

# Overcoming challenges in TB care: from policy to practice

## *Short Course Regimen (SCR) qualitative study – link to person-centred care*

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# Study background and aim

- Person-**centered** care is an internationally **recognized** priority, describing the involvement of people in their care and treatment decisions and the consideration of their needs and priorities within service delivery.
- Patient voice, experience, perspective relating to SCR = lacking

**Aim of study : To examine the views and experiences of patients with MDR-TB and practitioners regarding the SCR in Karakalpakstan, Uzbekistan to inform patient management, policy and practice related to SCR implementation**

# Methods of Data Collection & analysis

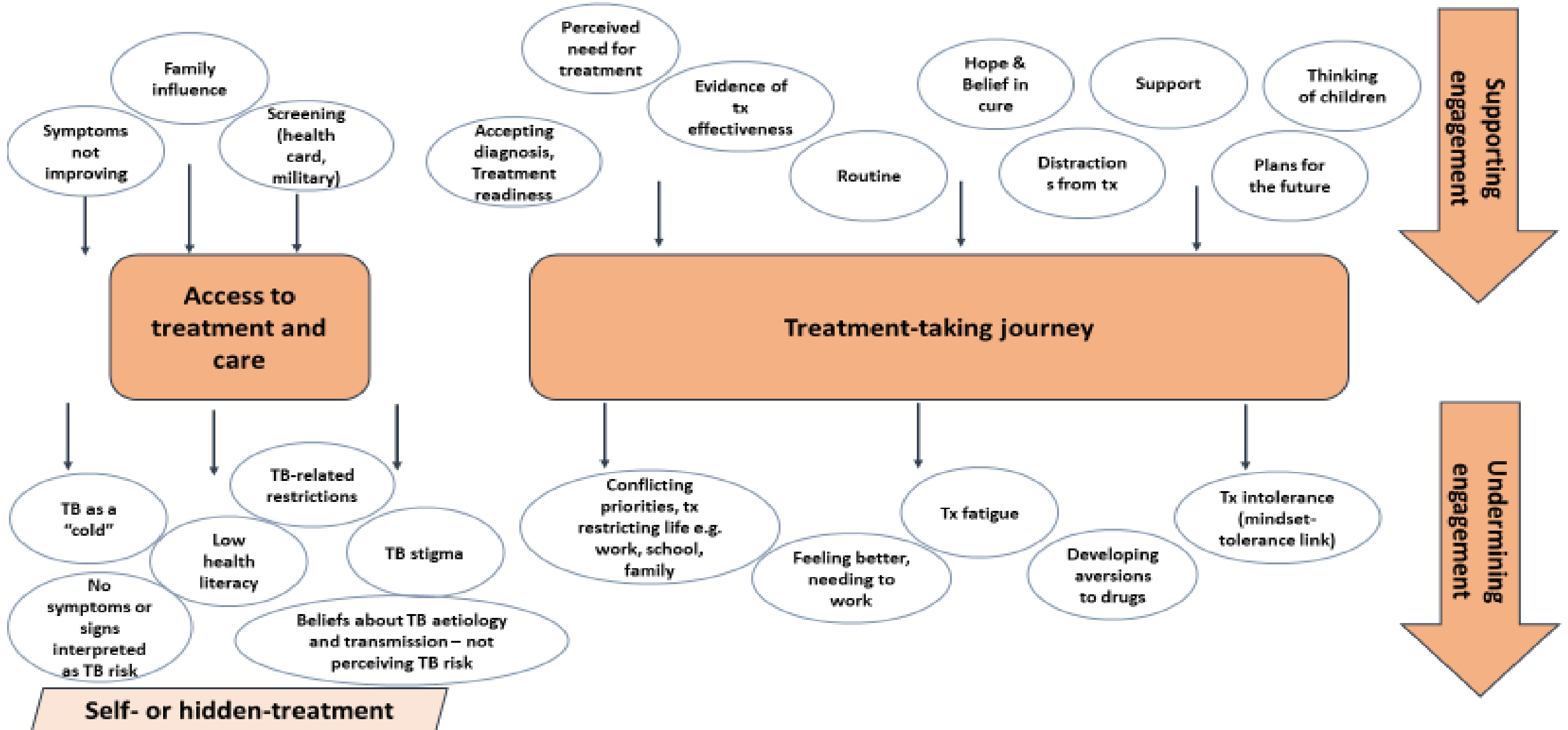
- Purposive sampling (including those best able to provide insight to the topic of inquiry)
- Recruitment continued until evidence of data saturation – when adding participants did not generate new findings
- 48 in-depth interviews
- Data analysed thematically – to identify emergent patterns, concepts and categories from participant accounts
- Aiming to identify findings inductively, reflecting participants’ perspectives and experiences as closely as possible rather than testing pre-determined hypotheses

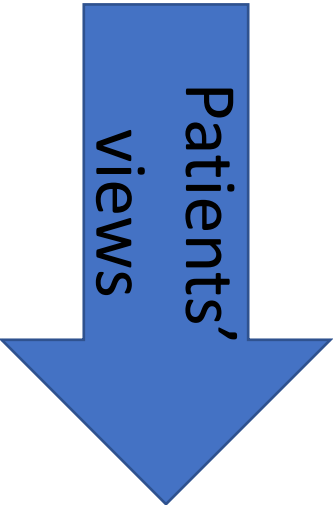
HCW participant information	Number
<b>Total HCW</b>	<b>20</b>
- Women/men	15/5
Role	
- Doctor	11
- Nurse	5
- Counsellor	4
Employer	
- Ministry of Health	12
- Médecins Sans Frontières	8

Patient participant information	Number
<b>Total patients</b>	<b>24</b>
- Women/men	12/12
- Age 18-24	8
- Age 25-34	9
- Age 35-44	2
- Age 45-58	5
Treatment category	
- On SCR treatment	15
- Completed/cured	5
- Treatment failure	3
- Lost to follow-up (LTFU)	0*
- Relapse	1
- Transferred/on standard regimen	4

\*It was not possible to recruit people who were LTFU: of 6 potential SCR LTFU individuals, 2 were inaccessible, 3 uncontactable, 1 no show

# Factors and views affecting patient engagement with care





Quicker return to "normal" life with SCR

Want relapse free cure – "effective" treatment

Priority = reduced pill burden

# Views about SCR

Shorter tx =  
↑mental health  
and ↓ stigma  
burden

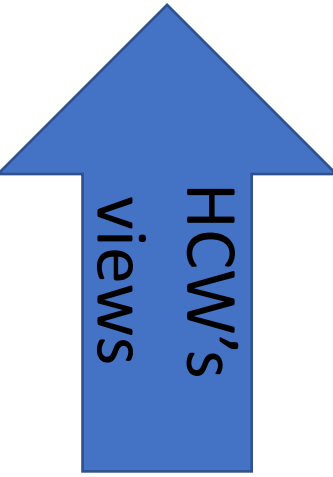
More confidence in LCR

Concerns about length & FLD resistance

Concerns about appropriateness

Inflexibility of SCR makes management challenging

Enables adherence & retention in care



Clarity around expectations & treatment readiness

Enacting choice for treatment location – ambulatory or hospital-based

Importance of information, understanding, ownership

Patients want to be involved in discussion

Peer to peer information valuable

Factors favouring

Person centred care

Unfamiliarity with concept of shared decision-making

DOT potentially undermines responsibility for treatment

Misinformation undermines engagement (and trust)

Prefer doctors to decide on appropriate regimen

Undermining factors

# Conclusions

- Benefits of shorter treatment: enabling quicker return to “normality”, reducing the burden of treatment including stigma and mental health, and supporting adherence
- HCW have concerns about SCR effectiveness and appropriateness which may influence who is offered it
- Person-centred care could be achieved through dialogue, information, understanding – supporting patient readiness for treatment and sense of ownership over health and treatment-taking

*“I want to be cured quickly and to start work like other people. To be honest, I am fed up coming here [clinic] every day.” P23*

*“It is my life, that is why I should know what is happening, what are they doing... I want to be told openly” P14*

*“In recent times, even if the patient matches low-risk SCR inclusion criteria related to age, condition, bearing in mind the possibility of future intolerance, we are not including patients into SCR, that is it!... Our doctors do not want to prescribe SCR.” HCW13*

Area	Recommendation	Examples
<b>Patient support</b>	<ul style="list-style-type: none"> <li>- Towards TB acceptance and treatment readiness</li> <li>- During first 2 months of treatment (which can be particularly difficult)</li> <li>- To maintain motivation later in treatment</li> <li>- Positive mindset, hope, distractions and plans post-treatment</li> <li>- Support for impact on daily life – school, work</li> <li>- Support to navigate TB stigma</li> </ul>	<ul style="list-style-type: none"> <li>- Information, support, visual aids</li> <li>- Conversations in DOT corner, reassurance for cure, encouragement, relationship</li> <li>- Offering evidence of treatment effect, peer support and information</li> <li>- Visualisation tools, aspirations</li> <li>- Economic and psychological support</li> <li>- Strategies to overcome isolation and navigate differential treatment e.g. by family/friends</li> </ul>
<b>HCW support</b>	<ul style="list-style-type: none"> <li>- Increase confidence in SCR</li> <li>- To translate SCR knowledge to practice</li> <li>- Increase familiarity with SCR results</li> </ul>	<ul style="list-style-type: none"> <li>- Dialogue, discussions, addressing concerns</li> <li>- Mentorship</li> <li>- Showcasing SCR pilot results and outcomes</li> <li>- Training for all doctors (not just TB doctors)</li> <li>- Participatory approaches to sharing and learning</li> </ul>
<b>Person-centred care</b>	<ul style="list-style-type: none"> <li>- Increase information, understanding</li> <li>- Encourage patient choice for treatment location</li> <li>- Foster trust within practitioner-patient relationships</li> <li>- Foster sense of ownership and responsibility</li> <li>- Consider alternative approaches to DOT</li> </ul>	<ul style="list-style-type: none"> <li>- Dialogue, discussions</li> <li>- Discussing options, seeking patient preferences</li> <li>- Open communication, sharing changes in results or treatment length</li> <li>- Family DOT</li> </ul>
<b>Community</b>	<ul style="list-style-type: none"> <li>- Raise awareness about TB</li> <li>- Address fears around contagion and blame for disease stemming from not taking care of self</li> </ul>	<ul style="list-style-type: none"> <li>- Information about TB disease, treatment, transmission</li> <li>- Play/radio/TV show?</li> </ul>



# Thank You

GRACIAS

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LOADING...



OBRIGADO

СПАСИБО



ありがとうございました