Formative research on behavioral determinants related to TB case detection and notification - Kinshasa, Lubumbashi, Mbuji-Mayi, Matadi

June 2024

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FOR SOCIAL & BEHAVIOR CHANGE

The burden of tuberculosis in the DRC

- Tuberculosis (TB): the 13th leading cause of deaths worldwide
- TB deaths, worldwide (2022): 1.13 million
- Democratic Republic of Congo (DRC): One of the 30 countries with the highest TB rate; accounts for 3% of the global burden
- Estimated total incidence of TB in DRC, 2022: 314,000
  - TB case notifications (new cases and relapses): 248,120 (79%)
  - Among notified pulmonary TB cases, bacteriologically confirmed cases: 72%.
- Tuberculosis patients (TSP) face catastrophic costs (2019): 56%.

WHO Global Tuberculosis Report 2023
WHO Tuberculosis profile: DRC, 2022

TB situation in the DRC's 'hotspots

- DRC: 10th rank for the gap between suspected and diagnosed cases of tuberculosis (2022); The gap of around 50,000 people.
- In 'hotspot' provinces, case notification is often higher than the national level
- But the number of TB cases is rising, with a high mortality rate, especially in Kinshasa.
- This confirms the need to improve the success of contact-seeking efforts.

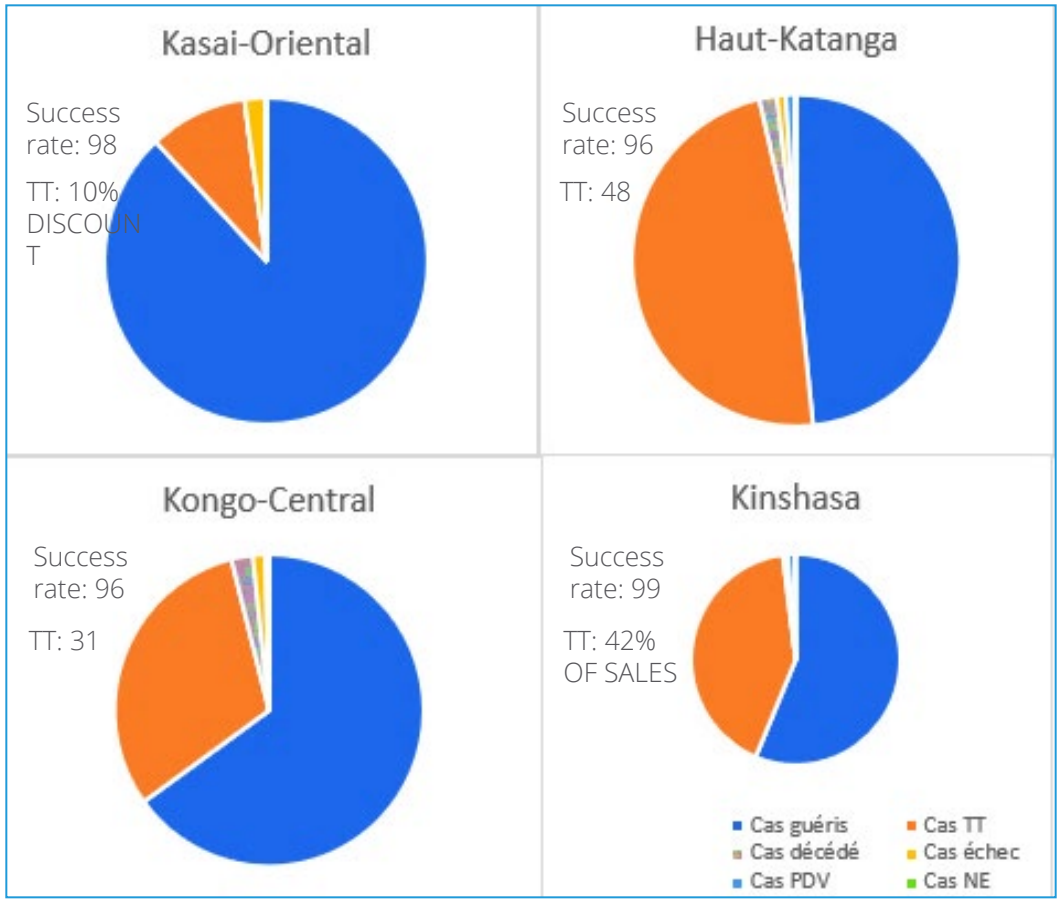
Province	Centres urbains	% Achèvement de notification des cas	Augmentation des cas TB	Population avec la TB	Décès TB
Kinshasa	(Kinshasa)	84%	14%	14%	17%
Haut Katanga	(Lubumbashi)	90%	20%	7%	9%
Kassaï Oriental	(Mbuji Mayi)	77%	4%	10%	3%
Kongo Central	(Matadi)	81%	8%	3%	5%
DRC		79%	7%		

WHO Global Tuberculosis Report 2023
PNLT 2021

TB Treatment results for selected sites - Quarter 4, 2023

- The treatment success rate (follow-up to completion) is already high, at 95% by 2021 (WHO).
- However, the provinces of Kinshasa, Haut Katanga and Kongo Central have a high proportion of TSPs who have completed treatment but are not cured.

Province	Healed	Terminated treatment (TT)	Deceased	Failure	Perdre de Vue (PDV)	Non-Eval.	TB all shapes
Kasai-Oriental	412	46	0	10	0	0	468
Kongo-Central	348	166	12	7	1	1	535
Haut-Katanga	668	663	24	12	12	2	1381
Kinshasa	740	549	4	6	15	1	1295



SNIS RDC access in 2024

Objectives - Strategy and study

- NTP goal: End TB epidemic by 2030
- National strategy goals: Improve case notification and reduce the number of deaths
- Study objectives: To gain a better understanding of the psychological, social and structural reasons that influence community members to adopt behaviors related to :
  1) Seeking care at the CS/CDT
  2) Getting tested for TB
  3) Announce their status to the household and help find contacts
  4) Follow-through to the end of the treatment plan

How do you identify a priority target?

Incidence of TB

Province	Health zone	TB Incidence	Presumed TB cases submitted for bacteriological examination (Frottis)	Suspected TB cases with positive smear test results	
				Workforce	%
Haut Katanga	Kenya (urban)	1036	2179	389	17,9
	Kipushi (suburban)	436	1392	319	22,9
Kongo Central	Matadi (urban)	504	533	158	29,6
	Nzanza (suburban)	619	1072	152	14,2
Kasai Oriental	Lukelenge (city)	2003	9913	991	10,0
	Tshilenge (suburban)	1116	5513	776	14,1
Kinshasa	Kikimi (urban)	1889	4322	1465	33,9
	Masina 2 (suburban)	1694	3320	1166	35,1
Total		**9297**	**28244**	**5416**	**19,2**

- These are provinces with a high incidence of TB
  - The province of Kinshasa has the highest proportion of positive cases, followed by the urban areas of Kongo Central and the peri-urban areas of Haut Katanga.
- High test positivity rates could be explained by the fact that suspected cases come late to screening.
- On the other hand, the low rates of positive cases in these 'hotspots' could indicate that there is a high proportion of suspected cases who do not come for screening.

These zones are characterized by :
- High population density;
- A high level of mining activity;
- A high proportion of the population living in poverty

All this has a negative impact on health infrastructures and the health of the population.

New cases and relapses by sex and age

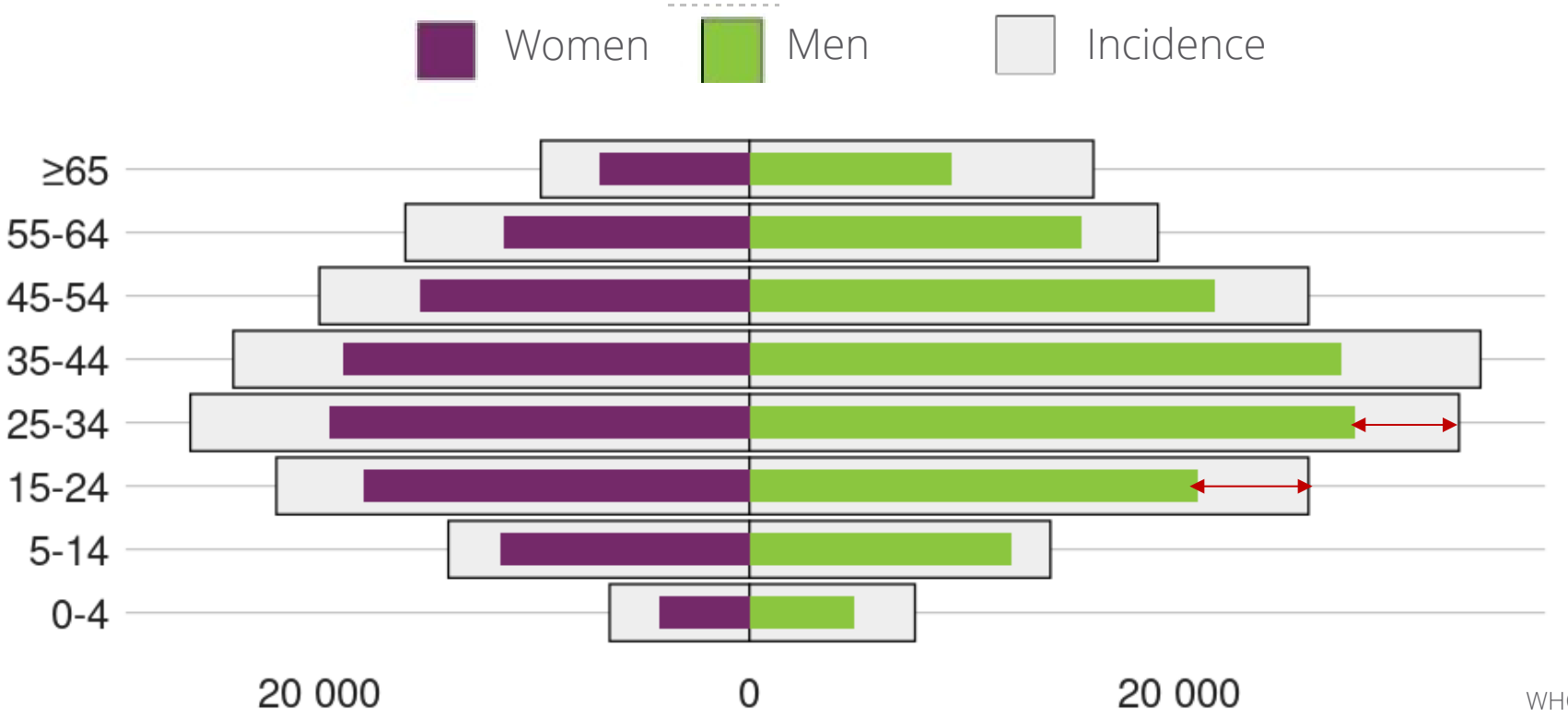
- The number of patients is higher in men than in women
- The 15-34 and 35+ age groups bear a heavy burden of TB, especially men aged 15-34.

Province	Health zone	New cases and relapses, Female				New cases and relapses, Male			
		0-4 years	5-14 years	15-34years	35+ years	0-4 years	5-14 years	15-34years	35+ years
Haut Katanga	Kenya	9	21	207	150	14	30	287	318
	Kipushi	9	13	77	85	9	8	109	126
Kongo Central	Matadi	1	16	95	67	4	21	166	134
	Nzanza	3	11	92	92		10	220	191
Kasai Oriental	Lukelenge	30	122	276	595	34	116	262	641
	Tshilenge	8	62	209	254	14	65	179	345
kn Kinshasa	Kikimi	33	101	342	309	30	85	508	481
	Masina 2	28	87	275	239	38	69	490	468
Total		121	433	**1573**	**1791**	143	404	**2221**	**2704**

PNLT 2021

Incidence, notified cases by age group and sex

- For greater impact, we need to focus on the 15-34 age group, which makes up the vast majority of the DRC's population.
  - Men aged 15-34 form a fairly homogeneous group, with a significant number of cases.
  - There are also discrepancies between incidence and reported cases for this group.
  - Thus, men aged 15-34 are a priority for social and behavior change (SBC) programs.



WHO Tuberculosis profile: DRC, 2022

Study methodology

Study pre-test

February 2024, St. Pierre CDT, Kinshasa

Completed activities

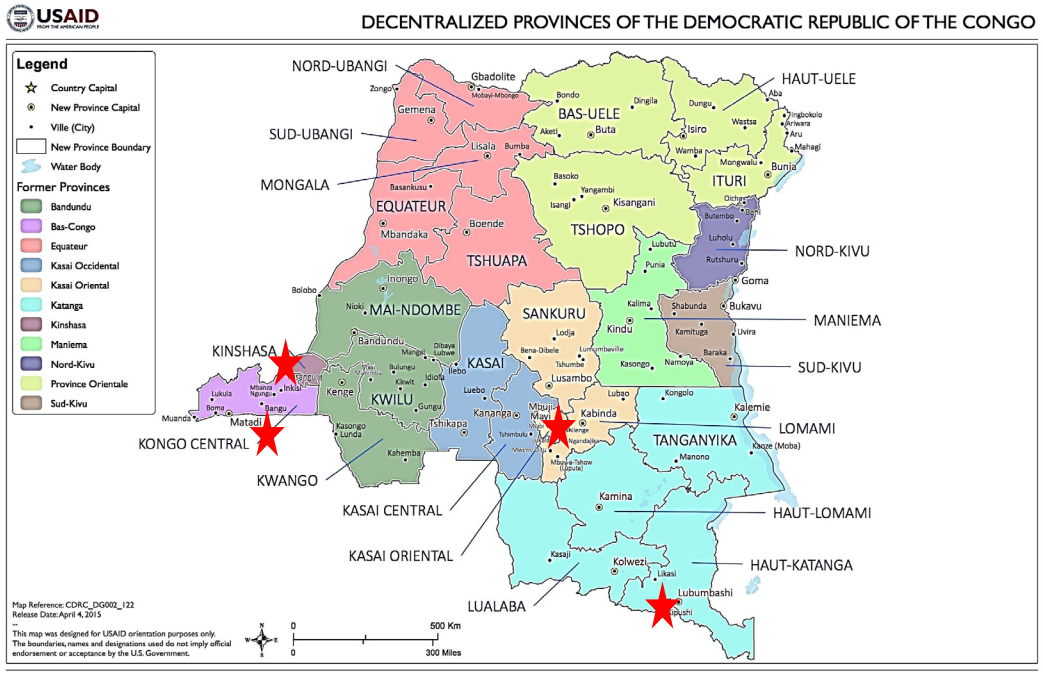
- Interviews
  - 2 RECOs
  - 2 Former TB patients
  - 1 Community Leader
  - 1 CDT service provider
- Focus groups
  - 1, male 18-34
  - 1, female 35-65

Refinements based on pre-test

- Eligibility criteria refined to avoid overlap, increase diversity of experience
  - Former TB patients not currently acting as RECOs
  - Former TB patients including 1 TB-susceptible, 1 TB PR/MDR
- Eliminate redundant questions between provider interviews and RECOs
- Guide length reduction
- Emphasis on stigma, screening and treatment may have varied from one GD to another
- Refresher on how to enter demographic data
- Discussion on how to ensure participants' comfort

Qualitative study sites

Province	Urban site	Peri-urban site
Haut Katanga	Kenya	Kipushi
Kongo Central	Matadi	Nzanza
Kasai Oriental	Lukelenge	Tstitenge
Kinshasa	Masina 2	Kikimi



Study audiences

MCZ

2 RECOs (non-former TB patients)

2 CDT service providers

1 Community Leader interested in health

2 former TB patients - 1 susceptible TB, 1 PR/MDR TB; not currently working as RECOs

4 Focus groups: Men and women, aged 18-34 and 35-65, who have never been TB sufferers themselves.

Background to study sites

- Across the provinces, busy work for providers and RECOs
- Kinshasa, where ~30% of TB cases are found, has the highest burden per CDT staff member.
- In Haut Katanga, a large number of RECOs help with the work.

Province	Average suspected cases/ Area	Personal means CDT/ Zone	Ratio of suspected cases to CDT staff	Medium RECO/ Zone
Haut Katanga	298,5	5,5	54	111,5
Kasai Oriental	448,5	7	64	9,5
Kongo Central	137	8	17	8,5
Kinshasa	519,5	4	130	5

- Of the 6 study sites that provided information, 2 urban and 2 peri-urban sites had equipment for rapid tests such as GeneXpert; Microscopy is done everywhere.

Participant characteristics: Former TB patients

- Former TB patients are resourceful (service sales and other professions)
- Over 9/10 have a large family (4+ per household)
- Half of all households have at least one child under the age of 5

These characteristics reflect the essential social factors of contamination

Demographics	TOTAL			
	URB	PERI	TOT	%
Age range				
- Patients aged 18-34	3	4	7	43,8%
- Patient age 35+.	5	4	9	56,3%
Marital status				
- Single	4	3	7	43,8%
- Married	4	4	8	50,0%
- Divorced	0	1	1	6,3%
Education level				
- Primary incomplete	1	1	2	12,5%
- Complete primary	2	1	3	18,8%
- Incomplete secondary	2	2	4	25,0%
- Full secondary	2	4	6	37,5%
- Superior	1	0	1	6,3%
Profession				
- Employee	0	1	1	6,3%
- Sales services	3	1	4	25,0%
- Unqualified manual	1	0	1	6,3%
- Qualified manual	0	1	1	6,3%
- Agriculture/Fisheries/Livestock	1	1	2	12,5%
- Others	3	4	7	43,8%
Number of persons - household				
- 1 à 3	0	1	1	6,3%
- 4 à 6	5	4	9	56,3%
- 7+	3	3	6	37,5%
Number of children <5 years household				
- 0	4	4	8	50,0%
- 1	3	3	6	37,5%
- 3+	1	1	2	12,5%

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Participant characteristics: Focus groups

- The configuration is almost identical to that of the general population
- Dominated by people engaged in informal survival activities adapted to the living environment
- 60% knew at least one person with TB - Of which ¾ outside the household means less intimate knowledge of TB

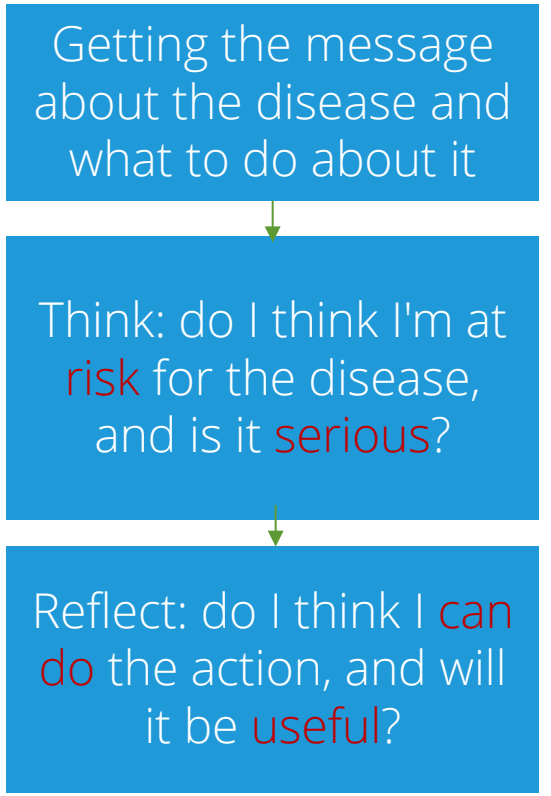
Demographics	TOTAL			
	URB	PERI	TOT	%
Gender				
- Women's	64	64	128	50,0%
- Male	64	64	128	50,0%
Age range				
- 18-34 years	64	64	128	50,0%
- 35and up	64	64	128	50,0%
Marital status				
- Single	65	47	112	43,8%
- Married	58	70	128	50,0%
- Divorced	1	6	7	2,7%
- Widow Widower	4	5	9	3,5%
Profession				
- Employee	8	6	14	5,5%
- Executive technician	16	11	27	10,5%
- Unqualified manual	7	10	17	6,6%
- Qualified manual	2	2	4	1,6%
- Sales services	31	32	63	24,6%
- Agriculture Fishing Livestock	0	16	16	6,3%
- Others	64	51	115	44,9%
Know someone from TB				
- Yes years household	13	23	36	14,1%
- Yes outside household	59	60	119	46,5%
- No	56	45	101	39,5%

EPPM" theory

Psychological determinants explored in the study

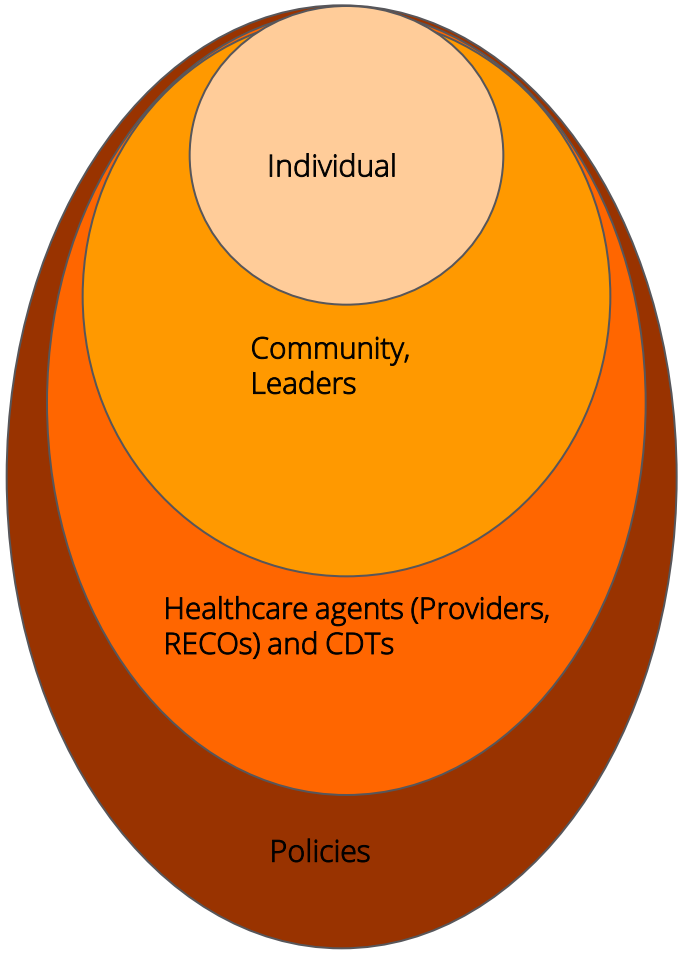
Psychological

- Knowledge of TB risk
  - Signs and Transmission
  - Profile of people at risk, including children
- Attitude that a cough could be serious enough to require CS/CDT care
- Confidence that care could be accessed at the *CS/CDT*
  - Especially free screening and treatment
  - …in spite of a bad image from the community if you access care at the CS/CDT
- Belief that TB can be prevented and its status announced to the household, and collaboration in contact tracing
- Belief that good health can be regained or restored through screening, receiving results and following treatment through to the end.



Socio-Ecological Model

Social and structural determinants explored in the study



Social/Interpersonal

- How do household members encourage or discourage the use of CS/CDT services?
- How social and gender norms circulating in the community and the values upheld by leaders influence TB-related health actions
- How does stigma play a role in care-seeking behavior, use of CS services and collaboration with contact tracing?
- How do health workers influence the behaviour of people suspected of having TB?

Structural

- How do factors such as poverty, distance, and costs associated with seeking care at the CS/CDT influence the use of services related to TB control?

Analysis methodology

1
- Team of researchers has developed an analytical framework
  - Preliminary identification of themes related to the EPPM model and the socio-ecological model
  - Organization of themes according to priority behaviors in the fight against TB
  - Refinement of themes to create key findings based on review of debriefing discussions in the field

2
- Participatory analysis workshop
  - Participants from government, research institutions and civil society
  - Independent reading of interview and GD transcripts. Link verbatims to predetermined themes and key findings

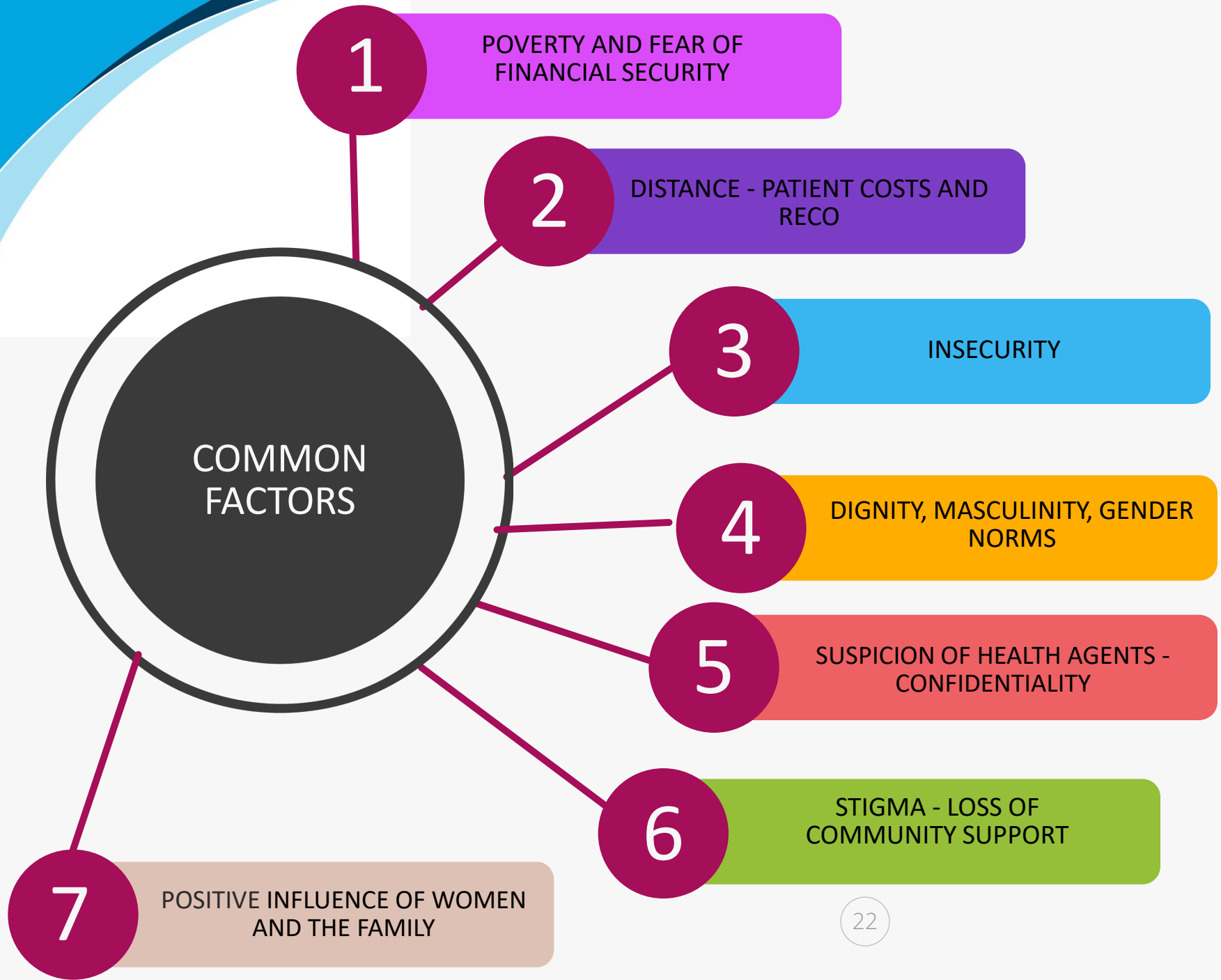
3
- Discussion of workshop participants by provincial team and study audience
  - Identification of common key findings by audience and variations by gender, age, or geography supported by verbatims in transcripts
  - Submission of verbatims to an electronic database

4
- Plenary discussion
  - Note themes that were not observed as frequently in a given province
  - Group these themes together to identify other key findings that are cross-cutting and linked to priority behaviours for TB control.

Results

Organization of the results section

- The results are presented in the form of key findings that describe the thoughts, feelings and motivations that accompany critical behaviors in the journey towards eventual TB diagnosis and treatment.
- First, we present the key discoveries that are common to all key TB behaviors.
- We then present key discoveries that are more specifically linked to each of the following behaviours:
  - Seeking care at CS
  - Screening
  - Results announcement and contact search
  - Treatment follow-up
- At the end of each sub-section, a figure shows how the key findings fit into a socio-ecological model, representing the multi-level factors that facilitate and inhibit the adoption of desired TB control behaviors.



Several themes have been associated with multiple behaviors along the continuum of TB experience. These key findings are discussed in detail in this section.

Poverty and fear of losing financial security

The problem

The DRC is one of the world's poorest countries, with three-quarters of the population living on less than $2.15 a day. (World Bank 2023).

The country also records an unemployment rate of 40% (World Bank, 2014).

In this context, work is an important aspect for the population. There is an opportunity cost for people who have to leave work or school in order to access health services.

Any situation that contributes to its loss or limitation is perceived as an obstacle to its development and affirmation.

The key discovery

TB is already perceived as a disease of the poor. People with TB fear losing their jobs or being unable to work, which amplifies their precarious situation. As a result, there is a tendency to reject any initiative to screen for tuberculosis.

Description

All provinces, all walks of life, and all age groups have fears about the impact of illness on their financial security. But the fear of autonomy and financial independence impacts men and women differently. For men, the perception of loss of financial security is associated with social status and dignity, leading them to avoid screening and diagnosis. For women, however, it's more acceptable to take time out to rest before resuming their activities.

Quotes

"Maybe that mom sells her bread and doughnuts. As long as she's coughing even the customers won't buy anymore. It's already starting to affect his life...This isolation is going to block his activities especially since he's the hub in his house...and the children too are no longer eating well, they're no longer living well, it's bringing in a negative impact." - Male 18-34, Haut Katanga Urban

"Even if he contracts this [TB], he won't even have the strength to go to work. All his activities will be blocked. Like dad here...can't walk to get anywhere." - Woman 35-65, Kasaï Oriental Peri-urban

"Tuberculosis destroys a person's life...Some jobs that you could do, you won't be able to do...Work that requires a lot of effort you won't know how to do. That's what destroys a lot of people." - Woman 35-65, urban Kinshasa

"This disease people say is more complicated because other diseases such as malaria, the person can end up at home just a few days. But with [TB], it takes months...almost the whole eight months of treatment and the person is forced not to work. That's why people say it's dangerous." - Male 18-34, Kasaï Oriental Urban

The distance to the CDT and the cost of services at the health center

The problem

Not all health centers have the same capacity to screen for TB. Some centers have the screening tests and drugs to treat TB. There are distances to travel to access the CDT, which poses problems in terms of transport costs.

Across the DRC's 519 health zones, only 343 of the 2,700 CDTs have rapid tests, most of them in the big cities (Kinshasa, Lubumbashi). The others rely on traditional microscopy tests. Microscopy is not sensitive enough to detect new cases, but is rather used for case follow-up.

The country is also experiencing price inflation, even at the health center.

The key discovery

The community doesn't always have the means to pay to get to the TDC, so these obstacles are barriers to using the services. There's also a poor explanation of why TB services are free. The message needs to be clarified, as this creates a misunderstanding between patients and the healthcare system. Although drugs are offered free of charge, there are costs to be paid, such as transport and the consultation form, before finding out whether a person is infected with TB (to benefit from the free service).

Description

There are costs involved - transport, forms, and perhaps other tests that centers will order while waiting for TB screening results. Especially at first, the pace of visits may seem untenable for patients. This situation is exacerbated in peri-urban areas, where distances may be longer and means of transport more expensive.

Women seem to find it easier than men to get to and from the health service, but the costs are still hard to bear. They are sometimes accustomed to going there for prenatal consultations, childbirth and childcare. For young men in particular, these costs can seem the most onerous, as they are not used to frequenting health centers. For all, paying these fees seems like a "hidden cost" in seeking care.

Quotes

"What can prevent someone from being able to go to the center is] the means. You pay, you pay... But you're going to pay for the card. This form used to cost seven thousand francs... Today it's fifteen thousand francs." - Woman 35-65, Haut Katanga Urban

"He says to himself when he gets there [to the health center], they'll tell him first give for this paper, give the money for this form. Even if his treatment is free, the form comes with the money." - Male 18-34, Kongo Central Urban

"The others think that if they come to be screened they'll pay the money, because everyone wakes up with a different calculation. When you tell him to go for a check-up, he'll look at his cent franc and go and pay it there. He says I'm not sick, I'm not going. He's just waiting for the day he gets sick to go and get himself checked." - RECO, Kongo Central Urbaine

"The examination, as I come here, there's no way of knowing, because here they advertise that it's free. You can come here, the medication, you need money while the other doesn't have any. He still thinks it's free - tests and medication. We ask: he stays like that to wait and the disease becomes serious." - Male 18-34, Kinshasa Urban

Insecurity on the road - a major obstacle for RECOs

The problem/context

In general, we live in a country where insecurity is becoming more widespread. The manifestation of insecurity differs from province to province. These factors influence the use of services.

RECOs need to follow patients home, even several times. However, in Kinshasa and Kongo Central, there are dangers in moving RECOs between the health center and patients' homes. The success of the tuberculosis program depends on the work of the RECOs.

Densely populated neighborhoods suffer from infrastructure problems (water and electricity), which also facilitate insecurity. Poverty, unemployment, lack of electricity and water mean that banditry can be more recurrent in certain 'red' zones.

The key discovery

Insecurity on the roads, including the threat of urban bandits, is more pressing than TB control, particularly in the country's major cities.

Insecurity makes it harder for RECOs to follow patients at home. The RECO has to travel from his home, to the CS, and then to the patients, where he is perhaps less known. If he's the person who has to support others who are ill, he'll find it hard to follow them if he can't get to the neighborhood, or if he's afraid to get there.

Description

Insecurity is one of the most talked-about factors in the big cities of Kinshasa and Kongo Centrale. Even if everyone is at risk, the dangers weigh more heavily on young people and women, and insecurity disrupts the work of RECOs.

Quotes

"There's also the obstacle of ... the bandits there, the Kuluna...on the security front." -RECO, Kinshasa Urbaine

"If you look at insecurity, people are very afraid of this in relation to tuberculosis. We ignore tuberculosis, because we don't know how it manifests itself...whereas it has tuberculosis inside. Whereas if a person hears insecurity somewhere, he won't leave, he'll avoid getting there." - Male 18-34, Kongo Central Urban

"With the Kuluna* phenomenon, I don't think you're unaware of this, you know it very well. It's due to family poverty. Poverty leads to what I just said about drug addiction. Poverty leads to murders here and there. It leads to a lot of disorder. Even among young girls. - Leader, Kinshasa Urbaine

**Kuluna: Urban banditry with the machete as the weapon of choice.*

Dignity, masculinity, and gender norms

The problem

In the DRC, health facilities are often considered a women's domain. They are associated with pregnancy and child care. Men are generally less involved in these matters, and so rarely visit health centers.

In advertising and popular culture, masculine values of strength and ability to provide are often emphasized. Men are rarely portrayed as fragile, as they might be when ill.

As a result, social norms subtly punish men by preventing them from using health services and admitting their illness.

The key discovery

Care-seeking, including screening, is reinforced by gender norms according to which the health center is a place for women but rarely for men. Going to the health center is considered unworthy of an active, productive man. The disease itself is also seen as stripping the man of his masculinity - whose values are to be strong and able to support the family or act in its interests.

Description

Masculine values that discourage service-seeking are shared by all provinces, and seem more evident in peri-urban than in urban areas. Given the previous discussion of women's influence on men's care-seeking, the social norm of masculine strength seems to be perpetuated especially among men themselves. Young men may have the greatest interest in projecting an image of strength, and therefore have the most difficulty overcoming this norm when seeking care and treatment.

Quotes

"[TB] is a disease of shame in people's eyes...What are people going to say in the neighborhood? I'm already getting weak." - Male 35-65, Haut Katanga Peri-urban

"It's only men who are into these stories, shame and fear. But we women don't give a damn - we're not very ashamed." - Leader, Central Kongo Peri-urban

"Yes, some young people lack the means to do so, but others, on the other hand, don't want anyone to know they're suffering from tuberculosis. Even if there are effects, he'll camouflage himself. Young people like to camouflage themselves in the face of disease." - Woman 35-65, Kongo Central Peri-urban

"This tuberculosis disease in communities like ours is already a shameful disease... We're going to ban you. You don't live by yourself. You live - all your needs are put aside first." - Male 35-65, Kinshasa Urban

Suspicion of health workers and CDT for lack of confidentiality

The problem

In a context where the stigma of tuberculosis is strong, the desire for discretion is great. Patients may seek services further away from the community in which they live, or even give a false address to avoid health workers visiting their home.

In the health center too, patients are concerned by the fact that services are organized in full view of others, their diagnosis is discussed openly by providers, and with the knowledge of other patients. Interactions between health workers and patients constitute a barrier to care-seeking, screening and treatment.

The key discovery

People think that health professionals lack a sense of confidentiality, so that seeking care including screening and follow-up treatment is tantamount to revealing one's state of health to the community. But health workers want to offer quality services, and they respect the importance of confidentiality in TB case management.

Description

In all provinces and for both genders, participants expressed a desire for the provider to exercise discretion in healthcare matters. The issue of provider confidentiality was most often raised by older participants, possibly due to their past negative experiences using institutional services. This mistrust was raised more often in peri-urban than in urban areas, perhaps because peri-urban communities are less densely populated and information about each other can therefore spread more easily.

Quotes

"If they have a relationship with the doctor, when he goes there, he'll think he knows me. In other words, he thinks the doctor will tell people I'm sick." - Woman 35-64, Central Kongo Peri-urban

"The same person who gave me the medicine, he's starting to spread the information outside...it's still going to cause shame in me so that I'll come again tomorrow to take the medicine." - Male 35-65, Haut Katanga Peri-urban

"Tuberculosis as we talk about it is a shameful disease. Another can go to the place where they sit. It's said that people with the disease are here. The mere fact that you're sitting down means you've got it. Someone comes by and sees us like this. Other people can't digest these things." - Male 18-34, Central Kongo Peri-urban

"We don't bring a speech there, because in this work, they have our trust, meaning you couldn't bring a speech from someone who is sick here and there, we have discretion." - RECO, Kongo Central Peri-urban

Community stigma equals loss of support

The problem

Family support is generally strong in the DRC, and especially outside the major urban areas, communities and religious institutions are actively involved in supporting families.

However, when someone is diagnosed with tuberculosis, community members often distance themselves from them, leaving them isolated and without the psychological and material support they need to get through a long period of convalescence.

The key discovery

Tuberculosis sufferers are whispered about and shunned because of their appearance, symptoms (coughing), and suspicions of illness at the very time when patients need support the most.

Description

The fear of community members being informed of a TB diagnosis was common to all provinces. While women seemed to perpetuate gossip about the disease in the community more than men, men more often said they felt isolated if the diagnosis of TB became known. This may be explained by the fact that women generally benefit from family support, whatever their age. In contrast, young men in particular do not have a wide support network, and tend to rely on friends as well as family. The interplay between gender and youth makes young men more vulnerable to rejection. Geographically, concerns about stigmatization and lack of support were more often expressed in urban areas. It may be easier to avoid the gaze of others in peri-urban communities, and social relationships may also be stronger, so the perception of reduced support was heard less often.

Quotes

"People find that this person with tuberculosis, they tend to abandon him... You'll see that this person, even if they lived together with him, even if he's their friend, they'll start to move away from him." - Leader, Haut Katanga Urbaine

"The shameful ones are there because if you look at me, the shoulders have become like this [hunched shoulders]. [Your body is] diminished the way your friends had seen you." - Woman 35-65, Haut Katanga Peri-urban

"If [I catch] an anomaly...friends will flee, work colleagues will also search...how will you live?" - Male 35-65, Kongo Central Urban

"Maybe this mom sells her bread and doughnuts. As long as she's coughing even the customers won't buy...That's why she won't be comfortable in her usual environment and she'll be isolated." - Male 18-34, Haut Katanga, Urban

"Moms at heart already know everything. They know all the diseases. When they look at someone, they already attribute that it's such and such an illness. Now they're already slandering you." - Male 18-34, Haut Katanga Urban

Positive influence of wife, family or friends

The problem

In the DRC, women are considered the main guardians of health within the household. She is also seen as the person most responsible for meeting the health needs of family members. Among married couples, the wife often plays a supportive role in the husband's health and, given their day-to-day interaction, she can be an important whistle-blower in drawing attention to persistent health problems. Children can also raise concerns about the health of family members with their mother.

Women are often the main users of health services to care for themselves and their children. They can therefore be ardent supporters of these services when they perceive them to be of good quality.

The key discovery

Encouragement from family members, especially the wife, is the main reason why a person seeks care at the health center and gets tested for TB. Although the announcement of TB disrupts the family order, families have found ways to support their patients, especially during the initial period when the patient has to stay at home and take treatment without working.

Description

In all provinces, wives are seen as important players in encouraging the use of health services. For men, it's the wife plus a close friend who are involved in their support. And for women, it's the family who supports the whole process.

As age increases, the use of services may be more encouraged by both sexes, and some young adult patients living with their families reported that their fathers supported them in their care-seeking.

Quotes

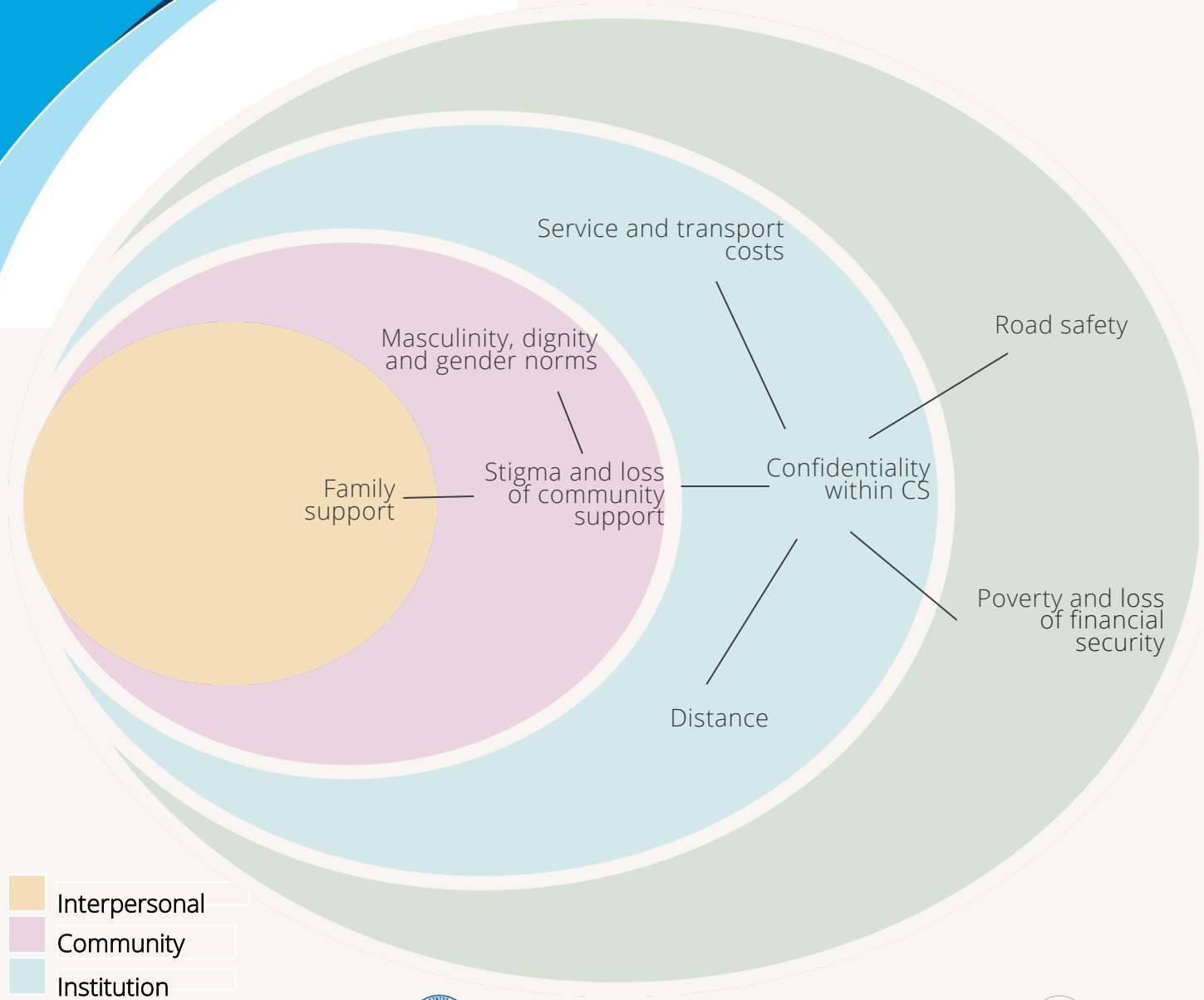
"Papa Christophe (the man in the scenario) has to tell his wife [that he has a cough] because she's very close to him; they share the same bed. She's the one who knows and understands how he spends his nights and how he wakes up too. That's how he can tell her this cough is bothering me a lot...come with me to the hospital." -Male 18-34, Kasaï Oriental Peri-urban

"If it was a man he's going to tell the woman, like the case of sickness for two weeks. Won't the kids observe that Mom's coughing and Dad's coughing? ...They can ask you that, 'We've been noticing lately that the cough's been hurting you a lot. Go ahead and tell Dad to go to the hospital. - Male 35-65, Haut Katanga Urban

"My children, my family members, my older sister who followed up on my treatment, my children would say to me, 'Mom do you have the medication? Aren't you taking the medicine? They helped me, even family members who came to visit me would ask, 'Do you have the medication?'" - Former patient Kinshasa Urbaine

"Yes, you know in life someone also has like my friend that I'm telling you here,... it's only my friend there that I had told that I have tuberculosis and after a while we came with him he came to accompany me." - Former patient, Kasaï Oriental Urbaine

SEM: COMMON FACTORS IN TB-RELATED BEHAVIORAL DETERMINANTS



The key findings discussed in this section interact with each other to form complex, multi-layered barriers to the adoption of TB risk-control behaviors. Facilitators of TB control behaviors must also address the needs of the individual who may be suffering from TB, as well as the intersecting challenges faced by the individual at community, institutional and structural levels.

Structural factors such as insecurity on the road to the health center are exacerbated by high rates of poverty in urban communities. Poverty has been associated with mining and the expansion of informal work sectors, which offer little financial stability and require a great deal of physical labor.

Poverty also increases the obstacles faced by community members in meeting the costs of health services, including transportation over the sometimes long and unsafe distances they must travel to reach the health center. Given these multiple difficulties in accessing services, confidence in the healthcare system has already eroded. Experiences and fears linked to the lack of confidentiality in health centers concerning patients' illnesses and situations further weaken trust in healthcare institutions.

Lack of confidentiality fuels community stigmatization and loss of community support for those who may be suffering from TB. Gender norms and expectations of men that prohibit the use of health services and showing signs of illness further exacerbate the stigma faced in particular by men affected by TB.

In the face of these intersecting challenges, the support of the family is a remarkable factor of solidarity, encouraging behaviors that favor the control and prevention of the spread of tuberculosis within the family.

Seeking care at CS

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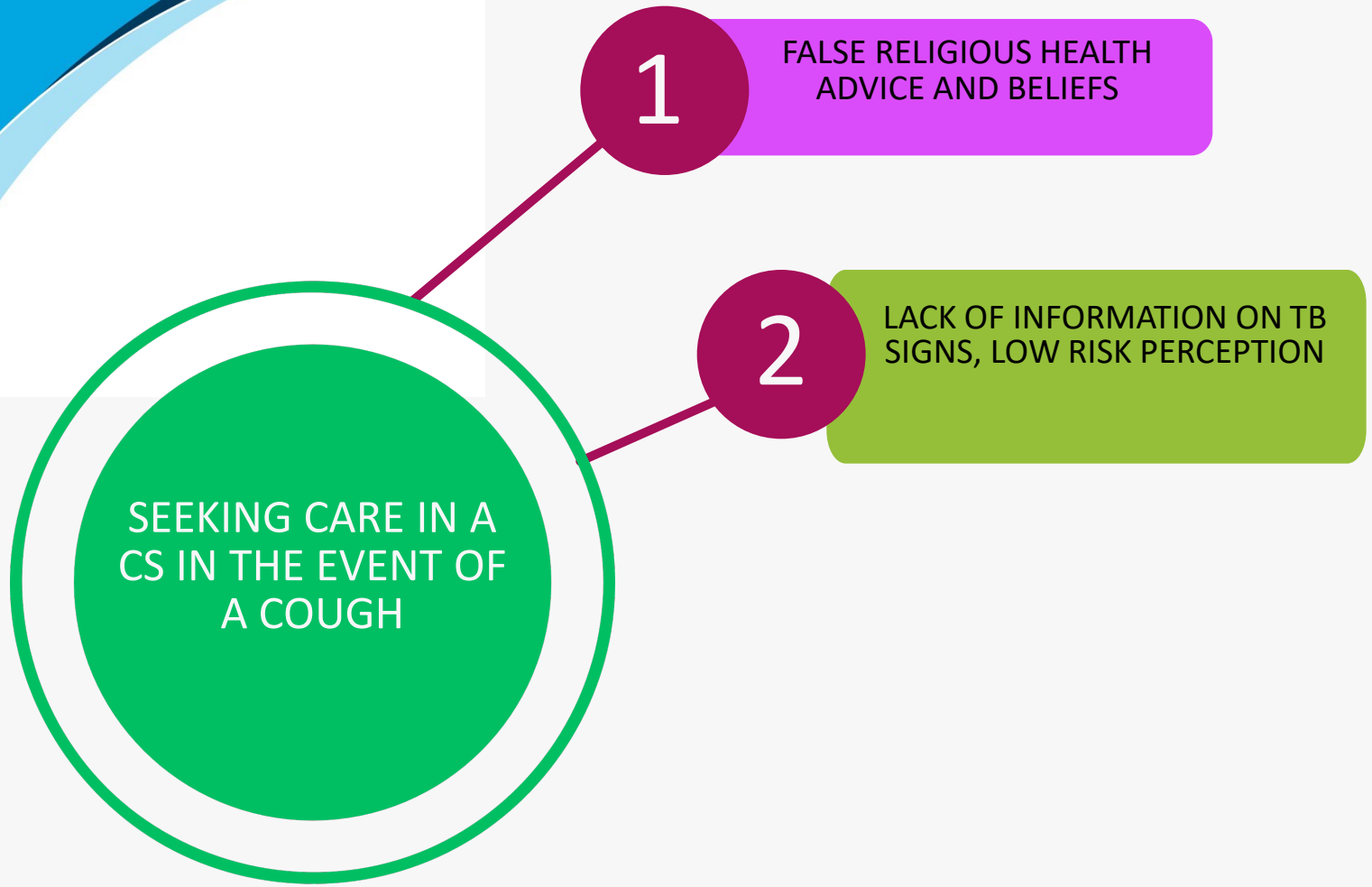


The first key behavior in the fight against TB is seeking care at the CS when coughing. In addition to the common factors presented in the last section, two other factors emerged as important in determining behavior at this stage of the TB experience.

False advice from the community and religious beliefs about health

The problem

Religion is strongly present throughout the country, with 49% Catholic and 35% Protestant and Revival (source: Vatican). Religious leaders consider that they have two responsibilities in their congregations: spirituality and social aspects. Health is part of the social aspects.

There is a perception that the source of TB is mystical. As a result, people turn to the religious for spiritual care and healing.

Key discovery

Since illness is believed to come from evil spirits, people believe that religious leaders can drive out evil spirits and cure illness. Some religious leaders believe they have the skills to cure any illness.

Description

The use of religious is almost universal, in urban and peri-urban areas, and across all age groups. In general, more women than men turn to clerics.

Quotes

"It was in the churches, among the prophets, that he went to weigh spiritual...'The illness you have is not tuberculosis,' there you were told. You're sick with a disease caused by evil spirits. - Leader, Kasaï Oriental Peri-urban

"At his prophet's house...He's going to tell him I'm going to pray for you...For you to have healing...For us to block your diseases. There, evil spirits." - Leader, Kasaï Oriental Peri-urban

Lack of information about the signs of TB, Low risk perception

The problem

In the community, there's a lot of misinformation circulating about TB, and providers aren't the first port of call for TB information.

This misinformation is a source of low knowledge about TB and therefore low perception of the risk and signs of TB.

This misinformation suggests that TB is transmitted by evil spirits or spells.

Key discovery

Lack of information leads to low risk perception. The first signs of TB (coughing, sweating, fever, weight loss) define the use of herbal teas and self-medication, based on local cultural practices and therapeutic experience. There are also sources in the community who communicate information that is not always recommended, leading community members to adopt these practices.

Description

These behaviors are recurrent in all provinces and in all environments, because they are practiced from generation to generation, and are perceived as the recourse of choice in both peri-urban and urban areas. These practices are less common among women, who are more likely to go to the health center. There is also no age difference in terms of lack of information.

The use of herbal teas and self-medication does not necessarily follow a pre-established order; these different treatments precede the visit to the health center.

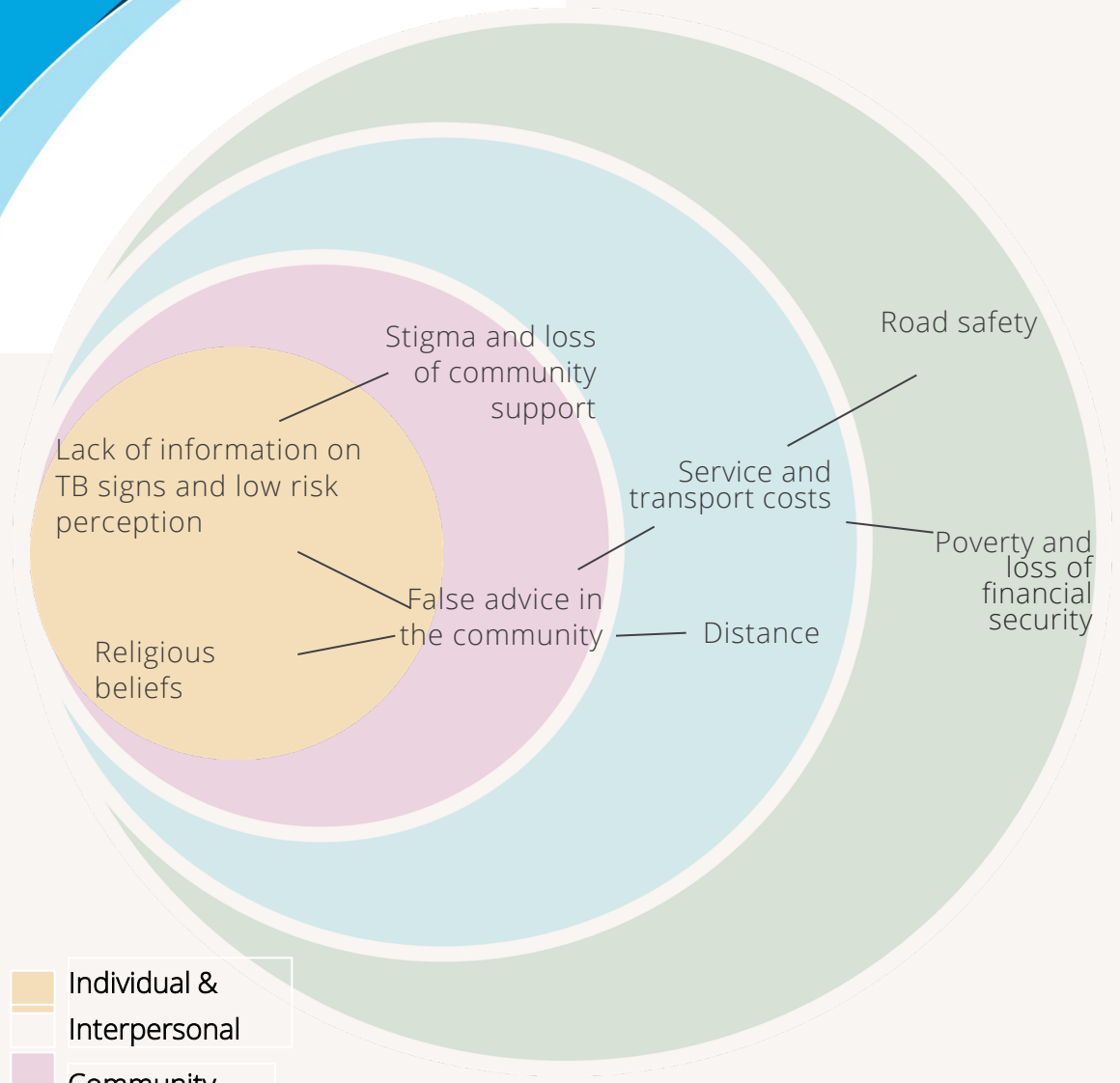
Quotes

"Traditional lemongrass plants, let her take the OCIMUM GRATISSIMUM, let her take the lemons, let her prepare all this even a cup to take for 2 days...If it doesn't always hold, she takes the lemons; six lemons, she takes the juice, she puts the sugar in the pot alone until it dissolves, she adds the lemon juice to this pot she drinks again." - Male 35-65, Kasaï Oriental Urban

"For me, the first thing to do is buy the tablets at the pharmacy and see what happens. If after taking the tablets you still don't feel well, you'll have to go to the hospital. - Male 18-34, Kasaï Oriental Urban

"If it starts with the child, you take the cotton leaves, you take them, you wash them, you boil them, you put them in a glass...If it's the child, give him the cure, in the morning in the cup, you follow...for two days, three days, the cough there will be calm. Conton leaves are very effective. - Leader, Kongo Central Urbaine

SEM : SEARCH FOR CARE



Two themes that emerged regarding care-seeking were a low perception of risk, linked to a lack of information about the sign of TB, and the influence of religious beliefs on care-seeking practices, often supported by false advice from community leaders, including religious figures. These themes are individual in nature, but are influenced at wider levels.

The constellation of structural challenges associated with poverty and insecurity increases the barriers associated with transportation costs and unforeseen expenses at the CS. Given these problems of cost and accessibility to the health center, alternative care is sought locally in the community, which may lead community members to turn to their religious institution and to traditional healers located closer by, who are perceived to be cheaper than the combined cost of travel and obtaining services at the health center.

The association of CS with TB and the stigmatization of TSP limit community members' perception of where they can seek acceptable advice when they are ill, i.e. from local religious leaders and traditional healers. However, these non-health agents are not trained to recognize the various signs of TB, increasing the risk of misinterpretation of the disease, allowing people to remain unaware of their risk of contracting the disease, and thus delaying care-seeking at the CS in the event of a cough.

Screening

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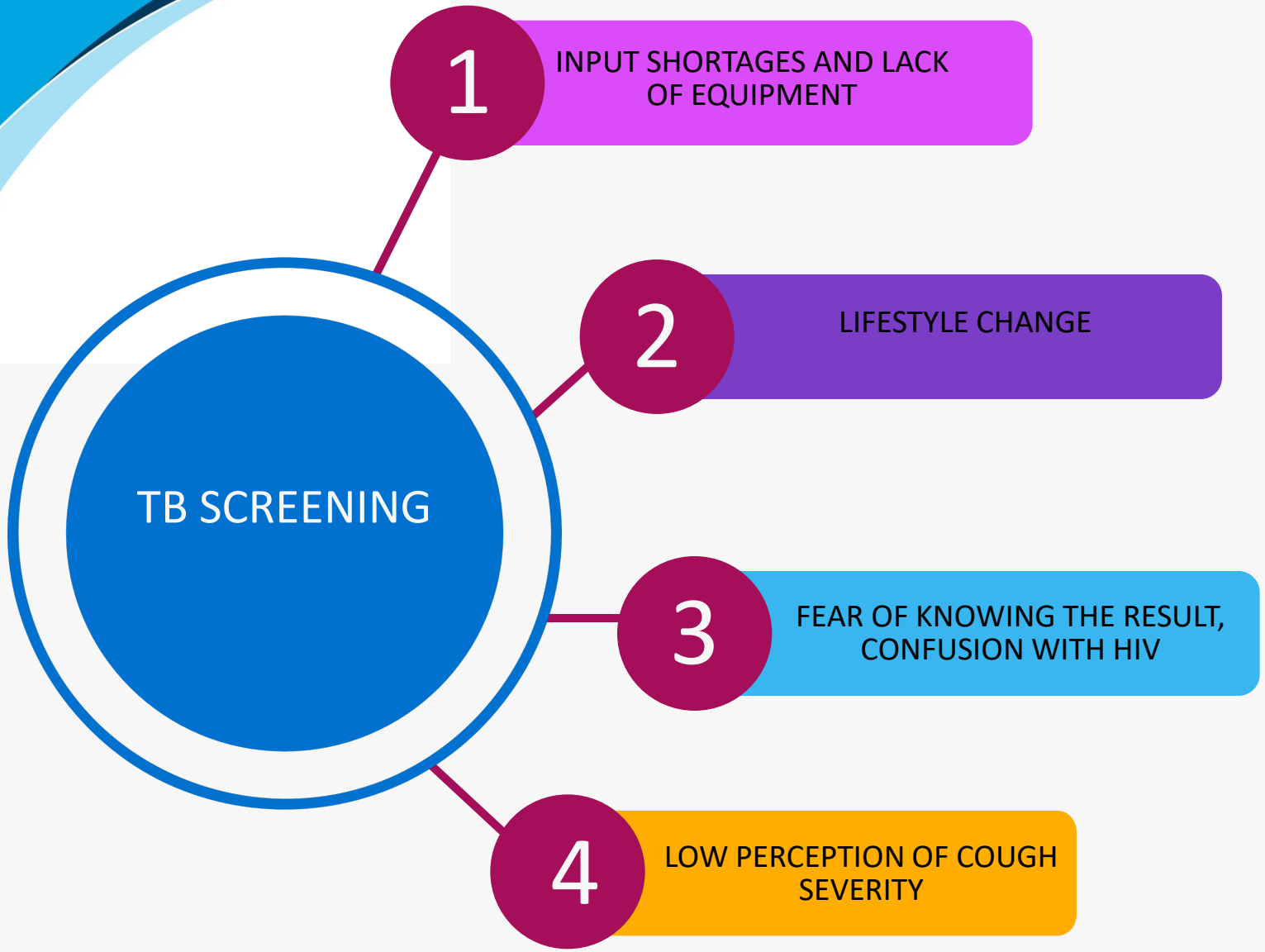


The second key behavior in the fight against TB is screening. In addition to the common factors that have been presented, four themes emerged as exerting an influence on the decision to undergo screening, on anticipated experiences, and on people's lived experiences at this point in their TB journey.

Shortage of inputs and equipment

The problem

In the DRC, the fight against tuberculosis (TB) is hampered by challenges linked to input shortages and lack of equipment in health laboratories. Microscopy and RDTs are all concerned.

This situation can compromise the effectiveness of TB screening and early diagnosis, with potential consequences for disease management.

Strengthening health infrastructures, ensuring regular supplies of medical inputs and equipment, and setting up efficient management systems will optimize TB screening and diagnosis.

The key discovery

Screening research can be confronted with input shortages and lack of medical equipment in screening laboratories. This leads to delays in waiting times and interruptions in the communication of medical results. This situation generates uncertainty, anxiety and worry among patients. These problems compromise the effectiveness of disease screening and diagnosis, and have a significant emotional and psychological impact on patients.

Description

These challenges were evoked in the provinces of Haut Katanga, Kassaï Oriental and in both urban and peri-urban areas. Older men mentioned the anguish caused by the delay in communicating results.

Quotes

"The difficulties can be that the bottles are sold out. That's what handicaps us. Also, as blades are not ready, and Methylene Blue, boxes to shelter. That's what stops the work. - Service provider, Kasaï Oriental Urbaine

"After the screening we have a result in twenty-four hours ...if there are no problems ... such as power interruption, ... we miss blades. ...spittoons, we sometimes miss that too."" - Service provider, Haut Katanga Urbaine

"I was sad, I said to myself, it's...it's what disease they're telling me to go ahead and come back only tomorrow, because they stayed with all the tests,...I came back still sad, instead of answering me only once and for all, ...they're telling me to come back tomorrow..... I always came home sad because I didn't know what the result would be" - Former patient, Kasaï Oriental Peri-urban

Lifestyle change

The problem

TB treatment requires the observance of certain restrictions which should be changes adopted for life, such as not smoking, not drinking, not eating a lot of chilli, and resting. The impression of having to adopt a different lifestyle serves as a psychological barrier to screening, and later to treatment compliance.

Men anticipate having to change their lifestyle following diagnosis. However, young single men in particular find it difficult to accept this change in lifestyle, as it reduces interaction with their friends. Patients don't understand how these restrictions will benefit their recovery.

The key discovery

The community's perception is that TB testing and treatment lead to the abandonment of their lifestyle in the long term. Restrictions deprive them of preferred activities. This attitude is reinforced by peer pressure, and the obligation to abstain from social life.

Description

This change in lifestyle is equally perceived in urban and peri-urban areas, and in all provinces. Men, and particularly younger men, most often cited lifestyle changes as an obstacle to testing and treatment compliance, probably reflecting social norms that encourage men to participate in social gatherings outside the home and women to be more family-oriented, whatever their age.

Quotes

"A person doesn't like to be deprived of freedom. Already your freedom will be curtailed. Why? ...You've got tuberculosis and...your courtship will diminish. No matter how much the person loves you...don't get close to him. Because she has this disease." - Male 18-34, Kongo Central Urban

"Look how we young people are here, she's going to take you a six-month course of treatment...you don't move...so you're out of the world first...it's only like half-dead." - Male 35-65, Kinshasa Urban

"We were asked to be disciplined, not to interrupt care, not to take things of a nature to compromise medical care." - Former patient, Haut Katanga Peri-urban

"But if someone doesn't take the medicine, he's proud...which I've realized. When he finishes taking the medicine...he's a slave to drink, he continues with these things, then he goes back to tuberculosis." - Provider, Kongo Central Urbaine

Fear of knowing the result, confusion with HIV

The problem

The two diseases - TB and HIV - are often screened together. Even the services are often offered jointly. This pairing of the two services, and the requirement for presumptive HIV testing, leads to confusion that the two diseases are identical. The idea of HIV becomes a psychological barrier to TB screening, as these services are perceived to be for people who are closer to death. Often, these diseases are linked to behaviors considered bad or shameful.

Fear of being associated with HIV services is one of the psychological barriers to TB testing, influenced by the way services are organized.

The key discovery

People don't want to seek screening for three reasons: TB is associated with HIV, HIV is associated with death, and both diseases are perceived as the result of bad behavior. As a result of these perceptions, TB/HIV patients find themselves in a situation of social isolation. For fear of losing everything, patients prefer not to know even if they have to die.

Description

Fear of the outcome was felt in all provinces and environments to varying degrees. Young and old alike expressed fear of the result and of knowing the diagnosis. Women, although more inclined to use health services for screening, evoked this fear of TB, with its consequences of social isolation.

Quotes

"Taking the results] I start asking myself a thousand and one questions. What will the results be like? What will the people around me say if the result is positive? Will I be alive? ... more questions are going through my head, and they're pushing me to get to the end of the line, and they're telling me to stay put." Woman 18-34, Kongo Central Peri-urban

"If I get caught, I'll be penalized. I'll be isolated. If I already start thinking, how was my life, and how will my life be? It's going to scare me.... To deprive myself of this freedom, it's better that I stay with the disease." - Male 18-34, Kongo Central Urban

"In any case, frankly doctor, I tell you, when I was told I had tuberculosis...My concern was that I would only commit suicide...That I would commit suicide because the way I had heard about the disease." - Former patient, Kinshasa Peri-urban

"Everyone is afraid of the disease [TB]...that the disease is the brother of death." - Leader, Kasaï Oriental Peri-urban

Poor perception of the severity of a cough, waiting for symptoms to worsen

The problem

PATI-6 requires providers to test all coughs. But the public is simply encouraged to go to the health center if they have a cough. It is therefore expected that people will try to relieve the cough before deciding to go to the health center. However, the unstated hope is that the delay will be minimal - around one to two weeks.

Coughs can have many causes, some related to the environment, others to illness. As a result, the perceived seriousness of a cough is low. Although it is one of the best-known signs of TB, coughing is not thought to be a strong reason for seeking care. So recourse to the health center becomes necessary only for other, more serious symptoms.

The key discovery

In general, coughs are not considered so serious as to require a visit to the health center. So, the first recourse is to herbal teas and then to the pharmacy. But if the treatment is ineffective, we turn to the health center.

Signs of severity are related to the duration of the cough, and the worsening of symptoms such as coughing up blood (hemoptysis) or sputum, sweating, and others that prevent daily activities and work. However, signs of severity are interpreted differently from one household to another.

Description

The low perception of cough severity is similar from province to province. Women worry about a cough earlier than men, and are more inclined to use so-called natural remedies first to relieve their cough, followed by recourse to the health center. Men seem more inclined to self-medicate their coughs. Parents of young children (0-5 years) may start by using a home remedy to relieve an infant's cough, but the perception of severity is higher and motivates a more rapid recourse to care. Few differences in perception were observed according to environment.

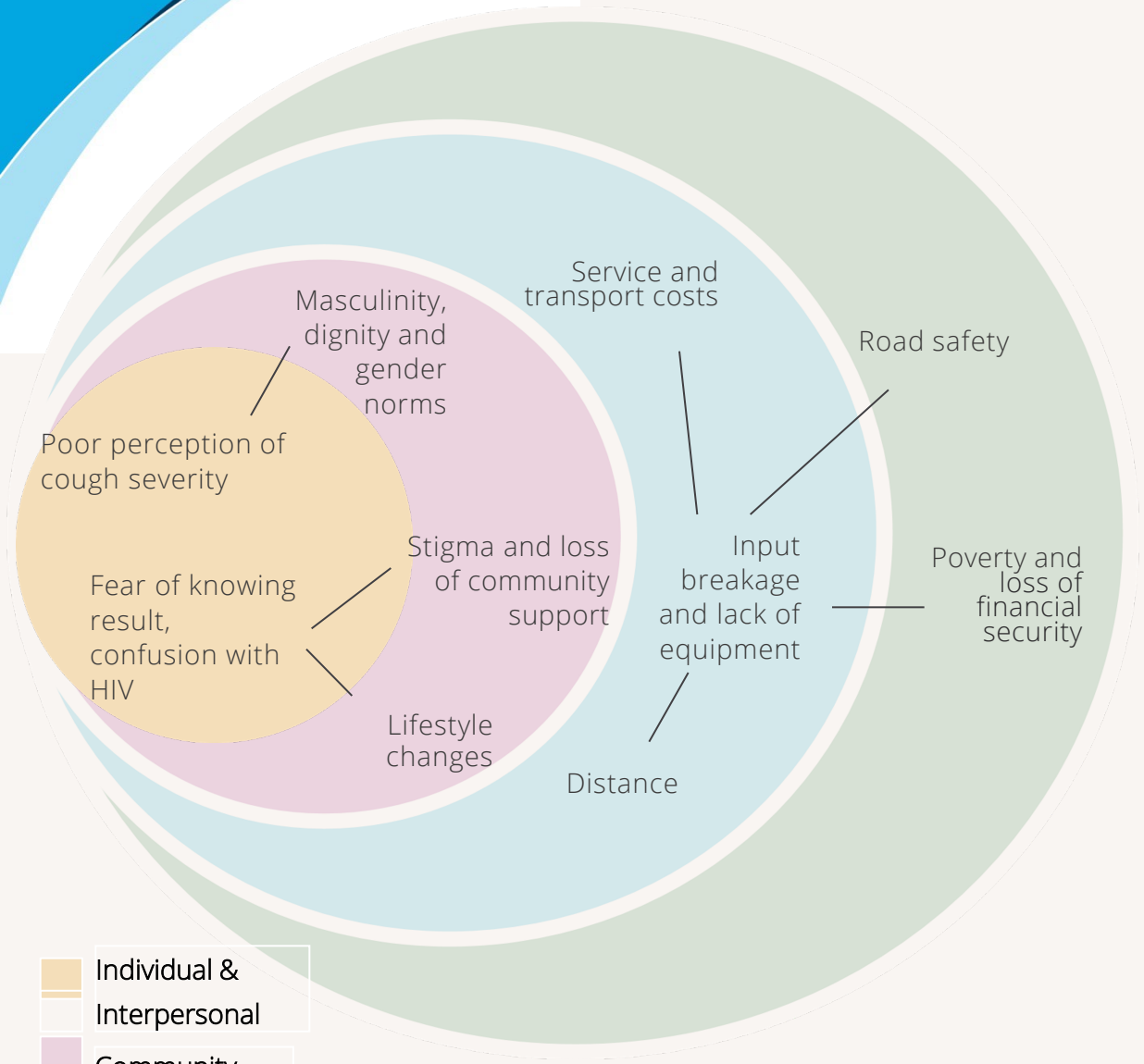
Quotes

We Congolese have more confidence in our *"nikanga bakichi"* [leaves, a traditional treatment]. The person starts coughing, you'll see, even small children with fever, you just tell him to take a pile of *bakichi*, well with the oil...before we come to detect if that cough is there...so that we know if it's what kind of cough." - Woman 35-65, Kinshasa Peri-urban

"It's different because that person is no longer going to work... You'll see that this person doesn't even have the strength to get by."- Leader, Kasaï Oriental Peri-urban

"There are certain coughs - if you cough the sputum comes out...if you cough it brings out the blood, that's not a good thing. Even yourself, when you see the symptoms in yourself, you'll say I'm not well, I need to go and get the doctor." - Male 18-34, Kongo Central Urban

SEM: SCREENING FOR TB



Poverty and other structural barriers to the use of services exacerbate the difficulties associated with a lack of rapid testing equipment and input shortages, adding to the burden of TSP by delaying the receipt of test results and the start of treatment.

Concerns about lifestyle changes, compounded by community stigma towards TSP, increase people's level of fear about receiving their test results. As the waiting period lengthens due to the time required to obtain the results of the microscopic examination, fear can intensify and create a greater psychological barrier to continued use of services.

These factors may come into play in the context of an already delayed care-seeking response to screening, due to the perceived low severity of the cough. Masculinity norms further discourage men from considering a cough to be serious, further delaying screening.

Results announcement and contact search

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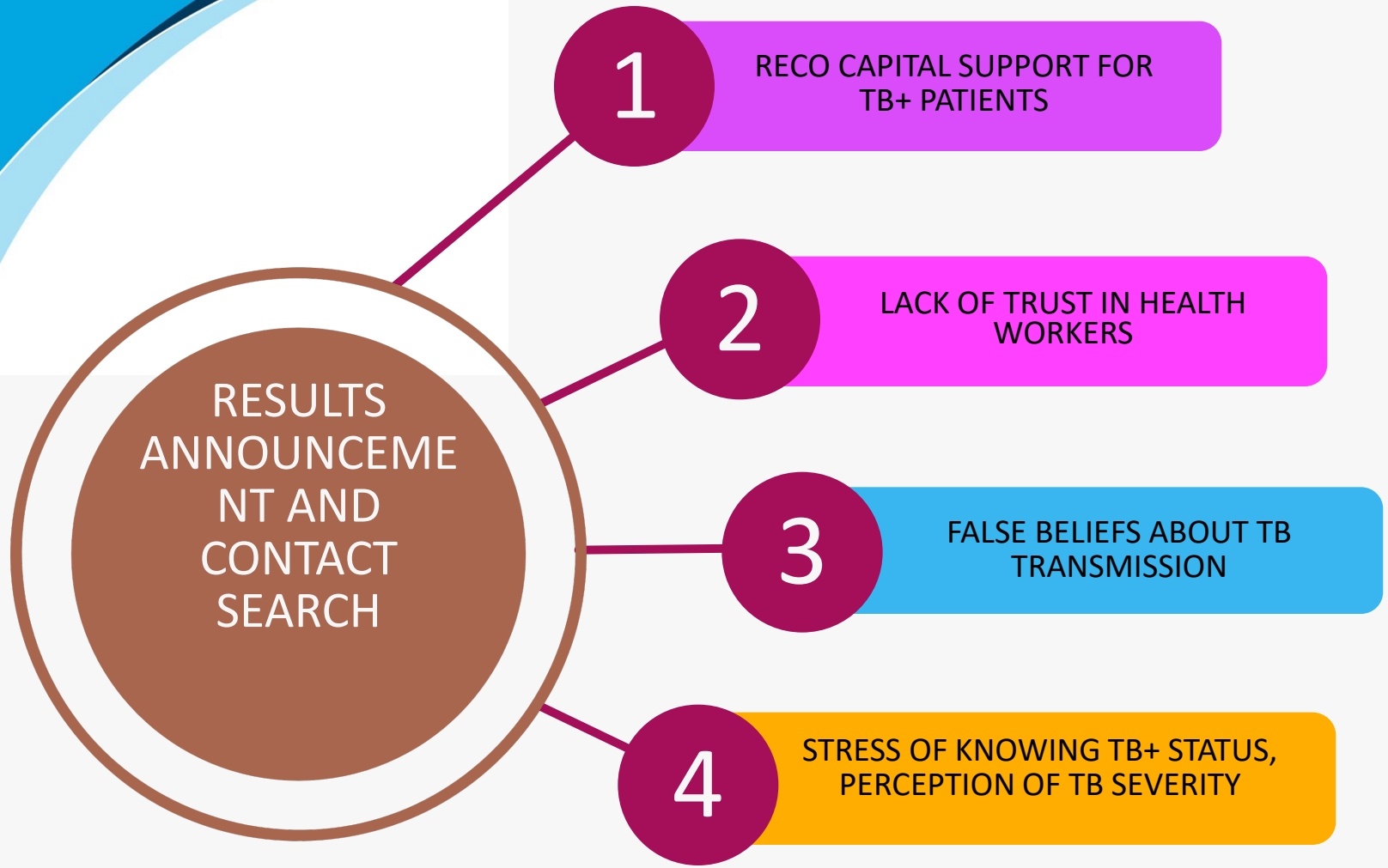


The third key behavior in the fight against TB is the announcement of results in the home and cooperation in contact tracing. By its very nature, this is a social behavior. In addition to the common factors presented, four themes have been identified at this stage of the TB journey as influencing this key behavior.

RECO support is crucial for TB+ patients

The problem

The TB version of the Community Relais (RECO) is a health system executive whose job is to refer suspected TB patients to the CS with a BILO, follow up TB patients who need treatment to limit the spread of the disease, and contribute to the NTP's goal of eliminating TB by 2030.

Although RECOs are volunteers (with no salary), their work is recognized by all as key to achieving results in the fight against TB.

The key discovery

The RECOs' constant, positive support of patients helps to create self-efficacy in patients to overcome TB. However, their work is not always easy, and this positive relationship takes time to develop. Early case-finding is complicated by initial resistance in the community and in the families of affected members. Despite the often difficult conditions, the RECOs show empathy towards the sick, so as to continue their much-appreciated work.

Description

RECOs are appreciated for their work, throughout the study provinces and communities. Verbatims from leaders and former patients describe this appreciation for RECO support. They provide positive support to the family.

Quotes

"The advice was often, calm my mind, follow the treatment and don't neglect, as I started my treatment." - Former patient, Kongo Central Urbaine

"Always talk with the kind of person...You talk, then you create a relationship...you know this person is complicated, you will look for a way by which you could reach him easily.....you tell yourself that right now here this person may be hungry, you look for something, one thousand francs, two thousand francs you give it to him...you will see that he will be nice to me." - RECO, Kongo Central Urbaine

"There are difficulties we encounter. [The] head of the household... points out to you the other members of his household, some of whom don't agree to go to the health center... the community relays can... provide them with explanations of the dangers that can happen if they don't prevent this disease. Show them the advantages of following the treatment... but you find that some people in the household and even in the immediate environment don't want to come to the health center. You have to be able to force them to go." - RECO, Kasaï Oriental, Peri-urban

"Some people will give you the real addresses... another person will give you a fake address..." - RECO, Haut Katanga, Peri-urban

Lack of trust in health workers

The problem

The cost of healthcare services presents an obstacle to seeking care. It is imagined that health service providers or RECOs take advantage of spitting to make more money. Sometimes the integrity of the healthcare provider is called into question.

These feelings may be fuelled by a lack of understanding of the symptoms of the disease and concerns about the reliability of tests.

The key discovery

The lack of information about how sputum samples are processed creates suspicion about what is done with these specimens. There is also an association between TB testing and distrust of the health workers who represent the health system. This distrust of the system makes them reluctant to cooperate with contact tracing.

Description

Given that men account for the largest number of tuberculosis cases, and in their capacity as heads of households, it is often they who bring the health worker to the home to begin contact tracing, which includes sputum collection. At the same time, some of them have a certain distrust of the health system. It's not clear whether the same feeling exists across age groups.

Quotes

"I've seen people walking around households, telling me to give them spit. So when they take the spit and leave with it, it's so they can go and put on other witchcraft diseases, (Laughs) so they can earn money. When they take this, it's so that they can add their own things to make money. - Leader, Kasaï Oriental Peri-urban

"They had taken the spit. [To do what with?] ...I don't know what they had done." - Former patient, Haut Katanga Urbaine

"They [health workers] are very snitchy. Some want him [the patient[to be sick, [so] it's a secret between him and the doctor. But some nurses: 'That guy's got tuberculosis. You have to be careful with him.' We all teach it to the nurses." - Male 35-65, Central Kongo Peri-urban

The false beliefs of TB transmission

The problem

Patients are often forced to resort to TB testing, to finally find a solution to their health problems. Often, patients have suffered for days or even weeks without being tested. Despite the delay in seeking care and testing, positive cases are bitterly disappointed by the results.

On top of this resentment, instead of being able to keep the diagnosis to themselves, they have to digest the news, share it with their family and encourage other members of the household to get tested. Moving from a mindset of stigmatization and denial to one of defensiveness is difficult, especially when they don't know exactly how they contracted the disease and how it might be transmitted to other members of the household.

The key discovery

Poverty creates conditions where people don't get enough to eat, work under difficult conditions, and fortify themselves with alcoholic beverages, cigarettes and even drugs. These behaviours are detrimental to the health of those infected with the TB germ. However, it's a mistake to believe that the source of infection is drink or cigarettes, or even heavy work. As a result, TSPs are held responsible for bringing the infection upon themselves.

Description

In general, young people in Kinshasa and Kongo Central are more at risk of coming into contact with the TB germ, given their behavior (living in communal courtyards, living in large families and sharing narrow spaces for smoking and drinking) - i.e., rather urban environments. But in Haut Katanga and Kasaï Oriental, we understand that the risk factors are more related to working in quarries or mines, which are peri-urban environments. Men are more likely to be infected than women in these environments, but there are women who wash stones or do other work in the mines, so they too are exposed to TB. Regardless of sex or age, there are false beliefs about transmission, and TSPs are made to feel guilty for contracting the disease.

Quotes

"For me, tuberculosis is a disease of the poor. - Provider, Haut Katanga Urbaine

"If we ask who has tuberculosis, we already know that it's those who drink a lot and smoke a lot. - Woman 18-34, Haut Katanga Urban

Over sixty percent of young people give themselves over to alcohol. But alcohol can also cause tuberculosis. It destroys the lungs. Many young people give themselves over to alcohol, cigarettes, hemp and very strong stories. That's how you see how widespread tuberculosis is." - Male 35-65, Kinshasa Urban

"Why is tuberculosis so prevalent? First of all, people work hard, they don't eat much, and this food is also a bit inadequate. People don't eat properly. You see Mom, since she went out hungry in the morning, she comes home in the evening and can't find anything to eat. So these worries can also increase tuberculosis. - Woman 35-65, Kinshasa Suburban

The stress of knowing one's TB+ status, strong perception of the seriousness of the disease

The problem

The treatment policy for people suffering from TB has evolved in the DRC. In fact, almost 100% of people who are screened have started treatment, and the treatment success rate is 95%. But at community level, people are not aware of this evolution.

here is a misunderstanding that, once detected, patients can be treated and cured. In fact, in the past, patients were isolated, with treatment lasting longer. These notions remain in the minds of people in the Congo. The result is that the diagnosis of TB continues to create feelings of fear and anticipation of stigmatization and death, even if it's undeserved.

The key discovery

The announcement of status is accompanied by shock and emotional stress. Although people have often been suffering for some time, they have no idea that this could be TB. They don't imagine that close friends or family could serve as a source of support. And they don't imagine that they can be cured.

Description

A TB+ result is perceived as stressful and painful across provinces and backgrounds. Women were more likely to report stress. But, in the study, former TB patients of all ages and genders showed their feelings during the announcement and all expressed that it creates stress. Leaders, speaking on behalf of the community, also seemed to recognize the stress experienced by the patient given his or her status.

Quotes

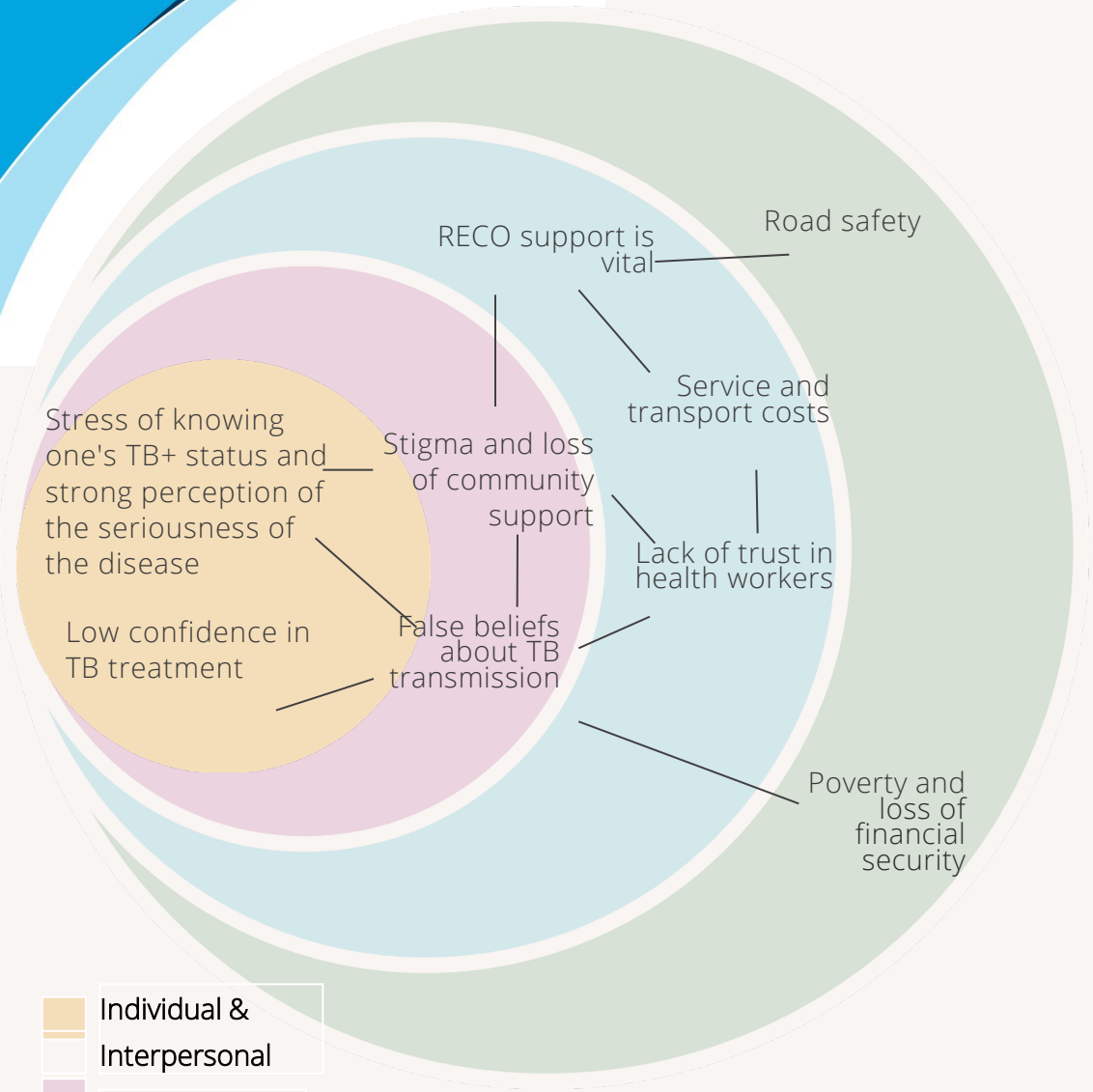
"In any case, frankly doctor, I tell you, when I was told I had tuberculosis...My concern was that I would only commit suicide...That I would commit suicide because the way I had heard about the disease." - Former patient, Kinshasa Peri-urban

"If a person has it, as I've just said, they'll be in isolation. And if they're a bit isolated, or the disease puts them in isolation, you can see that no, that person has to be quarantined, that they have to be there first. That's what causes a certain amount of shame when that person has tuberculosis." - Leader, Kinshasa Urbaine

"So if anyone even hears the word tuberculosis, they already see death!" - Leader, Haut Katanga Urbaine

"Sometimes you learn that someone died there because of tuberculosis." - Woman 18-34, Haut Katanga Urban

SEM: STATUS ANNOUNCEMENT AND CONTACT SEARCH



Many structural and community factors influence the experience of RECOs in the fight against TB. Like patients, RECOs have to overcome barriers of insecurity and cost of transport to move between the CDT and community members in order to act as a bridge and offer routine support, particularly to households with TSP. The role of RECOs in supporting TSPs is vital, but their initial presence can be misinterpreted and seen as detrimental, as it stigmatizes the family and household. Over time, the RECO can play a major role in helping the TSP and household to combat community stigmatization, and in imploring friends and relatives to provide stronger support.

Lack of trust in health workers, particularly when collecting sputum, is a particular example of the negative feeling RECOs have to endure at the start of their relationship with a public health team household. Suspicions may stem from a lack of familiarity with the health worker and reflect a lack of trust or previous perceptions of the health system taking advantage of the sick. It also reflects their lack of confidence in the confidentiality that health workers accord to their health status.

Given the conditions of poverty and the adoption of adaptive behaviors that weaken the body and make it more vulnerable to the TB germ, there is some confusion as to how TB is transmitted. This is reflected in the suspicion that health workers who collect sputum are introducing the infection, as well as in the negative associations people develop towards TSP and their guilt for the actions that caused the infection. The desire not to be judged negatively, and the fear of seeing the community marginalized, add to the lack of understanding of the source of the TB. The result is a high level of stress during the period of status announcement and cooperation in contact tracing. Overall, this may also reflect a lack of confidence in TB's ability to be treated and cured.

Treatment follow-up

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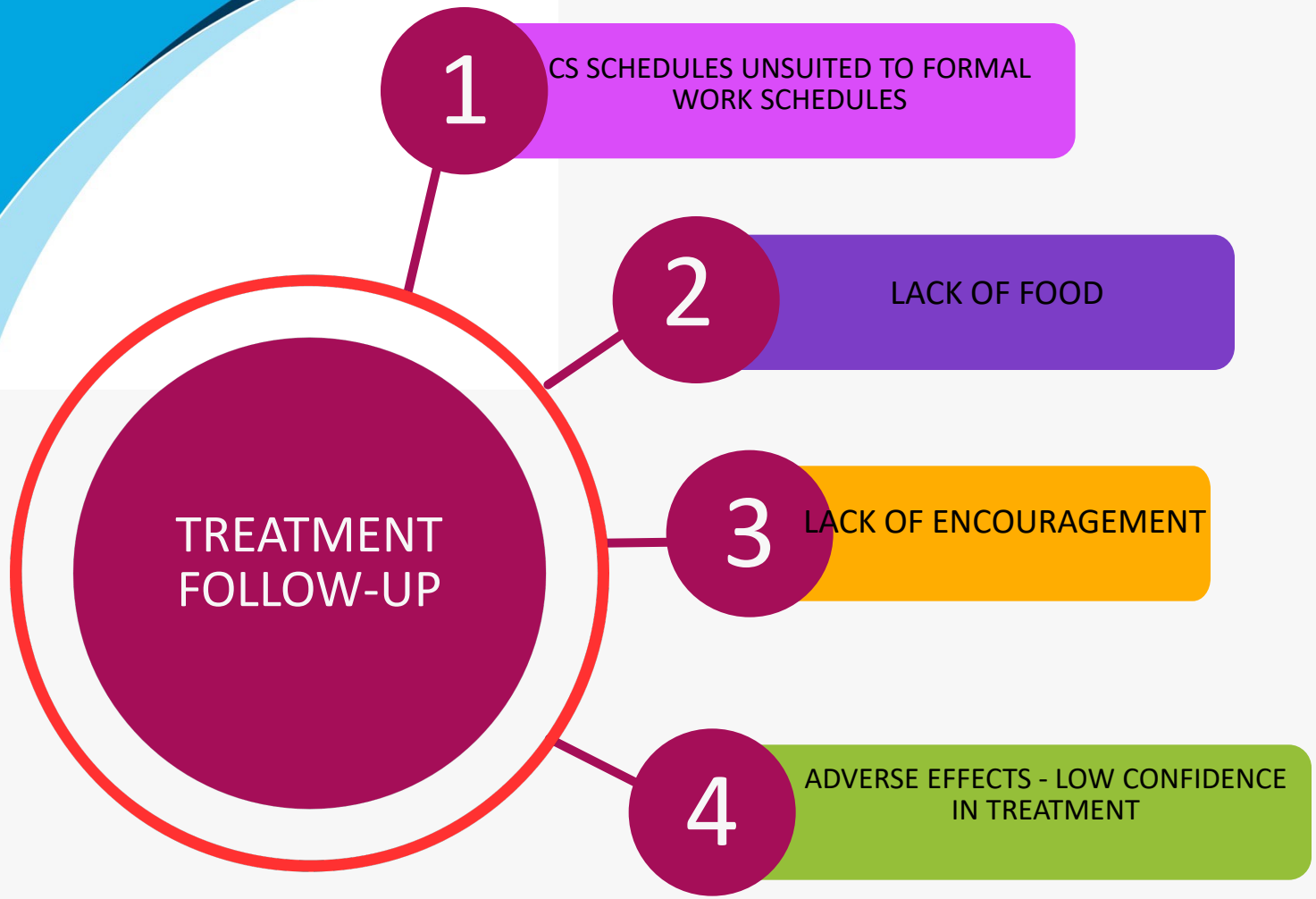
FOR SOCIAL & BEHAVIOR CHANGE



The final key behavior in the fight against TB is treatment adherence. Common factors related to access to CS, gender norms, community stigma and family support continue to play an important role in this behavior. In addition, four other themes emerged as particularly important at this stage of the TB journey.

Inadequate scheduling at CS for formal work

The problem

Treatment schedules are difficult to adhere to. Patients have to arrive very early to take fasting medication, yet these very early hours are perceived as restrictive. But this is simply the application of Directly Observed Treatment (DOT), the key to success in the fight against TB.

RECOs and CDTs can provide letters to employers for exemptions from work due to illness, but employers can still put pressure to arrive on time.

Informal sector workers, who are more often women and people of low socio-economic status, may have more control over their working hours. But this limits their earning power.

The key discovery

If the CDT doesn't make it easy for patients to take the treatment early, they arrive at work late. Over time, this situation creates tensions within the workplace, as the reasons for lateness are not discussed. Workers then have to choose between taking their treatment or keeping to work schedules. This has the effect of choosing work over treatment.

Description

Former patients from all provinces reported difficulties in managing treatment schedules while meeting other commitments. These difficulties seem to stem from both peri-urban and urban environments, but can be compounded by distance and increased transportation costs in peri-urban areas. Men most often reported that treatment schedules were a challenge for them, probably because their work may take them away from home and offer less flexibility for start times. The issue of treatment schedules was raised more urgently by working-age patients. While it's possible that schedules pose problems for young people who go to school, this issue wasn't raised by former student patients who were attending classes.

Quotes

"If another time improvement...Since we only put these medicines in at 6am, isn't time improvement possible!" - Former patient, Kinshasa Urbaine

"But what I hadn't liked now that since I'm already standing up...they want me to come every morning, I come from [a neighborhood far away], I come here? I had seen [coming back every day] as a difficulty." - Former patient, Kasaï Oriental Peri-urban

"If you [providers] start late, people [patients] will surround. And to do the distribution it will still be a problem. And that creates more noise." - Leader, Haut Katanga Urbaine

"Of all the time I took the medication, six months, I gave myself a two-month leave [from work]." - Former patient, Kasaï Oriental Peri-urban

Lack of food

The problem

During treatment, it is necessary to eat more than usual. The drugs increase patients' appetite, and as they fight the disease, the body weakens and needs more protein and calories. The extra food in turn helps the drugs to work more effectively. However, young men don't always have the means to eat more, and if they don't have support from family, friends, the community or other systems, they can't follow these treatment tips, and that discourages them.

Efforts have been made in this area, but dietary support only concerns patients with MDR/XDR-TB. However, the majority of TB cases are simple TB.

The key discovery

Patients know they have to eat after taking their medication. But they don't have the financial means to buy food, nor the time to go home and eat before starting their day. Not eating enough, they feel hungry and weak, and see no evidence of improvement.

Description

Lack of food was a concern in all provinces and all walks of life. This situation was more often noted by men, perhaps because women are closer to the kitchen and can therefore more easily find something to eat. Compared to other age groups, young children aged 0-5 have more nutritional support from their parents. Usually if a young adult lives with his or her family there is support for eating, but otherwise they are very preoccupied with this obstacle, which also suggests a fundamental unmet need as they begin to lead an independent life. As TB is perceived as a disease of the poor, this explains the lack of resources for food and medication, compared to patients from wealthy households who will take steps to ensure that the patient is well nourished to ensure recovery.

Quotes

"Now I have this disease. Now I take the medicine on an empty stomach. Now won't his medicines create other illnesses for me?" - Leader, Kasaï Oriental Peri-urban

"The medication] requires him to eat more. When you take it without eating, it weakens him even more. He can't even go out and fend for himself." - Male 18-34, Kasaï Oriental Urban

"It's free, but the treatment, eat first...When he drinks the medicine, he has to go home and eat...but eating in question, he doesn't have the means." - Male 18-34, Central Kongo Peri-urban

"Yes the rich family, I think they're going to put all the means possible...Very well eat. A TB patient, as far as I know, he can have [enough food], but you're going to see that his health is not really going to deteriorate in a rich family." - KIN_U_LEAD

No intermediate incentives

The problem

There are many challenges and changes to endure during treatment, especially during the first two months. At the very start of treatment, patients don't necessarily feel better immediately. Faced with a long course of treatment, there is no solid proof of the treatment's efficacy.

Even if he sees a health worker every day, he may have to wait two months before his first medical visit to obtain information on the state of his illness and recovery. While it's not possible to declare a cure, small steps forward are visible and can be monitored to reinforce belief in the efficacy of medication.

The key discovery

We still believe that TB is a disease that kills, and we don't know that drugs exist to treat it, or even that we could be cured. Knowing that TB can be treated and cured, and the promise of feeling better, gives hope and encourages adherence to treatment, but in the early stages of treatment it can be difficult to see this progress.

Description

Across provinces, geographies, genders and ages, community members spoke of tuberculosis as a disease that can kill. Similarly, in all segments, former patients often remarked that a return to health is proof that the drug works. Most of them described a return to health as their main motivation for continuing treatment to the end. The evidence could be small, such as weight gain, increased energy, or hearing less coughing. Any small improvement can help sustain the patient's commitment to treatment, especially in the first few months.

Quotes

"The moment when you're-you're going to start seeing the change...You see, you're back, life comes back to you. So in that sense of seeing your reality, that the treatment works. It works. - Leader, Kongo Central Urbaine

"When I'd leave [for the hospital], people [in my community] would say, you've put on weight, you've put on weight. Well, I went to get weighed, they tell me you haven't really increased in weight. That discouraged me again, and I thought, this drug isn't helping me or how. [But it was] my grandmother who had encouraged me a lot, that the medicine, it's little by little that it treats." - Former patient, Haut Katanga Peri-urban

"To convince him [of the efficacy of the drugs] you're going to go back to the new case in that family, to tell him, 'Did you see how your brother recovered his health?'" - RECO, Kinshasa Peri-urban

"At first, the body had no strength. But when the product went in for the next two weeks, I then felt balance in my body." - Former patient, Kinshasa Peri-urban

Drug side effects, confidence in treatment

The problem

Patients lack the self-efficacy to deal with adverse treatment effects, especially during the first two months of the intensive phase when drug dosage is at its highest. The smell, size and taste of the tablets are also difficult to cope with.

The dose of medication is based on the patient's weight, so heavier men than women are often prescribed more tablets per day. Because of this lack of self-efficacy, patients may drop out of treatment before the end.

The key discovery

Because of the side effects, young men think the drugs are making their tuberculosis worse and sicker.

Description

The lack of ability to manage adverse effects is common to all provinces and geographical areas. Men seem to complain more often than women about the effects of medication, which may be due to the fact that they have to take more pills at once. Compared to women, men - especially young men - may be less accustomed to taking medication and therefore very sensitive. Women, on the other hand, who receive a number of medications during pregnancy and are more accustomed to taking medication for a longer period of time, may be more tolerant of this discomfort.

Quotes

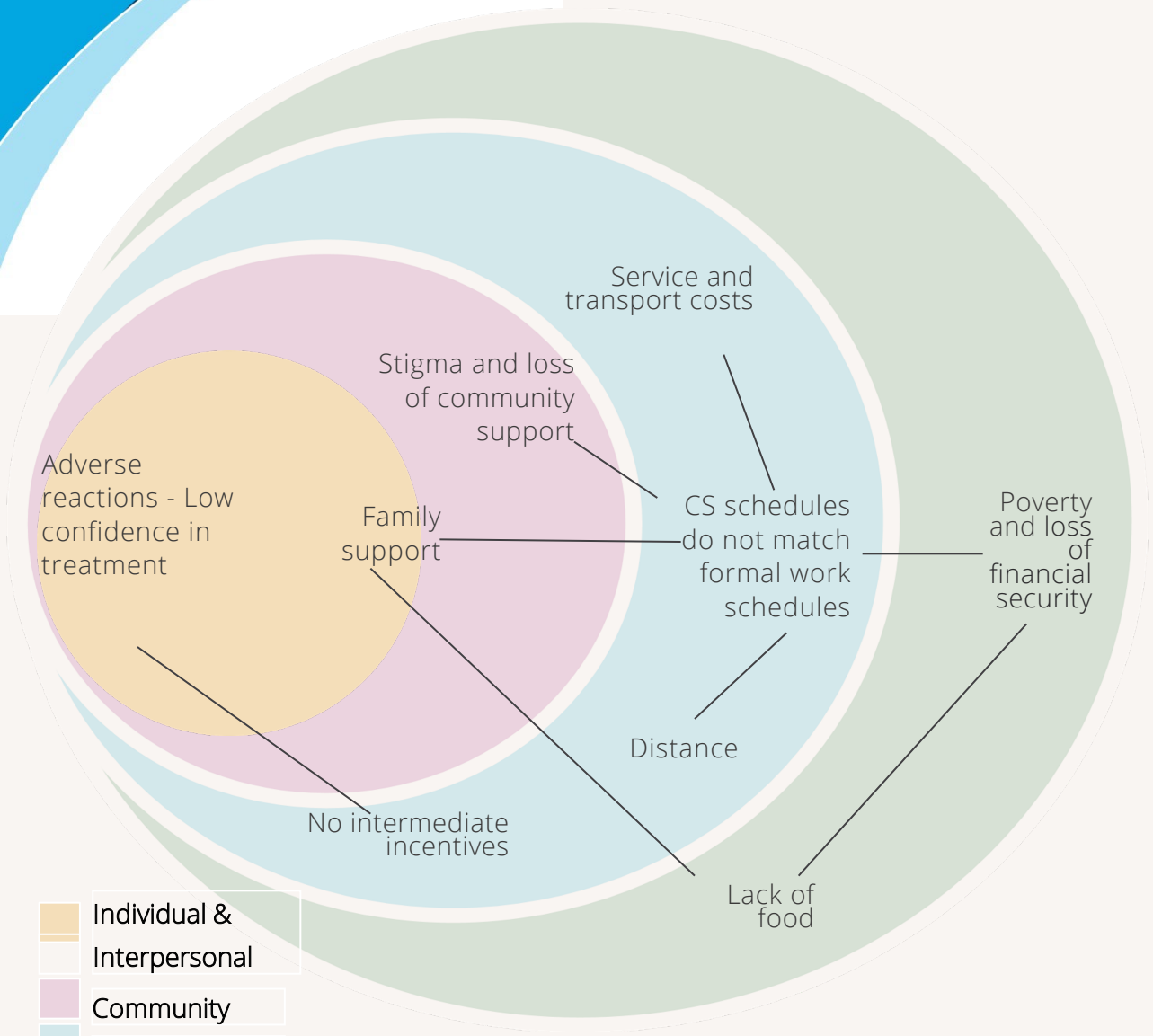
"When I started taking this medicine, my stomach immediately started to unwrap itself. Hum Hum! It was bloated and it hurt." - Former patient, Haut Katanga Peri-urban

"Every day you have to drink the medicine, so I don't know how many tablets of medicine...this medicine weakens your body first of all." - Male 35-65, Kinshasa Urban

"When I started the treatment, two weeks later I started to feel my feet hurting, and I came to tell old man [provider]. He told me that it was the medicine that had entered... The product had entered the body, it was doing its job... It didn't bother me... [because] the disease was known and I had to follow the treatment." -Former patient, Kinshasa, Suburban

"What worried me more before was always the taste of the drugs there." - Former patient, Kasaï Oriental Urbaine

SEM: TREATMENT FOLLOW-UP



We find that structural and institutional factors play a highly influential role in key TB treatment adherence behavior. Community and household support can help the TSP to adhere to treatment, but flexibility and support from the HC are essential, particularly in the context of poverty and financial insecurity. This context can increase the pressure on the TSP to prioritize work expectations, such as arrival times at so-formal work, which can conflict with treatment hours at the SC, especially considering the distance and costs involved in getting there. In general, it's only after the first two months of daily treatment under direct supervision that most current CS offer more flexibility for family or other community members to share the burden of collecting medication and making sure it's taken. At the same time, poverty also limits TSPs' ability to consume more balanced, quality food, to help the drugs work and reduce adverse effects. In the absence of adequate nutritional support and a clear change in their initial condition, TSPs may begin to doubt the efficacy of the drugs. This can be alleviated by encouraging providers on a daily basis and pointing out the small signs of progress they see in patients. However, at present, most patients only receive specific information about their recovery after two months, at their first follow-up appointment. Although it is the STP who must adopt the key behavior of following treatment, the results of this section show that their actions are strongly influenced by a support system within the household, the community, the HC and the organization of the health system and its services.

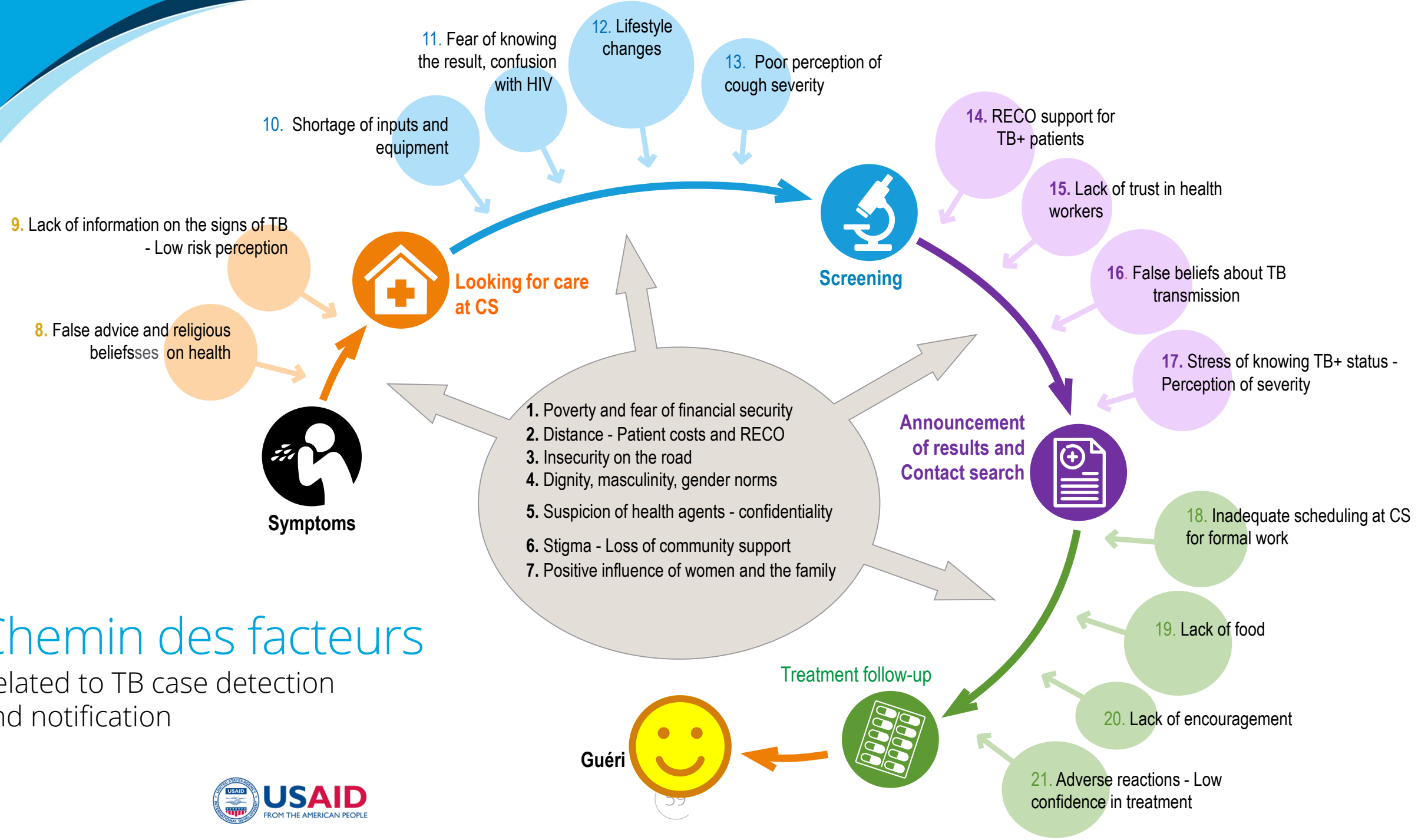
Discussion

Priority target: men, especially young adults, urban dwellers, living in large families

- Disease rate higher in men than women
- Norms of masculinity are stronger and the lack of support within the family may be more difficult for young single adult men.
- Case-finding is especially important in large families, since most TB patients come from large families averaging 6-7 or more people. Half of all households have a child under the age of 5, so these children are also at risk of TB transmission.
- 30% of TB cases are found in the Kinshasa area. Other high-prevalence provinces: Kongo Central, Haut Katanga, Kasaï Oriental, Ituri.
- Factors favoring transmission - living together in crowded conditions (family or yard); poverty; factors aggravating health - heavy consumption of alcohol and tobacco (cigarettes or other), work in pits/quarries, heavy labor; lack of rest; living or working in prisons.

Chemin des facteurs

related to TB case detection and notification

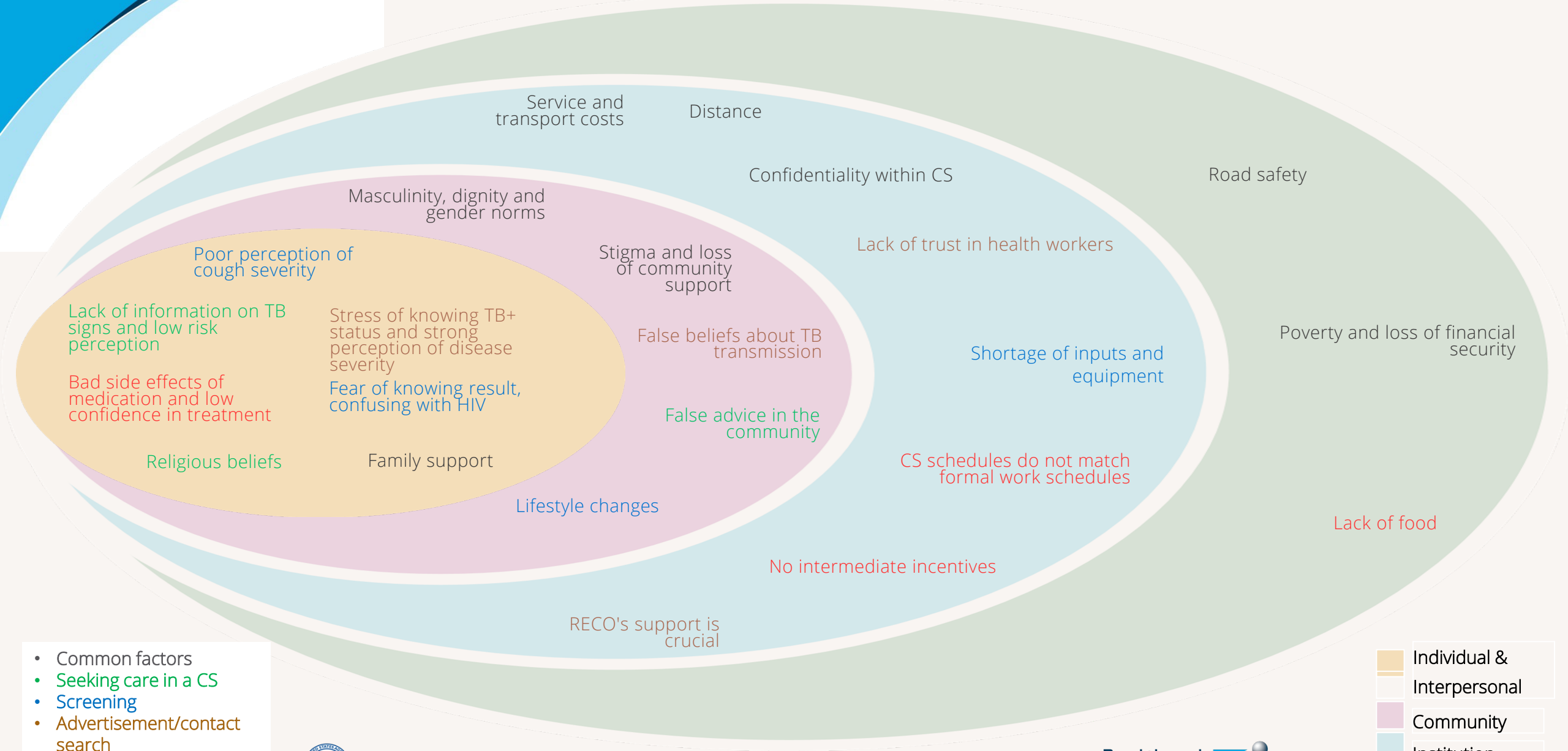


Factor path - Sequencing and prioritization considerations

The previous page presents the factors discussed in the report in the order in which they may appear in the experience of a TB patient.

- Common factors are part of the environment in which people live, and play a role throughout the experience of first symptoms, care-seeking, screening, status announcement, collaboration in contact tracing and treatment follow-up.
  - Taking these factors into account as a matter of priority can help to encourage all the key tuberculosis-related behaviors.
  - These factors have the potential to have a widespread impact on communities, not just on those susceptible to TB.
- Factors outside the circle may have more specific audiences, depending on the stage the person is at. While the factors between coughing and seeking care at the CS are broadly relevant, communication and interventions to address factors outside the circle can be sequenced and focus on smaller and smaller audiences, albeit those with the most interest, involvement and investment in improving TB care.

SEM: BEHAVIORAL DETERMINANTS RELATED TO TB



- Common factors
- Seeking care in a CS
- Screening
- Advertisement/contact search
- Treatment follow-up

Individual & Interpersonal
Community
Institution
Structural

Discussion: Influence of structural and institutional levels

- Structural factors linked to poverty and insecurity play a role in many key behaviors, reinforcing the urgency or challenges posed by factors that influence the practice of key behaviors.
- There is a wide range of factors at healthcare facility level that hinder the practice of key TB behaviors, and which could help to create a more supportive environment for these behaviors.
- Clarifying costs and improving transparency on how free services are delivered can increase trust in healthcare systems, in the same way that patients develop trust in individual service providers.
- Community support for TSPs depends on resolving institutional barriers such as lack of supplies and scheduling flexibility, and SBC can play a role in increasing the level of responsibility of institutions towards their communities.

Discussion: The need for community involvement

- Community and religious leaders can provide more support to institutional actors such as RECOs and providers, if they are more clearly oriented to understand how their mobilization can help overcome structural barriers, thereby increasing community support for TSP and effectively reducing feelings of isolation and stigma.
- Given that providers have a heavy patient burden, multi-stakeholder solutions can help coordinate the efforts of leaders, families and organizations who can collectively provide support to overcome structural challenges. Multi-stakeholder solutions may be better able to advocate on behalf of TSP to remove barriers to the healthcare system and employment that make it difficult to continue treatment for its duration.
- Family solidarity is an important protective factor and offers solid psychological support for STPs. Friends, neighbors and churches can provide the family with the material support it needs, particularly to overcome transportation and nutritional difficulties.

Discussion: The psychological experience of TB

- Individual and psychological factors are most often raised in relation to seeking CS care for coughs and screening behavior, but they are strongly influenced by the community.
- Risk perception is low, due to a lack of knowledge about the signs of tuberculosis and when it's time to put aside other remedies and go for CS screening.
- While the perceived seriousness of coughs is low, the perceived seriousness of tuberculosis is high. This can lead to postponing a visit to the health center to avoid information perceived as unpleasant, particularly due to misconceptions that tuberculosis is the same as HIV.
- Self-efficacy in seeking treatment at the CS, particularly for men, is strongly limited by community perceptions linked to gender norms and the stigmatization of male diseases in general and tuberculosis in particular.
- Belief that going to the CS can help is low, as there is a lack of confidence in the efficacy of treatment.

Discussion: communication channels and important partners

- Health workers, especially RECOs, are essential for building confidence in health systems and strengthening support for families of TSPs.
- Community leaders are important partners in the health system to reinforce correct information and increase community support and collaboration to create an environment conducive to the adoption of key TB-related behaviors.
- The media can be used by community leaders to convey messages about fighting the stigma of tuberculosis and building confidence in the treatment of the disease, to counterbalance the high sense of seriousness that people feel about the disease.
- Organizations such as TB Love, Action Damien and Club des Amis d'Action Damien, as well as existing community structures such as women's associations, can be used to find role models/champions. These people can speak out to break the vicious circle of gender norms preventing the use of CS care, and bring a sense that caring for a cough is an example of masculinity in the context of family and community care.

Recommendations

Theories of change

Theories of change

The theories of change are proposed to detail how to create changes to influence the following priority behaviors:

- Seeking care in a health center
- Screening for suspected cases of tuberculosis (TB)
- Informing the TB patient (PST) of his or her status to family and friends and seeking out contact cases, and
- TRP treatment follow-up

With these four theories of change, actors in the fight against TB will know how best to choose social and behavior change communication (SBCC) activities, the targets for these activities, the focus of intermediate changes in behavioral and structural determinants to ensure a change in key behaviors in the fight against TB.

Interventions based on behavioral determinants

- Each theory of change restates the behavioral determinants that influence the key behavior, as discussed in the presentation of key findings in the results section.
- The proposed activities respond directly to one or more behavioral determinants.

Theory of change: Cough care seeking

The activities

- Community discussions
- Guided tours of health centers
- Health clubs for schoolchildren
- Interpersonal communication (IPC) and mass media (TV, radio and social networks)
- Couples meetings organized by churches
- Testimonials from patients who have been healed.

Individual and community behavioral determinants

- Family members know what to do in the event of a cough and the benefits of going to the health centre for treatment.
- Family approves of and believes in the effectiveness of CS care
- Men approve of CS care-seeking and recognize that CS care-seeking is not a sign of weakness

- The community recognizes that good care is available at the CS and is motivated to seek care at the CS.
- Community and religious leaders approve and guide care-seeking at the health center.
- The community approves and supports care research in CS.
- The community knows that coughing is different from HIV/AIDS, and that the source of coughing is not mystical.
- The community knows the cost of CS services.

Intermediate results Or Behavioral objectives

Households seek care at the health center for coughs (as a first resort)

Healthcare providers look for TB in coughs

Health results

DRC to eliminate TB by 2035

Seeking care in a CS

- To encourage care-seeking behavior at the CS when coughing, interventions must increase the urgency to act while reducing barriers to accessing facility services.
- Community dialogues and guided tours can help increase the perception of the benefits of CS use and confidence in the institution, as well as correct misinformation about the disease.
- Clubs, interpersonal communication, the media, and testimonials can improve the perception that the community as a whole and men in particular support and encourage care-seeking.
- Couples' meetings organized by churches can help integrate supportive communication and reduce ideas of mysticism.

Theory of change: Screening for suspected cases

The activities

- Media campaign (radio, television, social networks, billboards and posters)
- Songs or theater
- Family dialogues/Couples' day
- Community dialogues and site tours to showcase CDT services
- Comparative costs' activity in community dialogues
- Create service cost sheets
- TB RECO recognition activity
- Capacity-building for providers in terms of reception, empathy and confidentiality
- Advocacy for continuous supply of TB laboratory inputs

Behavioral and structural determinants

- The suspect understands and accepts the need for TB testing.
- Allegedly able to inform spouse if coughing
- The suspect is motivated to go to the CDT for screening.
- The alleged diagnose accepts his test result.
- The TB patient understands the effectiveness and duration of treatment (to overcome stress, stigma and fears).
- The spouse feels able to recommend that the suspect go to the CS to seek care, including screening.
- The entourage (close family and community) approves of seeking care for screening at the CDT for men.
- The entourage recognizes the importance of the RECO in accompanying the suspect to TB screening.

- Providers believe that displaying costs is important for service quality.
- Providers understand the importance of empathy and confidentiality, and feel able to offer quality services (despite structural challenges).
- The provider understands the importance of transmitting the result to the TB patient as soon as possible, either directly or through the RECO.
- The health center staff and the PNLT feel able to ensure the continuous supply of lab inputs for screening.

Intermediate results Or Behavioral objectives

Suspected cases are screened for tuberculosis.

CS-CDT service providers offer tuberculosis screening tests systematically, with empathy, friendliness and confidentiality.

Health results

DRC to eliminate TB by 2035

Screening for suspected cases

- To encourage screening behavior, interventions need to generate family and community support, as well as a sense of trust and appreciation for health workers and the transparent, efficient services of the health system.
- Community-based media campaigns and educational entertainment can address the psychological determinants of TB testing in ways that attract attention and generate positive feelings.
- Family and community dialogues and can strengthen support for spouses and loved ones by encouraging screening and collaborating with RECOs in their work.
- Cost-specific activities and capacity-building can address the reluctance of individuals and families to undergo screening, while building confidence in the quality of services.
- Advocacy and recognition activities by RECOs can demonstrate community support for health institutions while putting in place accountability systems to ensure that services meet community needs.

Theory of change: TB patient status announcement (PST) and case-finding

The activities

- Health education
- Patient counseling on gender norms and other risk behaviors
- Strengthening implementation of the CAD approach, support groups and mentoring
- Intensify CIP (VAD)
- Training and capacity building for community and religious leaders
- Boosting sponsorship
- Advocacy

Behavioral and structural determinants

- TSPs understand how TB is transmitted, the benefits of knowing their status, and the importance of supporting contact tracing.
- TSPs know the benefits of sharing their status and believe that sharing status with loved ones can help them.
- Those close to the PST understand how important they are to the patients.
- Relatives feel able to support TSP from the moment it is announced to the end of the treatment.
- Community and religious leaders feel they are in a position to facilitate the circulation of information to ensure that contact subjects adhere to screening and treatment.
- Community and religious leaders understand the importance of breaking TB transmission, and support case-finding.

- RECO providers understand how to instill confidence in patients and families
- Providers believe in the importance of reassuring the new PST of the non-fatality of TB, the availability of free treatment and its effectiveness.
- Political and administrative authorities believe in the importance of RECOs' work, and understand how to create a favorable environment for RECOS' work.

Intermediate results Or Behavioral objectives

TSPs share their status with their families and the people they live with

and

TSPs support contact tracing

Health results

DRC to eliminate TB by 2035

PST status announcement

- To encourage the behavior of STPs who announce their TB status within their families, interventions need to provide strong psychological support for STPs, including strengthening the bonds they feel with health workers and other peers who have already been through this experience. Family skills must also be strengthened so that they can provide support.
- Counseling and the intensification of IPCs, including VADs, can help alleviate feelings of guilt and shame among TSPs and their families and increase feelings of hope for recovery, while emphasizing the benefits of sharing one's status to increase the likelihood of getting help. These activities can also reinforce a sense of responsibility to provide help to those close to TSP.
- DAC support and sponsorship amplification can provide the TSP with positive examples of the support that can result from sharing her status with her loved ones.

Case-finding

- To encourage collaboration in case-finding, interventions need to create a sense of community responsibility for TB control, including support for health workers involved in this work.
- Health education and capacity building for community and religious leaders can reinforce the need for leadership involvement and develop their skills to encourage cooperation with contact tracing.
- Advocacy can alert the authorities to the essential role RECOs play in the fight against tuberculosis, and to the need to guarantee the feasibility of their work in a safe and supportive environment.

Theory of change: Treatment follow-up

The activities

- Revise a support notebook (patient's notebook) in which everyone plays their part, using CBT
- Mass media, community events: Create scenes showing various patient situations to reinforce the empathy of friends and family.
- Explanation to the patient by the provider at the beginning and at each appointment of the restrictions and benefits of following them discussion of undesirable effects
- Increase home visits
- Recruit RECOs at CDTs with a high case rate, if the area does not have many RECOs.
- Sponsorship of a new patient by an old patient, according to age (small proofs)
- Community dialogue between parents, authorities and the CDT
- Create a savings bank to provide social support for the sick - food

Behavioral and structural determinants

- The PST is able to continue the treatment himself (TDO, follow-up appointments).
- Friends and family see the importance of psychological support for PST.
- Friends and family feel able to provide psychological support to the PST.
- The PST feels able to overcome the side effects.
- TSPs know the importance of restrictions during treatment.
- The PST is confident of the effectiveness of the treatment to cure
- Family, friends, neighbors, NGOs, etc. feel able to provide social support (nutritional support)

- Former patients, RECOs, providers understand how best to bring TSPs to the end of their treatment.
- TSPs, authorities and the provider/CDT believe they can change the patient's schedule by working together.
- The PST perceives positive developments in the treatment process systematically at each visit.

Intermediate results Or Behavioral objectives

TSPs adhere to treatment

TSPs keep control appointments

Health results

DRC to eliminate TB by 2035

Treatment follow-up, 1

- To encourage treatment adherence, interventions need to put in place a system of emotional, social and financial support for STPs at household, community and health facility level. In addition, activities should seek ways to encourage the flexibility of healthcare systems to promote long-term access to treatment.
- A supportive notebook and IPC by providers and former patients with TSPs and their guards can help build communication skills, confidence in the ability to follow treatment and trust in medications to lead to healing by addressing lifestyle changes, potential side effects and identifying small evidence of healing.
- The media, community events and VADs can show how family, friends and RECOs work together to help the TSP continue treatment.

Treatment follow-up, 2

- Community dialogue, savings banks and the targeted recruitment of RECOs in places where their numbers are insufficient in relation to the number of TSPs can create opportunities to develop community support for TSPs, including support for nutrition, finance and flexible systems for the provision of treatment.

Conclusions

Conclusions

- This study enabled a multi-stakeholder exploration, focusing on 4 key behaviours important in the fight against tuberculosis
- While psychological determinants play a role in care-seeking, screening and follow-up decisions, TSPs are heavily influenced by community norms and the systems in which they receive services. In addition, the context of poverty and insecurity has a major influence on the experience of tuberculosis across all key behaviors.
- The results and discussion provided many implications for activities that can be integrated into public health practice as well as the national TB communication strategy.
- Further research should be carried out through monitoring and evaluation of the recommended activities, to determine their effectiveness in promoting the 4 key behaviors in different geographical areas of the DRC.
- Advocacy is imperative to ensure that actors such as RECOs can continue to support the fight against tuberculosis, that more HCs have access to cutting-edge technologies and the necessary inputs for tuberculosis diagnosis and treatment, and that the health system is strengthened by trained psychosocial health workers to also meet the needs of TSPs.

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