outpatient TB clinics, and the University Teaching Hospital (UTH), the largest referral hospital in Zambia.

Eligible patients were aged ≥ 18 years and had microbiologically confirmed TB, diagnosed within 3 weeks prior to participating in the study. Routine clinical staff identified eligible patients at each facility from TB notification registers, and listed their names and contact information. The study team phoned listed patients to confirm eligibility and assess interest in study participation. After confirming that they were speaking to the correct individual, the research assistant (RA) explained who they were, how they obtained the participant's information and why they were calling, offering clarifications as needed. If will-

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ACKNOWLEDGEMENTS

The authors would like to acknowledge and thank the staff of the Social and Behavioural Science Group at the Centre for Infectious Disease Research in Lusaka, Zambia, the staff at the individual health facilities, and the study participants who made this work possible. This research was supported by a grant from the National Institutes of Health, UCSF-Gladstone Center for AIDS Research, San Francisco, CA, USA (P30AI027763). ADK was supported by the National Institute of Allergy and Infectious Diseases, Bethesda, MD, USA (grant number T32 AI060530). The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript. Conflicts of interest: none declared.

KEY WORDS

tuberculosis; COVID-19; qualitative; Zambia; care engagement

Received 2 September 2020
Accepted 23 October 2020

PHA 2020; 10(4): 141–146

ing to be interviewed, RAs discussed individuals' preferred schedule and availability of charged mobile phone. Most participants asked to reschedule their interview, with some choosing after work hours. If someone was unreachable or declined participation, the next listed person was contacted. An approximately equal number of participants, balanced for sex and HIV status were purposefully sampled from the three facilities. Recruitment was closed once data saturation was reached.¹⁶

All participants provided verbal informed consent in their preferred language (Nyanja, Bemba or English). The study was approved by the University of Zambia Biomedical Research Ethics Committee (Lusaka), the National Health Research Authority of Zambia (Lusaka, Zambia) and the institutional review board of the University of California, San Francisco (San Francisco, CA, USA).

Data collection

After verbal informed consent, all participants completed an in-depth interview by phone. Phone interviews were undertaken in order to keep both TB patients and research personnel safe from COVID-19 by avoiding prolonged close contact. A semi-structured interview guide was used, which contained open-ended questions exploring knowledge and attitudes towards COVID-19 and TB, the potential impact of COVID-19 on TB health-seeking behavior and TB treatment, as well as patients' recommendations to encourage other individuals with TB to engage in healthcare services during the COVID-19 pandemic. All interviews were digitally recorded with permission from participants and lasted 45–60 minutes. Experienced RAs fluent in the local languages used in Lusaka (Nyanja, Bemba), as well as English conducted the interviews and transcribed them verbatim into English.

Data analysis

The qualitative analysis software, Dedoose v7.0.23 (SocioCultural Research Consultants, Los Angeles, CA, USA) was used to help organize and code transcripts. We undertook a thematic analysis using a hybrid approach to coding that included both inductive codes from prior research and also codes inductively developed by the study team.^{17,18} Participant statements were initially coded into parent themes, including knowledge, attitudes, and perceptions related to COVID-19, the impact of COVID-19 on TB diagnosis and treatment, and patient recommendations. An iterative process was then used to generate sub-themes within the initial coding scheme while further refining parent themes to include how COVID-19 related (or did not relate) to TB and the impact of COVID-19 on their daily life and financial security. All transcripts were independently coded by two study team members (CM and ADK), and any differences were resolved with the help of the third (AS).

RESULTS

Of the 32 individuals approached for study participation, 12 could not be reached by phone despite multiple attempts, 1 was too unwell to participate, and 2 terminated the interview early. Participant characteristics of the 17 individuals who agreed to participate and completed in-depth interviews are summarized in the Table.

COVID-19 knowledge

Most TB patients demonstrated correct knowledge regarding typical COVID-19 respiratory symptoms—'cough, difficulty in breathing, chest pain'—which were being broadcast by the MOH at the

TABLE Socio-economic and clinical factors among participants (*n* = 17)

	Overall (<i>n</i> = 17) <i>n</i> (%)
Clinical site	
Kanyama First-Level Hospital	5 (29)
Matero First-Level Hospital	6 (35)
University Teaching Hospital	6 (35)
Age, years, median [IQR]	40 [31–50]
Age category, years	
18–29.9	4 (24)
30–49.9	8 (47)
≥50	5 (29)
Sex	
Male	9 (53)
Female	8 (47)
Marital status	
Single	3 (18)
Married	12 (71)
Divorced/separated	2 (12)
Highest level of education	
No formal school	3 (18)
Primary school	5 (29)
Secondary school	7 (41)
Tertiary school	2 (12)
Income generating activity	
Unemployed	7 (41)
Piece/casual work	5 (29)
Self-employed	2 (12)
Formally employed	3 (18)
HIV status	
Positive	7 (41)
Negative	8 (47)
Unknown	2 (12)
Prior history of TB treatment	
Yes	0
No	17 (100)

IQR = interquartile range.

time. Only one patient mentioned fever as a COVID-19 symptom and no patients mentioned less common COVID-19 symptoms. Some patients explicitly noted that, '...[For] these two (TB and COVID-19), the symptoms are almost the same.'

Although TB patients had heard of COVID-19, they had differing levels of knowledge regarding its route of transmission and measures to prevent its spread. Some patients likened the airborne nature of COVID-19 to that of TB, with one explaining that, '...if you talk of TB it's inborn and it's airborne at the same time. COVID is also airborne.' This understanding supported the uptake of MOH recommendations for COVID-19 prevention, including universal masking and physical distancing. However, there was no discernable understanding on the mechanisms of these measures. For instance, one participant said, 'On COVID-19, I know that it is an airborne disease so you must wear a mask.' But then went on to elaborate that, '...if you don't wear a mask, you can get the virus,' suggesting a lack of awareness of their own risk of transmitting COVID-19. Similarly, while participants correctly cited staying at home, physical distancing and hand hygiene as prevention measures, they did not explicitly state how this interrupted COVID-19 transmission:

I also started telling my friends that you are not supposed to stand close; you are supposed to be at a meter apart and wash your hands with sanitizer and soap. (Male, HIV-negative, Kanyama)

You are not supposed to move around because through those movements that is how you can get the disease and transmit to the people at home. (Male, HIV-positive, Kanyama)

Patients noted that they had received COVID-19-related information from a number of sources, most commonly from television, radio and other media sources 'where it is spoken of a lot,' as well as family members (spouse) and peers. They also received information from health professionals, albeit on mass (radio) or digital (SMS) media, and not at healthcare facilities, as made explicit by one male HIV-positive participant:

When I went to the clinic, they didn't tell me anything about coronavirus.

Several individuals expressed a desire for greater information and communication related to COVID-19, especially how it is transmitted and spread in their community, saying that:

We don't know anything, we are just hearing that there is a disease called coronavirus. We don't even know where it's from or what kind of disease it is, so we need to be taught. (Male, HIV-positive, Matero)

COVID-19-related perceptions and attitudes

The request for information sprang from perceived susceptibility to COVID-19 and its perceived severity 'because people are dying badly.' Participants expressed a high level of fear and anxiety about getting COVID-19 because it had no known treatment, required prolonged periods of social isolation and, at its most severe, could be fatal:

TB is better because there is medication for it, unlike COVID-19 where you will just need to be quarantined ... and they will just try to bring down your temperature. Otherwise, it's just by the grace of God. (Male, HIV-negative, Kanyama)

I think it is a very dangerous disease because once you are infected, you will have to be quarantined without any family member visiting you. It has no treatment ... So when you have it, it's either you die or you will have to be quarantined for a long time ... (Male, HIV-negative, Kanyama)

Most TB patients, irrespective of their HIV status, did not perceive TB as putting them at a higher risk for poor COVID-19 related health outcomes, with one clarifying that, 'I don't think I am at a great risk [because of having TB]; it's just having great fear of contacting the virus.' Some managed their fear by putting their trust in the doctor and their fate given 'that when we are born, we are just waiting to die.' However, a few individuals thought that TB and COVID-19 co-infection was a lethal combination given the severity of the two diseases and the burden that COVID-19 might put on the already strained health system; this is evident in the quotes below:

What I heard is that people with TB are at high risk when exposed to this virus, so one should take care of him or herself. (Male, HIV-positive, Kanyama)

... Tuberculosis and coronavirus? Those things are bad and the symptoms are same. When you have both that means your time has come. (Male, HIV status unknown, Matero)

I was just thinking that if corona[virus] hits Zambia how are we going to survive? ... These other countries have money and you cannot compare them to Zambia ... Yet their people are dying. So when it reaches Zambia, are we going to survive? (Male, HIV-positive, Kanyama)

Impact of COVID-19

Although individuals discussed changes in many aspects of their daily lives due to COVID-19, they most frequently mentioned the impact of lockdowns on their financial security as a distressing change. With livelihoods threatened, individuals worried about having sufficient food and housing for themselves and their families, and that they may have to choose between hunger and COVID-19. Furthermore, during COVID-19, they could not rely on their usual social capital and monetary reserves because everyone had a similar concern or experience:

[COVID-19] has really brought about confusion in the whole world, because many people are living in fear. Businesses have gone down and also a lot of companies have closed, which has affected many families ... So, we just look up to God for help. (Male, HIV-negative, Kanyama)

... My lifestyle at home, how to find food and rentals [have been changed by coronavirus] ... When you go 'round to borrow, or to collect money from your debtors, or to look for work, they will just tell you they are in the same situation ... (Male, HIV status unknown, Matero)

If you don't go and search [for work] in the name of being scared of coronavirus, you will die of hunger, because hunger also kills, and that's where the challenge is ... (Male, HIV-negative, UTH)

Individuals also described how the lockdowns had negatively impacted their regular social activities, restricting their meeting with friends and loved ones for special occasions and preventing them from going to church and other public gatherings of socio-cultural importance. Although many expressed fear of contracting COVID-19 during visits to the clinic, they sought help for their TB illness and returned for continued TB treatment because they wanted to understand what was wrong with their health and to improve their health.

Although I was scared, I just had to go so that I know ... What I know is that when you are not feeling well you need to go and get help at the hospital whether there is corona[virus] or not ... (Male, HIV-negative, Kanyama)

I will have to go back next week because my drugs are almost finished. I'm scared ... [but] If I get scared how will my health improve? (Male, HIV-positive, Matero)

In general, patients were able to manage their fear because they knew that their symptoms had appeared before the advent of COVID-19 in Zambia ('I already knew that I had a problem') and trusted that the recommended COVID-19 preventive measures would protect them during their follow-up visits:

When going for (medical) reviews, you have to put on a mask and sanitize your hands. We just have to follow [the guidance] that is there. But in my heart I know that I am following my TB treatment; I am not following corona[virus] ... (Male, HIV status unknown, Matero)

Others preferred not to think about the possibility that their symptoms could be due COVID-19, which was perceived to be a

debilitating and stigmatizing disease, as eloquently expressed by one HIV-negative woman at the UTH, who said, 'No, ... I can't even think like that ... That's a disease that shouldn't be spoken about or even thought about ...'

Advice and recommendations for peers and health officials

Newly diagnosed TB patients advised their peers to take possible TB illness seriously and to not delay care despite the risk of COVID-19. They emphasized timely healthcare seeking because of the similarity in TB and COVID-19 symptoms and the possibility of a further deterioration in their health, which would endanger their own life and that of their loved ones:

... When you have to rush to the hospital, it can be COVID or it could be TB, so you need to know which is without delay, because the two are similar in symptoms. If you have any cough, just go to the hospital so that you don't affect the family members. (Female, HIV status unknown, Kanyama)

One participant alluded to TB-related stigma and advocated for early diagnosis and treatment at a public health facility:

Let us not be uptight because TB comes due to different reasons. So, if you don't feel fine it's better to go to the clinic and get tested. If you are found with TB you have to take your medicine. That's the only way you will be healed ... For us TB patients, our help is at the clinic. (Male, HIV-negative, Kanyama)

TB patients made several recommendations on how TB services may be improved in the era of COVID-19. Many recommendations related to the decentralization of services to avoid prolonged time spent at a hospital, such as 'a stand in the community for TB testing', and home delivery or clinic-based pick-up of medication:

What would be easy is getting medication from the clinic rather than going to [the centralized] hospital because you find ... the coronavirus that has become a problem. If you go to the clinic, [it] is quicker to get medication. (Male, HIV-negative, UTH)

I think finding people who can be bringing the treatment to our homes ... that can be easier instead of going to queue up! (Female, HIV-negative, UTH)

Some people added that protective measures should be implemented to keep them safe from COVID-19 while engaging in TB services, but put the onus of action on the government rather than patients:

These two diseases are almost similar in terms of symptoms... that's why you should take all the precautions ... by putting on these masks. Unfortunately, in Zambia the Ministry of Health is not doing much to give people these masks for free ... you know they are not enough. (Male, HIV-negative, UTH)

DISCUSSION

Although highly fearful of COVID-19, newly diagnosed TB patients sought TB diagnosis and treatment to regain their physical health. To note, this drive to better health did not appear to differ by sex or HIV status. Patients expressed a strong desire for continued dissemination of COVID-19-related information, decentralized TB services to shorten time and risk of exposure to COVID-19 in crowded and busy hospitals, and the implementation of COVID-19 prevention measures to keep them safe when health facility visits were required.

As of August 2020, 75% of TB programs across 106 countries reported service disruptions due to COVID-19,¹⁹ highlighting the

need to improve access to TB care during this public health emergency.¹⁻³ This study suggests that the decentralization of TB services to community-based clinics and home delivery of anti-TB drugs could be effective in encouraging and sustaining positive TB care engagement behaviors in Zambia. Additional international recommendations include household TB contact tracing,²⁰ which had already been implemented in Zambia and which was sustained during the pandemic, with particular attention to infection control measures, and other community-based active case-finding strategies that were initially suspended, but have subsequently resumed.²¹⁻²³ Recommendations also include extended duration of TB medication refills, which was implemented, as well as telephone and/or digital adherence technologies and treatment assessments, which some facilities in Lusaka are using for telephone-based counselling of TB patients and close contacts. Each of these strategies bring services closer to patients and addresses the issue of patient reluctance to visit hospitals for fear of contracting COVID-19.

Most patients in our study were fairly well-informed on what was known about COVID-19 at the time, but wanted ongoing and up-to-date COVID-19-related information, especially on transmission and preventive measures. However, patients did not appear to be aware that COVID-19 could be indirectly transmitted through contact with contaminated objects and surfaces. This suggests that individuals may have differential access to platforms where COVID-19-related information is commonly disseminated and a missed opportunity to provide COVID-19-related information at health facilities. Targeted information through multiple channels on COVID-19 transmission may help individuals to make sense of current public health advice, including masking and social distancing, which have unintentionally disrupted a highly social Zambian culture. These measures can compromise the physical, mental and emotional wellbeing of individuals, and potentially perpetuate stigma, with detrimental effects on care-seeking.²³⁻²⁵

TB patients sought reassurance that effective preventive measures were being practiced at facilities to keep them safe from COVID-19 while making the required hospital visits for TB care; some also wished that the MOH would provide them with masks. Collectively, this suggests that continued dissemination of information on COVID-19, along with education regarding the protective measures in place at health facilities will be necessary to encourage continued TB care engagement. Such an approach will be especially important if the COVID-19 epidemic continues to worsen and heightens the fear and stigma that may keep individuals away from health facilities despite progressive illness from TB, HIV, or other non-COVID-19 diseases.

TB patients consistently expressed concern about the impact of COVID-19 on their financial security, including their ability to afford housing rents and sufficient food for themselves and their families. Confronting these realities in the context of social isolation not only negatively impacts the mental health of socio-economically vulnerable individuals,²³ but also threatens their very survival. Individuals who are food insecure may be less likely to adhere to TB treatment, increasing their likelihood of experiencing poor treatment outcomes, including death.²⁶ Also, increased financial stress may make travel unaffordable and further delay evaluation and/or continuation of treatment. To safeguard the wellbeing of individuals with TB and their households during COVID-19, programs should consider adopting a holistic care model, including social interventions such as food assistance²⁷ and/or cash transfers.²⁸⁻³⁰

This study does have some limitations. Our findings that the COVID-19 epidemic did not impact health-seeking for TB are limited to those seeking care for their illness and to the early COVID-19 onset period. Hence, we did not capture the unique perspectives of those who never sought care for TB, or any changes in care-seeking behaviors as the epidemic evolved and fears related to COVID-19 worsened. Also, while newly diagnosed TB patients voiced strong commitment to their TB regimen, their adherence to their TB regimen could wane over time, especially as they begin to feel better and perceive the possible risk of contracting COVID-19 as outweighing any additional benefits of completing TB treatment. We therefore recommend complementary data analyses to evaluate the potential impact of COVID-19 on TB notification and treatment completion rates in Zambia.

In conclusion, newly diagnosed TB patients in Zambia were willing to seek care and remain engaged in treatment services to improve their health despite substantial fears of contracting COVID-19. To protect individuals with TB and support their continued engagement with TB services during COVID-19, person-centered strategies should be coupled with public health messaging that encourages timely care seeking and highlights the infection control measures being undertaken at health facilities to protect these vulnerable individuals.

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Introduction : Le retard au diagnostic et au traitement de la TB perpétue le fardeau de la mortalité et de la morbidité lié à la TB dans un contexte de ressources limitées. Nous avons exploré le potentiel de la COVID-19 à compromettre encore davantage l'engagement dans la prise en charge de la TB en Zambie.

Méthode : D'avril à mai 2020, nous avons sélectionné 17 adultes ayant eu un diagnostic récent de TB dans trois structures de santé publique de Lusaka, Zambie, pour des entretiens approfondis par téléphone. Nous avons réalisé des analyses thématiques avec une approche hybride.

Résultats : La majorité des participants ont été très préoccupés de l'impact du confinement sur leur sécurité financière. La plupart n'ont pas été inquiets d'un éventuel diagnostic de COVID-19 quand ils ont sollicité des soins pour leur maladie car ils se sentaient

déjà mal avant le début de l'épidémie; ils étaient cependant anxieux à l'idée de contracter la COVID-19 lors de leurs consultations. La COVID-19 a été perçue comme une menace plus grande que la TB en raison de sa grande contagiosité et de l'absence de traitement, causant la peur d'un isolement social et de la mort parmi les participants en cas de contamination. Les participants ont néanmoins affirmé qu'ils voulaient continuer leur traitement de TB et avaient besoin de consultations pour améliorer leur santé.

Conclusion : La pandémie de COVID-19 ne semble pas dissuader les patients de solliciter des soins de TB. Cependant, à l'ère de la COVID-19, les messages doivent encourager une recherche de soins rapide en rassurant le public sur les mesures de lutte contre l'infection prises dans les structures de santé.

Marco de referencia: El retraso en el diagnóstico y el tratamiento de la TB perpetúan la carga alta de morbilidad y mortalidad por TB en los entornos cuyas fuentes de recursos son limitadas. El estudio examinó la capacidad eventual que tiene la COVID-19 para agravar la atención de la TB en Zambia.

Método: En abril y mayo del 2020 se realizó un muestreo intencional de 17 adultos con diagnóstico nuevo de TB en tres centros de salud pública de Lusaka, en Zambia, para realizar entrevistas exhaustivas por teléfono. Se realizó un análisis temático con un enfoque híbrido.

Resultados: La mayoría de los participantes mostró una gran preocupación por las consecuencias del confinamiento sobre su seguridad financiera. En su mayor parte no temían el diagnóstico de COVID-19 al buscar atención por su enfermedad, porque habían

sentido el malestar antes del brote epidémico; estaban no obstante muy preocupados por contraer la COVID-19 durante la visita al consultorio. La COVID-19 se percibía como un peligro más grave que la TB por ser sumamente transmisible y no tener tratamiento y despertaba en los participantes un temor de aislamiento social y muerte en caso de contagio. Sin embargo, los participantes afirmaron su intención de continuar los medicamentos contra la TB y asistir a las citas necesarias para mejorar su salud.

Conclusión: La pandemia de COVID-19 no parece disuadir a los pacientes de buscar atención por TB. Sin embargo, los mensajes sobre la TB en la era de la COVID-19 tienen que incitar a la búsqueda de una atención oportuna, dando garantías a las personas sobre las medidas de control de infecciones que han adoptado los centros de atención de salud.