

Stigmatization of TB Patients and Health Care Providers in Cameroon: Insights from Qualitative and Cognitive Interviews

FINAL REPORT

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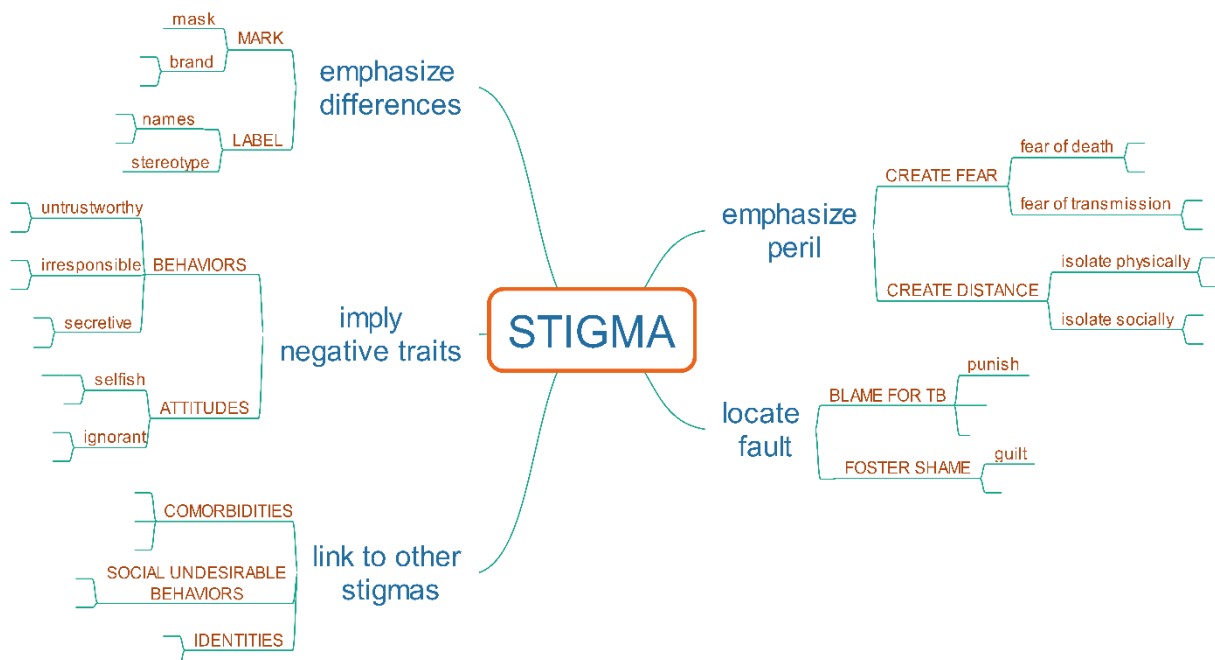
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Introduction

TB Stigma in Cameroon has been measured in surveys and qualitative research, but rarely from multiple perspectives. No studies have yet examined the pivotal role of health care providers as mediators, amplifiers, and recipients of TB stigma. This study sought to triangulate the view of TB patients and those of various cadres of health workers to identify critical stigma engines and points of intervention.

Methods

We purposefully sampled 21 health care workers including community health workers (ASC (CHW)), nurses, lab workers, TB providers, and general practitioners to explore a full range of views on TB patients, TB care provision, COVID-19 impacts, and challenges in the workplace in open-ended interviews via telephone. We conducted 11 cognitive interviews via telephone with health care workers to explore key terms and concepts in specific detail. We conducted 14 in-depth interviews and an additional 15 cognitive interviews with TB patients via telephone or in person. TB patients were randomly chosen from a database of TB patients. Health workers were chosen randomly from lists of workers from 5 NGOs involved in TB case-finding. Both health workers and patients were offered a token of 1000 CFA for their time. Interviews were conducted in French, English and Pidgin and most were recorded with consent. Field notes of interviews were analyzed using framework method with manual ETIC coding.[1] Interview recordings were crosschecked and selective transcriptions were made to illustrate key concepts. Figure 1 describes the classical “back bone of public stigma” developed by Pescosolido et al.



In the discourses of health care workers and patients we are listening for the classic signs of stigma as well as stigma manifestations and discourses unique to Cameroon. For example:

1. social distance—the reluctance to interact with members of devalued groups
2. traditional prejudice—adherence to the belief that all members of the “marked” group are categorically inferior to others

3. exclusionary sentiments—the willingness to reject persons with TB from the full benefits of citizenship
4. negative affect—popular public views that people with TB are difficult to interact with
5. perceptions of dangerousness—fear that persons with TB represent a threat of infection to others
6. treatment carryover—assessments that being known to have received TB treatment carries long-lasting consequences
7. disclosure spillover—negative consequences of revealing TB

We are also listening for the signs of self-stigma or internalized stigma among TB patients (e.g. endorsement of negative stereotypes).

Results

The results are organized according to the themes identified a priori and those revealed through the interview process. Tables 1, 2, 3 and 4 in the annex describe the participants in this study.

Health care workers' Stigmatization of TB Patients

We found that health care providers' attitudes reflect many of the prevailing stigmatizing beliefs of Cameroonian society toward TB generally.[2] Health care providers who did not work directly with treatment of TB patients were more likely to voice stigmatizing assumptions and tropes about TB patients than those who worked in a dedicated TB service. We some found evidence of negative stereotypes (e.g. secretiveness, stubbornness, carelessness, addiction).

A nurse

TB patients are careless, ignorant and sometimes stubborn. They are mostly poor people.

A nurse

“Refuse they do not have TB even after their results come out positive.... skip drugs because of side effects like joint pains and change of skin color... some patients lie about haven taken their drugs... some even accept their results at first but when they leave the Hospital they don't come back again

A GP -Limited TB experience

TB patients are poor, mostly malnourished, some have drug resistant TB, some are ashamed.

“TB treatment is free... so I cannot say poverty is affecting the patients... as for food even me I don't have a balance diet so what more of patients...”

Prejudice was greater toward relapse patients with some providers blaming them for initial treatment failure. One GP when asked to describe DR-TB patients described people with DR-TB as more angry and frustrated, mad, poor, and having a feeling of shame.

ASC (CHW)

Many relapsed due to not following instructions. many relapsed people drink the local alcoholic drink called "arqui" and smoke cigarettes. I found many young people I was following drinking this local drink called *arqui*, it is the drink that the young people here like to drink.

A nurse

"you even can identify those relapse and loss to follow up patients from the first day they come to consult.... When you ask for their phone numbers, they will ask you 'what you need it for?'..... Some give us numbers that are not going through... for some the number will go through for the first time and after that it will never go through again.... We even take the initiative to go the houses of some patients but from the way they welcome you, you will just understand that they don't welcome you...."

Some DR-TB patients described initial mistreatment by health care workers as a rationale for changing treatment providers.

DR-TB patient

So I came to the hospital for the first diagnosis. I explained the symptoms () the woman gave me the boxes to provide her with the sputum. I told her that I don't have the sputum coming out. She told me that I breathe in and breathe out three times I pour into the box. I did that I came to give it to her, she came to the lab, she told me to come by at 2pm for the results; I came by at 2pm she started talking to me badly... saying that 'we ask for the right spit for the right diagnosis I give the saliva'... she did like that I changed hospitals... I went to the regional hospital of nkongsamba...".

A common stereotype of TB patients among HCWs was to see them as deserving of pity, lacking in agency. The idea of TB patients as innocent, high need and precariously supported, evoked empathy in some providers.

A nurse, TB patients

Reasons for getting sick: Natural contamination, as in not from something they do. It's not their fault, but that is contrary to what some of the patients think.

A GP who does TB screening.

TB patients are afraid of the association of TB with Covid 19 and HIV, they are poor, cannot even afford decent accommodation

A GP

Vulnerable, need care, need help from their loved ones,

A TB expert

Vulnerable, needs constant follow up, usually abandoned in the hospital

A TB expert

“.. when some of these patients get abandoned by their caretakers and loved ones I sometimes have to sacrifice and give the food and even clothes sometimes.... But it is very tricky to be sympathetic with these patients because your sympathy may make them not to take drugs Sympathize but insist on the need to take drugs on time

TB Doctor

They usually link the patients to special service so that they might be able to get financial aid.’ Sometimes I even go as far putting in my personal efforts, but I can’t do that for all the patients”

Interestingly TB patients themselves did not routinely self-identify as pathetic or vulnerable nor did they necessarily recognize the concept of ‘TB stigma’ when they were asked about it using the term stigma. Rather they reported a wide range of attitudes toward having TB and a diversity of opinions on the TB stigma in their lives. Most people who were feeling better after months of TB treatment voiced various ways of deflecting and resisting stigmatization, demonstrating resilience and rejecting labels and frames that cast them as inferior or blameworthy.

Man with TB: “I don’t know that word stigma”

Interviewer (M): Don’t feel bad-

Man with TB: I’m not feeling bad!!

Interviewer(M): Do you think people will talk about you even after you recover?

Man with TB: If somebody talks about me? I don’t care. If people talk about me I don’t even care because I am well.

Yes, people are looking at me but I was not even having their time because I knew that it’s not a bad thing because I’m not the one who made myself to be like that. – driver, on 3rd month of DS-TB treatment

Religious faith and the airborne nature of TB were two themes that helped TB patients to signal their lack of responsibility for having acquired TB.

Interviewer (M): If you feel people are treating you unfairly, what do you usually do?

Woman with TB:: Ah.. ..for me.. I believe God knows best. ..I did not bought it [TB] in the market... Secondly I believe it is an airborne disease.. Thirdly, I believe if I take my treatment for six months without [inaudible] I will be fine again.

Two men and one woman with drug susceptible TB did not think the avoidance of social exclusion would be permanent. Some identified social exclusion as a short-term (and even logical) response to infectiousness.

Interviewer (M): Have you felt you were less respected in the last two months?

Woman with TB: Yes. Yes.

Interviewer (M): Why do you think that was?

Woman with TB: Because I myself was not feeling free. Others, when I cough around them, they don't feel free. You go to meetings. There are others they isolate from you. Others they use tricky words. So.....It has not been easy.

Interviewer (M): Oh. But please know you are going to get better. Don't mind about anything, OK?

Woman with TB: No. I don't even care. It is even over!...

Family and friends as sources of support,

"My friends ... " Yes yes I told them (...) that I'm sick ...() I informed them, I told them about my illness I told them that we were not going to see each other during this period because I am sick I have this illness(...) and the doctor's recommendation(...) is that I should not receive(...), I should not expose others to the illness until I am non-contagious..." No, they left, uh-- not angry,-- but they really encouraged me. They supported me through this difficult time, a lot of encouragement (...) I would never have thought that I had to have such a mobilization towards me...". (DR-TB,)

Some did not anticipate loss of respect or loss of roles in the long term, while others saw status loss as an enduring problem of having had TB. Two women anticipated that exclusion from family and community gatherings would extend into their recovery.

DR-TB Stigma

For persons with DR-TB the impact of stigma could be greater. For persons who believed they had acquired drug-resistance, the issue of self-stigma was sometimes an issue, with some TB patients endorsing negative stereotypes (carelessness).

Man with DR- TB

I feel guilty because I am—maybe if I had been taking the drugs the way I was supposed to be, I would be fine for a long time.

Part-time teacher

...so there I knew that I was the one who had done the stupidity to not get better, since I missed days of pills... There were days that I woke up, that 5:00 a.m. had already passed, and days when I couldn't even take the medicine. Since it was my first time I thought it was right, that it was a joke. If I skip a day without taking the medication what will happen to me? Nothing. I was thinking like that 't respect what I was told() at the hospital... I had to take the pills every day and there were days that went by that I hadn't taken them. So I knew in me that (...) this disease is coming back because I didn't walk as I had been told at the hospital ...

It is often suggested that people with DR-TB are more susceptible to stigmatization due to longer hospitalization and more explicit fear and avoidance behaviors by health facility staff. Preliminary formative data analysis suggests that may be true in Cameroon as well. One reported that he was regularly the object of gossip. Given the complexity of treatment regimen and their dependence on laboratory and clinical staff, one man with DR-TB reported feeling neglected and in limbo during five months in hospital, unclear about treatment progress and duration. He did not feel his intelligence was recognized and nurses seemed be afraid of him, not wanting to come close. Another man framed the DR-TB treatment as a fight that was as much mental as physical.

After the containment period "...I felt really relieved that the worst was already over and that it was behind me and that now I would have to try to recover and, because() from what the doctor had made me understand is that the fight would not only be to recover physically but the biggest fight will be the morale() yes because it is the ultimate battle there to be able to recover so tell yourself that no I will heal and I have to do everything to heal so first of all it is in the mind. So I was relieved (of leaving) this period of confinement and I tried to look at how I have to do certain things to regain strength and regain my physical abilities, so I even started doing some exercises at home... it wasn't easy at first but I persevered..." After the treatment : ...my own goals... I said to myself... I have to take into account that I have respected at least one of these commandments to go and multiply. (man, young, part-time teacher)

Resilience, Strength and Resistance

As challenging as TB treatment was for many people, those who endured it were often very clear as to their future directions and their goals.

I have a lot of projects(...) concerning life after the treatment(...) I have projects concerning my business, how to develop in my business? how to invest? it makes me wait only the moment that my treatment finishes that the disease finishes definitively". (young food trader, Western Region)

Non-adherence was not routinely ascribed to individual moral failings or flaws by TB care providers, but rather to poverty and stigma. A tendency toward hospitalization of TB patients was also described as a potential motivation for treatment avoidance and abandonment.

A nurse, TB patients

Patients are often reluctant to stay in hospital for long periods of time because of their activities (e.g., women say they have young children).

young, part-time teacher TB patient

...when I arrived at the hospital the major checked my notebook, and when she saw me she asked me how I was taking my medication. I made her understand that I was taking my medication but there were days that I wasn't taking it, and there were even days when I was taking things that I was not allowed to take. She made me understand that it's not surprising

that this illness is coming back, that it all depends on me, she just let me know that this time, if I make the effort not to commit the same stupidities again, I'll be cured once. It's simple, we just talked to each other".

Obedience to the treatment as the only route to survival was a recurring theme in all the interviews, emphasized by all health care workers. However some patients were skeptical of the need for hospitalization in the absence of medical need. Several patients reported feeling pressured to stay in the hospital even though they were ambulatory. Hospitalization was perceived as a loss of privacy, loss of income, and entailed having to disclose TB status to family members. One patient's market stall was robbed while he was hospitalized.

In Bafoussam they offered to intern me, I said that 'no, I can't stay here because I don't have anyone. I want to be sent back to Nkongsamba to take care as I have family there who can also try to take care...' they said that there is no problem.

Providers who worked directly with TB patients regularly were more aware of (and empathic towards) the challenges faced by TB patients. They had a much more nuanced understanding of the diversity of TB patients. They identified many of the challenges faced by TB patients as structural (lack of access to good nutrition, the myth of 'free treatment') and social (familial exclusion). They identified the heavy mental health burden of isolation a key challenge.

TB Doctor

Some patients are willing to continue with treatment but do not have the financial means to continue. Their general behaviour too depends on how severe their symptoms may be. Some are very afraid of death. Some are optimistic about their health situation, some do not even have an idea of what TB is. Working with DR-TB patients, they need more care and attention, because the TB strain they have is more difficult to handle.

A GP

"mostly poor patients who cannot take care of their health needs.... Even though drugs are largely free, they still need a balanced diet for these drugs to be effective.

Providers acknowledged that the TB stigma influences client communications and even clinical decisions. Some health care workers' attitudes toward patient autonomy and rights tended toward paternalism. Several health care workers described testing clients for TB without their knowledge in a well-intentioned attempt to reduce their anxiety about the stigmatizing disease. Several justified their limited TB counselling prior to testing by suggesting that clients would not agree to test if they knew what the test was for.

A lab technician,

The HCWs do not give appropriate instructions on how to produce their cough samples... Also, the other HCWs are advised not to mention the TB name for fear of driving the patients.

A lab technician,

The patients realise that when you are given a cup then you are already a suspect for TB. So they need to convince them like “mami abeg with ya cough yaa, we jo wan know the kind medicine for gi you” not to give the impression that it is related to TB.

A lab tech

Some of them do not want to know their status. So they refuse to the test.

GP, TB Screening

Some of them don't have enough finances. Some of the TB patients deny to do the TB test, for fear of stigma that comes with TB. So they prefer not knowing their situation

HCWs describe the challenges of normalizing TB for family members to ensure that TB patients are properly supported by their relatives.

A nurse

“we often go the houses and quarters of patients and talk to them on how manage their TB so as not to infect their loved once, we talk to their families about the fact that TB is just a disease like any other and anyone can have it and that they should not abandon their loved one but instead take care of them till they recover because that is possible.

A nurse

In some situations, the patients don't want their family members to be informed of the fact that they have TB. This is because they fear abandonment, blame. And the HCWs usually have to convince them to avoid psychological trauma because friends and family distance themselves from there. They have no one to visit them or bring them food or take care of them. Because of the isolation idea.

TB nurse

..what I did was convince the man to accept to tell the wife in my presence so I can have the opportunity to educated the wife on how to live with a TB patient at home... the wife looked troubled as she asked so many questions about when the disease will be treated.

TB patients also identified family members as potential sources of blame and shame, but not always because of TB itself, but rather risk behaviors. Two patients reported that their families blamed them for developing TB because of their having smoked shisha and/or cigarettes. Both family and health providers attributed TB disease to taking shisha and cigarettes and were open in scolding patients for this behavior. Health providers also associated TB disease with addictive behaviors and HIV.

A nurse, TB patients

It is easier to work with patients who have accepted their conditions than those who are still in denial. Some are cigarette addicts, and find it difficult to let go of it.

A GP who does TB screening.

"we work closely with the HIV departments because TB is highly associated with HIV.... The co-occurrence of TB and HIV is common.... Patients [more] easily accept being TB patients than being HIV patients.... So when they have these two diseases together we start by making them understand and accept TB before presenting the HIV results.... this is because the first reaction is always doubt and denial...

While familial abandonment was a common theme among HCWs, it was not a common theme among people with TB. Most people with TB described receiving varying degrees of support from their families and friends. TB patients also described how they supported each other in the hospital and tried to motivate each other to resist stigmatization and resignation.

I told only my friends who are close to me... I told them that I am sick, I was in the hospital, that's what they told me, I'm already taking the medicine too... they told me it can be done. They talked to me like that and then it's fine... nothing has changed with them" "My fiancé... I told her (...) I'm sick (...) we can't get married first I'm going to do the treatment a little (...) 6 months if I get better, we'll do it if I'm not fine then". She told me "no, we have to cure you, we'll get married". (man, a bulb trader who works with his big brother)

For several people spoke of fervent belief in the power of the TB drugs, which represented a source of reassurance to cling to during difficult times. When drug dispensing was delayed or drugs were not available due to a stock-out, TB patients perceived drug stockouts as dangerous and even discriminatory.

Two weeks they did not give the drugs. I only got them when the doctor called to check on me. (woman DS-TB)

Discrimination is when they give some drugs to one patient and not to the another. (man with DR-TB)

Financial precarity and catastrophic costs of treatment as engines of Stigma

One of the major concerns of TB patients and health care workers was the financial dependency and precarity of people with TB. Inability to pay and fear of hidden and catastrophic costs were felt by all stakeholders to be a reason to avoid TB testing, refuse or abandon hospitalization, and several felt that food insecurity contributed to poor response to treatment. Catastrophic costs of hospitalization were especially destructive for DR-TB patients. Two reported being threatened because of owing money to the hospital.

"Only one woman who shouted at me, but I just understand that the woman was pregnant, maybe it was the pregnancy that made her to be angry. By the time that they discharged me, she was going round about paying of bills. So I told her that I've not yet prepared to pay my bill-- that I'm still waiting for somebody to bring money and pay my

bills. So she shouted at me that I should allow the hospital room on that day because if she is not supposed to know about my bills. That I can go to the kitchen and stay there and stay there when the person brings the money I can pay before I go. She took my identity card and go and allow it to the security guard that I might escape. So, I went and explained it to the security guard and he gave back my identity card.”- a driver in 3rd month of DS-TB treatment

The need to borrow money from family and friends to pay for TB tests, medicines, and hospitalization put strain on relationships that were already burdened by stigma. One parent described having to borrow money from her son’s savings for education to use for TB treatment, and her shame at jeopardizing his future.

patient’s right to confidentiality and infectious disease risk in households

Privacy and confidentiality

People with TB did not always feel that their right to visual and auditory privacy was upheld.

The only thing I can say is that they should keep people’s privacy. People should have their privacy because I don’t think that if I know that you’re taking it when I enter your office you allow it open so that if any other person, they will just look at me as if I’m the last person that has the sickness. What I’m saying is that yesterday when somebody was taking her own, I was sitting outside then I was seeing the woman inside which is not correct --because I was not the one-- because I cannot enter like that and tell you to allow your door open. You must close it. I know my own life also. But when I was coming, the other woman who was to take her own was supposed to take her own the door was open and when they were giving her the drugs the door was open. (health care worker with TB)

Health care workers described challenges in balancing the need to respect their patients’ right to privacy and the obligation to safeguard the health of family members who may be close contacts. Individual HCWs seemed to manage the tensions in different ways, with no uniform strategy for whether or how to undertake contact investigation and treatment support when TB patients were not planning to disclose their illness to family members.

“TB and TB patients are generally perceived and looked at like outcasts.... It is a disease that is socially not accepted..... it brings psychological trauma.... It destroys and breaks families”. “ the most difficult experience I had was with a couple.... The man had TB and was not able to tell the wife.... This is where your ethics as a doctor is tested because you are caught between trying to ensure

confidentiality of medical records and preventing further spread of the diseases.....

ASC (CHW)

Lorsqu'on a le résultats du patients on lui demande d'abord si il veut partager son résultats avec sa famille et si il accepte on fait une descente dans la famille le même jour pour la recherché des cas contact, les enfants aussi de la famille. S'il refuse, on organise une descente ordinaire sans dire à la famille qu'il y a un malade et on essaie de les convaincre à faire le dépistage.

ASC (CHW)

Certains patients nous demandent de garder confidentiel leur résultats. Mais par soucis de l'état des autres membres on fait une descente pour chercher des cas.

A TB expert

... it is the responsibility of the patient to use their mouths and explain their situation to their loved ones and plead with them to take care of them for the two weeks in the hospital...

A nurse, TB patients

Plead with the HCWs not to do so. The HCWs have to convince them on why it is important they let someone know. Because it will help them follow up more with their treatment if they had someone to that with them.

Dilemmas of disclosure and personal protection in the community

To avoid deductive disclosure, community workers emphasized the importance of mask avoidance when doing household visits to TB patients. Not wearing personal protective equipment (PPE) in the community was recommended as an anti-stigma measure for ASC (CHW), which could place them at risk for TB transmission.

ASC (CHW)

To avoid stigmatizing people with TB, we do not wear masks when we enter their homes, and avoid wearing service clothes that will allow the community to identify us directly, so they confuse us with other outreach programs.

Indeed one ASC (CHW) expressed relief that the COVID crisis had relaxed the prohibition on mask wearing and reduced the risk of deductive disclosure. Another positive impact of COVID mentioned was the ability of some hospitals to finally separate TB patients from the general in-patient population.

ASC (CHW)

La COVID a également fait que le port du masque est obligatoire, tout le monde porte le masque et cela ne dérange pas les patients quand on porte le masque.

GP, TB Screening

Isolation, in the hospital. As in the wards. They may put the TB patient a few beds away from other patients, but generally in their wards they usually have mixed patients. But with this covid 19, they created an isolation room, so the last (TB) patient they had, they put the patient in that room.

Trade-offs between high-touch medicine and fear of TB transmission

A majority of HCWs were concerned about risk of TB transmission. Multiple HCWs reported having limited access to masks and other PPE. HCWs described a mixture of fear and resignation about TB infection and shortages of protective equipment. The fear of contagion caused some providers to render care at a considerable distance from patients. Lab personnel complained that health workers were afraid to collect sputum samples.

Médecin Généraliste (Prise en charge des patients TB et patients avec la MDR-TB et patients HIV)

Les personnels ont souvent cette peur de la contagion à la TB et stress par rapport à l'affectation dans le service de maladie infectieuse, la prise en charge des patients atteints de TB.

A nurse

"I just ask patients to stand as far as possible away from me... there is a veranda outside the large window of my office..... I ask them to stand before that veranda and talk aloud so I can hear them through the window."

A nurse, TB patients

Fear of infection: Yes. In as much we know we have to take care of these patients in the best way possible, we also need to make sure we are in the best condition. Because we are no good to them sick. So we try our best to provide them treatment, but we also do our best to protect ourselves because TB is very infectious .

A nurse

" I think about my safety every day at work... if I get sick I won't be there tomorrow at my job post"

A lab technician

"it is for our own safety so we keep a distance from patients who really look bad."

The reluctance to engage with TB patients in the TB wards was more common among staff outside the TB service. Health care workers reported that fear sometimes led to neglect or avoidance of clinical care for TB patients.

A TB expert

“... Nurses always feel that when you go to the quarantine center to administer drugs you will come back infected so they... “... you are right, TB stigma in patients comes mostly from the health care providers... for instance you ask a nurse, you instruct a nurse, please at 5am move to the TB unit and serve the patients their medications and you will get straight forward responses like ‘no oh... a no want go me deh ohh, the windows were closed all night and I don’t want to catch TB there’...someone will just tell you straight into your face like that even in the face of the patient. Even to go and bring vital signs of the patients the nurse will not want to go... Doctors too abandon the TB Unit to the patients. They do not come for their normal rounds for the fear of infection...

By contrast, TB providers considered the TB wards to be safer than other departments because at least the TB patients were identified and on TB treatment. The interviews revealed a lack of evidence-based understanding of TB transmission hotspots by some clinical staff.

TB Doctor

“Our other colleagues look at us like we might get infected at any time, but on the contrary [TB ward] is the safest place. Probability to get infected is lower, because they are aware of the risks, so they take the necessary preventive measures. Unlike the other departments where they think they are safe.”

Associative Stigma of Health Care Workers

Among HCWs who work primary in TB care and identify as TB providers, there was a mix of associative stigma, pride, and fear. There were some who acknowledged that their work was not always well-regarded by their peers. The difficulty of their daily work even led one to discourage others from joining her ranks.

TB Doctor

HCWs working in other departments always look at them as maybe they are infected, and try to distance themselves from them. Always making comments asking them to do the TB test. They get stigmatized too from the community, the way the community always looks at them.

TB Doctor

Colleagues distance themselves from them. “When we meet in the cafeteria, they will keep their distance and be like ‘go check yourself’ Now it’s not as bad as before, the stigma is not as before, but there is still some stigma.

A nurse, TB patients

If a close person informs me she wants to work with TB, I will discourage them very strongly. not that its bad working here or something, but I will just encourage them to take on something else, because I know what it entails and the risks involved.

A GP -Limited TB pt experience

Being a healthcare worker requires extra care, not to infected with TB. They also have to deal with discrimination in the community and in the hospital with workers of other departments.

ASC (CHW)

Les gens demandent si je n'ai pas peur d'être infecté d'attraper la tuberculose.

At least one TB patient also recognized TB providers as agents of anti-stigma efforts. One man with drug-susceptible TB explained how TB was normalized by his doctor and how this changed his self-perception.

The time that I discovered that I had this sickness I was very very embarrassed and it made me to feel somehow bad. But the doctor advised me it is a normal illness. You can take it through cigarettes. The man counselled me very well. Now I am taking the treatment for five months.....I'm really strong now. I'm really good. I don't have any problem. So they are just advising me not to smoke... The doctor... I was with him. He counselled me very well. I was very happy with the doctor because the doctor made me to come back to life. He said there was no problem with me that I should just take my drugs easily. The man gave me assurance. (man mid-forties, drug susceptible TB)

A woman with TB shared how a nurse told her not to be ashamed of her status because she too once had it and she was fine now. The words of the nurse comforted her and motivated her to take her drugs. Several people derived comfort from the encouragement of TB providers.

Institutional Support for TB Providers

Compounding the complexity of TB work, several TB providers described feeling unsupported by their institutions and colleagues. They perceived a lack of administrative concern for their department. One remarked that the administrative neglect of the TB clinical area was a further signal to TB patients that they were not valued.

A nurse

“we receive a heavy population of patients here... you know it's partly because of the internally displaced coming from the conflict hit northwest and south west regions.... The burden is really heavy on us”

A TB expert

... it is so heavy on us as the whole hospital abandons all TB patients and even suspects to us...

You can see how much we in the TB unit are being abandoned... this reaction is understood by patients and it makes them feel bad the more.

Associative stigmatization of TB providers also extended to the familial sphere for some respondents. TB providers faced concerns of their family members that they not infect household members. The ambivalence of family toward TB work was an added stress. Some managed associative stigma by not telling people that they worked in the TB field or by not informing family members of a TB diagnosis. Even health care workers with TB did not tell their co-workers.

ASC (CHW)

I have a colleague who has contracted tuberculosis and she got treated without telling her family for fear that she would get sick.

A nurse

As for me, my husband understands this and supports me.... He always advise me to be extra careful not to get infected and bring it home.

A nurse, TB patients

When people ask what you do what do you say? "It's really stigmatizing if people know, so I just say "I am a nurse naa".

One health care worker who tested positive for TB was in a state of total disbelief due to lack of severe symptoms. She asked to be retested, feeling that perhaps there was a mix-up with the samples. However she was not permitted to challenge or confirm the diagnosis. She was afraid of being hospitalized due to fear of actually getting 'real' TB in the ward and worries over her children's care and she successfully avoided attempts to hospitalize her through appeals to key administrators. She continued working throughout her treatment and did not disclose her TB to coworkers. She had challenges adhering to treatment because she did not believe she had TB.

At the same time, several TB care providers pointed to satisfaction and professional fulfillment because they served a patient population that is marginalized by others. Offering life-saving care to persons who are under-served was motivating and instilled a sense of purpose.

ASC (CHW)

La confiance c'est installé : ce sont les gens de la communauté même qui parfois oriente les gens qui ont la toux vers moi, ceux qui prenaient le traitement et que je ne savais pas même se présente maintenant à moi pour les conseils.

Médecin Généraliste (Prise en charge des patients TB et patients avec la MDR-TB et patients HIV)

Oui "j'ai fait de cela mon combat... il y a des mois où on n'enregistre pas de décès et mes collègues sont étonnés et moi je leur réponds que je m'occupe bien de mes patients... quand un patient recouvre la santé cela me motive...j'ai beaucoup appris avec les patients TB..."

Médecin Généraliste (Prise en charge des patients TB et patients avec la MDR-TB et patients HIV)

Les personnels ont souvent cette peur de la contagion à la TB et stress par rapport à l'affectation dans le service de maladie infectieuse, la prise en charge des patients atteints de TB. J'ai appris à comprendre les patients, à les informer. Cela m'a également emmené à beaucoup lire, cela a éveillé la curiosité pour comprendre et pour trouver les mots à dire au patients pour l'encourager à suivre le traitement, aussi j'ai acquis une expériences dans l'accompagnement psychologique des personnes pas seulement pour mes patients mais peut également permettre d'aider des proches. Pour travailler avec les patients TB il faut être capable de s'épuisé pour les aider "par exemple il peut avoir un problème et il faut l'aider... il faut questionner le patient pour qu'il s'ouvre à toi et qu'il vous fasse confiance... et parler au membres de la famille en counselling pour qu'il n'abandonent pas le patients..." Le service de TB est un service ou beaucoup de médecin ne veulent pas aller quand on les affectes là-bas parce que c'est la TB "mes collègues me demandaient si je vais m'en sortir, tu va toujours voir la tuberculose, tu va te contaminer, tu va boire ça là-bas". Mais le médecin spécialiste m'a encourage et m'a dit que je vais beaucoup apprendre avec lui".

TB Nurse

"... The issue with TB is that when I was just recruited as a nurse, I found passion in managing cases of TB.... Because I saw that the people who were there were highly vulnerable and because of the way that I saw that they were being maltreated... they were being stigmatized.. so it was my own wish to be part of the management team so I can encourage them..."

ASC (CHW)

J'aime ce travail, j'aime assisté les autres et les aider et j'ai toujours voulu travailler dans la santé, je crois que c'est ma vocation d'aider les gens. J'ai choisi de travailler dans la recherché des cas de TB

A TB expert

“.. Ha ha ha no... For my ten years working with TB I don't think I have been treated differently by my family or community because I work with TB... I have treated many patients and I have never been diagnosed of TB

These discourses helped to combat prevailing views of TB care as dangerous, difficult and devalued (3D) work relative to HIV, reproductive health, and other more prestigious technical areas.

Discussion

TB Stigma in Cameroon appears highly dynamic and varies in its manifestations, duration, and severity. TB stigma affects both people being treated for TB as well as those who care for them. Some health care workers with limited contact with TB patients had erroneous assumptions and prejudices about them which affected the quality of care they provided. HCWs also had low regard for TB care providers and TB providers perceived a lack of administrative and peer support for their often difficult jobs.. Fear of TB transmission is a major concern of health care workers and shapes their behavior and relationships.

Persons taking TB treatment described an array of challenges and strategies for coping with an infectious cough and for interacting with friends, family and providers. Those with drug susceptible TB described a journey with various phases, with TB stigma reducing for some as infectiousness ebbed and health was restored. As physical health was regained over the course of treatment, they often felt better equipped to deflect, resist and ignore attempts to de-value them. Belief in God, faith in the virtues of drug adherence, and social support from loved ones were central to resilience and keeping despair, discrediting talk and self-criticism from changing their self-perceptions. People requiring treatment for acquired drug-resistant TB felt acutely judged and at least one reported guilt.

While some HCWs echoed the negative stereotype that TB patients are *secretive* about their disease, we found that HCWs could also be untransparent about what they were testing for, what treatments were required, and how long hospitalization would last. The absence of full information was disempowering and impaired patients' ability to understand, participate in, and endure their TB treatment. Testing clients for TB and HIV without their informed consent and engagement appeared a common practice, ironically undertaken with the paternalistic aim of shielding patients from shame and embarrassment. TB patients reported not feeling that they were given choices or asked for input on how, where, and with whom they were to take their treatment. This is noteworthy given the wide ranging levels of family support, disease severity, and needs described by patients.

TB stigma impacts the acceptability, accessibility and quality of TB care and support services. We found that TB facilities, goods and services are not fully respectful of medical ethics or sensitive to the needs of different patients. The qualitative interviews highlighted how TB patients were told that they must be hospitalized. Only TB patients with access to powerful stakeholders or dependents were able to escape.

This was a limited analysis including interviews with 32 HCWs and 25 TB patients. To build on these findings and develop a better understanding of TB stigma in this setting, we are currently conducting larger quantitative studies. Nevertheless these interviews provide some clear directions for future policy making and programming.

Recommendations

1. Policy makers need to elevate TB on the national health agenda to increase the resources available for TB workers and TB patients. This is critical to addressing the fundamental drivers of TB stigma (e.g. catastrophic costs, transmission fear, patient disempowerment). In addition, accountability mechanisms are also needed to ensure that human rights are respected and protected in the TB response.
1. Health care workers need greater competence on ethics, human rights, patients' rights, and stigma reduction to help them navigate a wide range of real dilemmas and challenges. Capacity building should be planned and organized using best practices learned from successful programs elsewhere. Rather than removing workers from their work stations, it may be worthwhile to provide it individually using digital or self-learning, with communities of practice to reinforce norms. HCWs can learn about stigma with some privacy to address their shortcomings outside of their peer group.
1. Integrate stigma into some technical content that HCWs value – like MDR-TB training, infection control or health care worker's rights. Things that they care about and perceive as vital.
2. Administrative and environmental controls are needed to provide occupational support, recognition and safety for all HCWs performing TB-related work, including efforts to improve peer support. Policies for measuring the air safety, regular TB screening, and adequate ventilation in out-patient departments other hot zones are necessary to increase their retention and safety at work.
3. Primary care providers and those who do not work in TB seem like the most important target group for stigma reduction as they seem to have a less nuanced, more stereotypical, less empathic view of TB patients. Interventions with a patients' and HCWs' rights focus are preferable to those with a kindness focus—with a strong emphasis of structural stigma. It should not necessarily be labelled as 'stigma reduction' but rather to empower and enforce specific behaviors and attitudes.
4. TB patients should have a clear role in the TB response as part the Patient-centered care approach. This include the engagement and empowerment of people affected by TB to know their rights and report the human rights barriers preventing them from being successfully treated, for a rights-based, people centered, accountable, and equitable TB response.
5. "Stigma" is not a universally recognized term, and the concept has to be locally defined in regions, cultures and languages. Cameroonians identified catastrophic costs and drug stock outs as disrespectful and discriminatory, and anti-stigma efforts in Cameroon should encompass these matters.
6. Patient-centered care, that better matches the expressed needs and preferences of TB patients, is important. Cameroon's habit of hospitalizing TB patients in the first two weeks of treatment is not aligned with global policy and may create a more dangerous workplace for all types of health workers and a more stigmatizing environment for TB patients. Hospitalization decisions should be based upon clinical needs not social needs or financial interests of institutions; non-hospital alternative housing is needed for TB patients who cannot be well cared for in family settings. Unnecessary hospitalizations cause lack of trust in the TB program.

Conclusion

We found that health care workers at all levels of the health system who interact with people with TB need increased support to do their jobs better and to continue to provide services. People working actively to detect and care for people with TB report being devalued in workplace hierarchies and the perceived dangerousness of their work creates fear and lowers job satisfaction. Pride in serving the community and a sense of

accomplishment may buffer against associative TB stigma from peers and family. Nevertheless, HCWs need support and recognition of their important contributions to increase their retention and safety at work. Occupational safety and patient confidentiality are two core principles of TB care that should not be sacrificed for each other.

This study has shown the different ways that TB patients are made to feel responsible for having TB disease and responsible for ensuring its cure. People with TB are not monolithic, yet the challenges they face often include negative stereotypes and prejudices, violations of their right to privacy as well as informed consent, and a highly variable quality of care. People with TB are vulnerable to lose their sense of self-worth, means of economic sustenance and community standing via high costs of diagnosis, prolonged hospitalization, and care that does not routinely empower them to take a decisive role in their own treatment. Having TB is challenging, but it is particularly daunting in the absence of a constructive and equitable partnership with health care providers based on transparency, mutual respect, freedom and trust including exchange of pertinent factual information on testing, treatment, and costs. The unequal power dynamic between patients and service providers and policies which are not evidenced-based do not further the goal of TB elimination.

This study identifies key areas for improvement in the situation of TB patients and the providers who serve them. Improved cooperation between these key stakeholders is both possible and necessary. The most important is also to empower people affected by TB to know and claim their rights in the TB response.

References

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Table 1: Qualitative interview with TB patients

gender	TB type	Months on TB TX	Date of interview	Length of interview in minutes	Language	Description
woman	DS-TB	3	30/11/2020	35	English	She's a health personal, out spoken
man	DS-TB	3	30/11/2020	28	English	He is a driver by profession, a married man, sounds like he is not that happy
woman	DR-TB	6	5/12/2020	41	English	She is a young student in the university, friendly and well spoken. She recently learned that the treatment failed and she will take it again for another three or six month.
woman	DS-TB	4	5/12/2020	34	English	She is a health worker. From the discussion she lacks financial support.
man	DS-TB	4	20/11/2020	24	English	He is 38 years old, he is polite, jobless, single with one kid.
man	DS-TB	4	19/11/2020	30	English	He is 40 years old. He does art work. He has two children but they don't live with him. Not too open and not too learned. He came with his wife and she also took part in the interview. She gave some answers to complete the uncompleted answers he gave. She is his carer throughout his TB journey.
man	DS-TB	4	04/12/2020	31	French	He is a young, part-time teacher, diagnosed with TB and has been under treatment for 4 months. Very open, he shared his experience and his life with TB since the diagnosis, the beginning of the treatment to this day. He is a person who was affected by the conditions of confinement and isolation at the beginning of his treatment (the first two months). These were difficult times for him.
man	DS-TB	3	03/12/2020	33	French	It is about a man, a bulb trader at the central market of () who works with his big brother. He lives with his family (parents and brothers) and there are about 13 people in the family home. He was diagnosed with tuberculosis and has been on treatment for three months. He seems to be confident of his recovery and is following his treatment as recommended.
man	DS-TB	5	27/11/2020	33	English	Very well spoken, a family head working as a () technician with the ().
man	DS-TB	4	27/11/2020	33	English	He is married, no kids. A bricklayer(builder) by profession. He is well spoken. He is not currently working for now due to his health situation
man	DS-TB	5	4/12/2020	39	English	He is a phone technician, well spoken too

man	DR-TB	4	05/12/2020	42	French	He is an unemployed (resourceful) youth residing in () but is currently at the treatment center in () for the treatment of MDR-TB. He has relapsed after 5 months of DS-TB treatment.
man	DS-TB	6	20/11/2020	44	English	He is a business man. Not married but has a kid.
man	DR-TB	16	04/12/2020	49	French	He is a young food trader, residing in the region of() and who has currently stopped this activity because of his state of health (since he became ill). He is nostalgic for his activities that have stopped because of the illness but confident of his recovery..

Table 2: Cognitive Interviews with TB patients

DATES	GENDER	LENGTH IN MIN	TB	LANGUAGE	DESCRIPTION
9/10/ 2020	Female	55:25	DS-TB	English	She is married but lives with her children. She was polite and fluent and has been coughing and did her TB test for 3 times before having to do an X-ray test that's when she realized it was TB. She felt most of her pains before treatments and during the treatments her symptoms got better, She also went to confinement because of the feeling of stigma from neighbors, friends and had also side effects from her treatments during treatment but has no feelings of hurting herself. She also has ambitions for her life after treatment.
9/10/2020	Male	52:46	DS-TB	English	He is a matured and outspoken man married and retired been working at a plantation in (redacted). Been on drugs for 2 months and is mostly indoors because of hypertension. He was also frank about his financial status and was very angry about it which made him very angry to talk. But was very nice. He has no feeling of stigma and doing any harm to himself and all he wants is to be able to provide for his family and get well.
10/10/2020	Male	1:33 HR	DS-TB	English	An outspoken and fluent man and believes hygiene, smelling areas and places are essential to prevent TB infections because that's how he believes he contracted TB. He also said the health workers were kind and gave him all information's about his illness.
13/10/2020	Male	23	DS-TB	English	He is a nice young man who is not well fluent and believes smoking and alcohol is the cause of his TB and He feels ashamed to tell his friends he has TB and is not much of a social person because people take advantage of him because he doesn't talk much so he mostly stay out of friends to avoid trouble and mockeries from them.
13/10/2020	Female	54	DS-TB	English	She is sincere and outspoken about her illness and she said she said she felt lots of stigma especially in her social milieu with friends and meetings by using hard words or body languages because she used to cough too much and she regrets having told some particular people about her illness but she always receives support and assistance from some other people so it pushed her to find the comfort of her home confinements but she is better now and she has decide to always sensitize and comfort any person she finds who has TB and is advising us to sensitize especially in the Rural areas because she observed lots of them are suffering and very stigmatized of TB .
14/10/2020	Male	37	DS-TB	English	He was very embarrassed and sad when he realized he had TB and when he was counseled by the Doctor that its normal. His been on treatment for 5 months now

					and went for test and realized the bacteria was few and he decided to stop smoking. He thinks separating TB patients is discriminating, He also said TB was his fault because he used to indulge in smoking and he was stigmatized by his friends but would stop after he would be fine.
14/10/2020	Male	25	DS-TB	English	He is a young kind man not fully fluent in English. He tries to take his treatments seriously and he did many tests but didn't initially find TB. Only after he visited the [redacted] Hospital. His family thinks TB is his fault because he used to drink cigarette and alcohol but has stopped. His family lives in Limbe and His been avoided by friends because of TB at work and believes his been avoided in social places and meetings and njangi.
13/10/2020	Woman	40	DR-TB	English	Began the treatment but stopped because she traveled to a different town for an operation.
12/10/2020	Man	50	DR-TB	Pidgin	Started treatment but ended it half way because he was escaping from the socio-political crisis. He equally interrupted his treatment by taking alcohol.
12/10/2020	Man	56	DR-TB	Pidgin	He has been to prison and he believes that he got contaminated while he was imprisoned. Now is out of prison and hustling.
13/10/2020	Man	45	DR-TB	English	Has been taking TB treatment for one year and some months. But couldn't continue going to his health facility due to the gunshots in the aera. He seems to be getting better.
13/10/2021	Woman	50	DS-TB	English	It seems like initially she found it hard to accept the fact that she has TB. But now she has accepted it and is believing God for healing.
14/10/2020	Woman	40	DS-TB	English	She is open and attentive and seems to be confident that she will be cured.

14/10/2021	Woman	43	DS-TB	English	A student but hadn't been able to go to school anymore because of her health condition. She lives with her sisters.
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Table 3: Qualitative Interviews with health care workers

Date of interview	length of interview in minutes	language	Description of respondent
25/09/2020	57	French	General Practitioner (Management of TB patients and patients with MDR-TB and HIV patients)
24-09-2020	24	English	A nurse, TB patients
24-09-2020	45	English	Nurse Screening patients with TB symptoms for DTCs
25-09-2020	30	English	A lab tech
23-09-2020	34	English	Doctor Screening clients with TB symptoms for DTCs
24-09-2020	28	English	GP, TB Screening
25-09-2020	28	English	TB Doctor
24-09-2020	78	French	ASC
25-09-2020	60	French	GP (Consulte des patients avec symptômes de TB)
25-09-2020	35	English	A lab technician, screening (head of service) working with all the benches in the lab
24-09-2020	20	English	A GP -Limited TB patient experience
25-09-2020	39	French	ASC
26-09-2020	64	French	ASC
24-09-2020	47	French	Nurses for TB patients
25/09/2020	45	English	A lab technician who accepts to take part in the interview just for formality. Not will to discuss with examples. I think the
23-09-2020	32	English	A nurse
25/09/2020	58	English	And expert with more than 10 years of experience working with TB, provides specifically TB care.
24-09-2020	36	English	A GP in a small health center who does TB screening.
24/09/2020	43	English	A GP

Table 4: Cognitive Interviews of health care workers

Date of interview	length of interview in minutes	language	gender	Description of respondent
02/09/2020	28	Fr yb	FEMALE	HCW
04/09/2020	39	Fr yb	FEMALE	HCW
24/09/2020	34+37	Fr-m	FEMALE	CHW
25/09/20	44	FR YB	MALE	CHW
25/09/20	42	Eng m	FEMALE	TB nurse
26/09/20	23	ENG yb	MALE	HCW
28/09/20	1:26 HR	ENG yb	MALE	HCW
28/09/20	38	FR M	FEMALE	CHW
01/10/20	34	ENG yb	MALE	CHW
12/10/20	25	FR yb	MALE	ASC
01/10/20	19	ENG yb	MALE	DTC