Self-driven solutions and resilience adapted by people with drug-resistant tuberculosis and their caregivers in Bengaluru and Hyderabad, India: a qualitative study

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Summary

Background One-fifth of people with drug-resistance tuberculosis (DR-TB) who were initiated on newer shorter treatment regimen (with injection) had unfavourable treatment outcomes in India as on 2020. Evidence on self-driven solutions and resilience adapted by people with DR-TB (PwDR-TB) towards their multi-dimensional disease and treatment challenges are scarce globally, which we aimed to understand.

Methods In this qualitative study using positive deviance framework, we conducted semi-structured in-depth interviews among consenting adult PwDR-TB (7 women, 13 men) who completed shorter treatment regimen (including injections) with maximum treatment adherence. The study was conducted in the southern districts of Bengaluru and Hyderabad, India between June 2020 and December 2022. Caregivers (14 women, 6 men) and health providers (8 men, 2 women) of PwDR-TB were also interviewed. Interviews were conducted in local language (Kannada, Tamil, Telugu, Urdu and Hindi) and inquired about practices, behaviours, experiences, perceptions and attributes which enabled maximum adherence and resilience of PwDR-TB. Interviews were audio recorded, transcribed, and translated to English and coded for thematic analysis using inductive approach.

Findings Distinctive themes explanatory of the self-driven solutions and resilience exhibited by PwDR-TB and their caregivers were identified: (i) Self-adaptation towards the biological consequences of drugs, by personalised nutritional and adjuvant practices, which helped to improve drug ingestion and therapeutic effects. Also home remedies and self-plans for ameliorating injection pain. (ii) Perceptual adaptation towards drugs aversion and fatigue, by their mind diversion practices, routinisation and normalisation of drug intake process. and constant reinforcement and re-interpretation of bodily signs of disease recovery (iii) Family caregivers intense and participatory care for PwDR-TB, by aiding their essential life activities and ensuring survival, learning and fulfilling special nutritional needs and goal oriented actions to aid drug intake (iv) Health care providers care, marked by swift and timely risk mitigation of side-effects and crisis response (v) Acquired self-efficacy of PwDR-TB, by their decisive family concerns resulting in attitudinal change. Also being sensitised on the detrimental consequences of disease and being motivated through positive examples.

Interpretation Synthesised findings on self-driven solutions and resilience towards the multi–dimensional DR-TB challenges provides opportunity for developing and testing new interventions for its effectiveness in DR-TB care settings globally. Designing and testing personalised cognitive interventions for PwDR-TB: to inculcate attitudinal change and self-efficacy towards medication, developing cognitive reinforcements to address the perception burden of treatment, skill building and mainstreaming the role of family caregivers as therapeutic partners of PwDR-TB, curating self-adaptive behaviours and practices of PwDR-TB to normalise their drug consumptions experiences could be the way forward in building resilience towards DR-TB.

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Research in context

Evidence before this study

Current evidence on person-centred care for people with drug resistant tuberculosis (DR-TB) mostly focus on the challenges and barriers they have experienced, while undergoing treatment regimens with injections. Research on person-centred care for DR-TB in India mostly emphasise on strengthening provider side factors and long-term strategies which are resource intensive. Studies focusing on feasible and implementable patient level solutions to improve for DR-TB care are very scarce. Published studies from India on DR-TB care had mostly focused on people who underwent longer DR-TB treatment regimen (24 months with injections). Also, these studies have predominantly focused on either patient side or health services related issues in India. Globally in the present era of shortened treatment regimen (9–11 months), studies exploring self-driven solutions and resilience of people with DR-TB in addition to perspectives of their family caregivers are not available. There are no published studies which had used the positive deviance framework in the context of DR-TB to theorise and explain the resilience of people with DR-TB. Our assessment of the evidence before this study was based on PubMed, Scopus, and Google Scholar searches from database inception to October 2020, using combinations of search terms "resilience", "caregivers", "injections", "side-effects", "treatment", "psychos-social", "barriers", "perspective", "person centric ", "solutions" "challenge", "tuberculosis" and "drug-resistant tuberculosis". No language restrictions were applied to these searches.

Added value of this study

This study fills in the evidence gap with regard to the resilience of people with DR-TB in overcoming their treatment related challenges and barriers. Using in-depth qualitative methods and a conceptual framework for positive deviance, this study had explored and identified solutions adapted for people with DR-TB and their acquired resilience in coping up with disease and treatment challenges in Bengaluru and Hyderabad Districts, India. This study provides a perspectival shift to understand the DR-TB person's self-driven solutions and to incrementally build resilience towards the multi-dimensional nature DR-TB challenges. The study specifically delineated adaptations of people with DR-TB towards the biological and psychological adverse consequences of DR-TB medications. The intensive care and participation of their primary caregivers in enabling the survival and adaptations of the people with DR-TB was revealed. Moving beyond the knowledge and behaviour change notions, the study uncovered the importance of positive attitudinal change experienced by people with DR-TB, which enabled them to acquire self-efficacy and turn resilient towards this dreadful disease.

Implications of all the available evidence

The challenges and needs of people with DR-TB are multi-dimensional and the health provider services are limited to address and fulfil them. The need for comprehensive person-centred interventions for mitigating the challenges and diverse needs of people with DR-TB are yet to be realised. Focusing at the prevalent gap between the limitations of the present provider driven DR-TB care and the proposed long-term goals for person-centred care, the present study provides evidences on existing DR-TB person's self-driven solutions and scopes for developing new interventions and testing it for replication. Designing and testing cognitive interventions with family-centred contents and life value notions for people with DR-TB, could be a potential way to inculcate changes in attitude, promote self-efficacy and incrementally build the resilience against DR-TB challenges. Holding hands (caring touch) and enabling personally tailored nutritional and adjuvant practises could be potential in mitigating the adverse side effects of DR-TB drugs. Normalisation of pill consumptions experiences would be an important priority for caregivers and counsellors, even if injection related challenges could be avoided with all oral regimens in near future. Designing the DR-TB care provision and interaction environment with positive feedbacks, nudges and cognitive reinforcements are some possible solutions to manage the perception burden and treatment fatigue. Skill building of the family caregivers on aspects of DR-TB management including goal setting, micro-planning, problem solving, crisis handling, motivational techniques and nurturing person-centred communication would be helpful in enabling the adaptations of people with DR-TB towards the adverse consequences of disease and its treatment.

Introduction

Drug-resistant TB (DR-TB) remains a challenging infectious disease condition to treat and cure. People with DR-TB (PwDR-TB) experience physical and mental health deterioration, which is accentuated by its treatment complexity and side effects involved.[1,2] The nature of DR-TB and the invasive regimens (18–24 months) were associated with poor treatment adherence and suboptimal treatment success rates as low as 50%.[3] Even with the introduction of less invasive shorter treatment regimens, the treatment success rate has remained suboptimal between 60% and 73%.[4]

India is home to almost one-fourth of the global burden of multi-drug resistant TB (MDR-TB).[5] India has 28% of PwTB, who are resistant to any drugs and 6.19% have MDR-TB. India also shares 27% of the worldwide burden of rifampicin-resistant (RR) TB.[6–8] In 2021, a total of 48,232 people with multi-drug resistant/rifampicin-resistant tuberculosis (PwMDR/RR-TB) were diagnosed (90% of which treatment was initiated). Estimates from 2020 highlight that of the total 30,985 PwMDR/RR-TB initiated on shorter regimen, only 55% had successfully completed treatment and recorded higher loss-to-follow up (10%, n = 3203) and death rates (11%, n = 3558) in India.[9] A range of treatment related challenges and associated psycho-social barriers which adversely affect the PwDR-TB have been documented worldwide and in India.

Interventions like individual and group counselling, monetary support, nutritional provisions and decentralised[10,11] care services are prioritised for PwDR-TB worldwide and in India.[10,11] Still these interventions have not fully realised their potential in the context of DR-TB, as compared to people with drug-sensitive TB.[12] Estimates of poor treatment outcomes of 60–70% for PwDR-TB initiated on newer shorter regimen underscores this continuing phenomenon. The dynamic and multidimensional challenges of PwDR-TB are characterised by disease severity, treatment complexity, psycho-social issues, special care and resource needs, remains elusive for the national TB programs to address them comprehensively in India and similar high burden and resource poor settings.[13,14]

Conceptualising and implementing person-centred interventions to address the challenges and needs of PwDR-TB have been emphasised in the national TB elimination program of India (NTEP) and other programs worldwide.[15,16] As a way forward, research and recommendations have focused on developing person-centred interventions for DR-TB.[15,16] Increased resource allocation, decentralised health system care and larger community participation are emphasised to address the DR-TB challenges from a person-centred dimension.[8] While the importance of these recommendations is crucial in long term from a public health dimension, still interventions which are implementable and readily realisable at the level of individual PwDR-TB, who experience the adverse consequences in their day-to-day life would be timely and crucial.

The multi-dimensional nature of challenges and issues experienced by PwDR-TB, necessitates a solution focused and individual resilience driven approach, which is scarce in previous literature related to DR-TB.[15,16] Focusing between the existing provider driven interventions and long-term structural interventions, studies focusing on adaptable self-driven solutions for DR-TB persons, which could incrementally build their resilience towards their disease and treatment challenges are required.

Research in India on DR-TB care had mostly focused on challenges at the level of patients and barriers at the level of health systems.[14] Furthermore, studies reported worldwide on adult DR-TB care have not explored self-driven solutions and resilience of PwDR-TB in addition to perspectives of their family caregivers.[1] In this background, we attempted a perspectival shift to explore and understand the prevalent behaviours, experiences, perceptions, and attributes of a sub-set of solution focused and resilient PwDR-TB and their caregivers in India.

Methods

Study setting and participants

This qualitative study which was conducted among PwDR-TB between June 2020 and December 2022 in the Southern Indian districts of Bengaluru and Hyderabad. During the study period, 252 and 116 DR-TB cases were line listed in Bengaluru and Hyderabad respectively which was almost one-tenth of the total DR-TB cases notified in the respective states.[14] Considering the varied categorisation and treatment regimens implemented for DR-TB in the study setting, we broadly considered all persons who underwent shortened DR-TB regimen (9–11 months) with injection for inclusion [NTEP Treatment Guideline 2021].[8] People with HIV and DR-TB co-infection, monopoly resistance and XDR-TB (Extremely Drug Resistant Tuberculosis) were excluded considering significant variations in treatment time, severity, and underlying challenges. The study was conducted in accordance with the Declaration of Helsinki. The Institutional Ethics Committee of the ICMR-National Institute for Research in Tuberculosis in Chennai (123/NIRT-IEC/2020, date: June 17, 2020) and the Institutional Ethics Review Board of St. Johns Medical College & Hospital in Bengaluru (IEC number 114/2020, date: February 25, 2020) approved this study. A detailed participant information sheet was administered before data collection and written informed consent was obtained from the participants (consent also to publish this paper). Participants were provided opportunity to ask questions and to withdraw from the study at any time. Interview participants received refreshments and INR 150 (US$ 2.5) as transport

reimbursements. Privacy and confidentiality were maintained during interviews.

Study design and theory

This qualitative study was driven by positive deviance theory of exploring and identifying the existing model behaviours, strategies and attributes among the "deviants", who demonstrated unique solutions and resilience in dealing with the critical problems they faced as compared to their peers.[13] In the context of PwDR-TB, we defined positive deviants as those who completed the DR-TB treatment with exceptional adherence, through self-driven solutions and coped up to the multidimensional treatment demands, adverse effects and the related psycho-social barriers they experienced.[14]

Study process

Defining positive deviance in DR-TB context

Positive deviance for this study was defined with insights from literature on the proportion of PwDR-TB who could have perfected adherence.[17,18] This study defined positive deviance as "maximum treatment adherence i.e. PwDR-TB who had less than two consecutive days of treatment interruption and treatment completion in prescribed duration".

Determine the presence of positively deviant PwDR-TB

A three -step process involving criterion sampling was used to determining the presence of positive deviants among PwDR-TB who completed treatment during 2019–20, within a year before the study initiation period (October 2020) in the study districts to ensure data collection with limited recall bias.

Step 1: PwDR-TB who completed treatment under the study districts within a year before the study initiation (October 2020) point were line listed using "Ni-Kshay, a web enabled patient management system used by NTEP which records the treatment intimation, adherence and completions details for individual persons.[19]

Step 2: Informal qualitative feedbacks interviews and probes were made with the Senior Treatment Supervisors (STS), Health Visitors (HV) and DR-TB counsellors and co-coordinators who supervised the treatment of PwDR-TB to validate the treatment details obtained from NIKSHAY. The health workers were asked to freely line list such treatment completed PwDR-TB individuals during the study period. Supervisory experiences and events during the treatment time were discussed which helped the health workers to recall details of such PwDR-TB individuals.

Step: 3 Shortlisted PwDR-TB and caregivers were approached individually and their treatment adherence status was ensured with verbal inquiry and cross verification of treatment cards and treatment registry details. A total of 368 PwDR-TB who were mostly middle-aged (aged 35–40 years) and males (>65%) were line listed from the NIKSHAY in the study districts, of which 116 (31.5%) were shortlisted as positive deviants as per the study criteria. On further appraisal 86 (25.8%) people were found confident and consenting to share their experiences and perspectives as positive deviants. Reasons for exclusion were mostly language barrier, non-willingness for audio taping, and not willingness from care givers (n = 28). After shortlisting participants were prospectively selected for interviews based on their availability and no specific criteria were further employed. Rapport was established with participant PwDR-TB and were was requested to identify their primary caregiver and health care provider who had enabled him or her to be a positive deviant. The caregiver was not restricted within the household but was defined as anyone whom the PwDR-TB considered as a primary supporter for completing the DR-TB treatment.

Identifying self-driven solutions, practices, behaviours, experiences, perceptions and attributes of positively deviant PwDR-TB, their care givers and health care providers

Face-to-face, semi-structured in-depth interviews (SSIs) were utilised for collecting qualitative information from eligible PwDR-TB from two different perspectives in a pre-determined sequence. Paper-based interview guides were used for probing the challenges and barriers which the persons encountered during the diagnosis and treatment period with respect to their biological and biographical aspects of life including their physical health, mental health, familial and social life roles (Supplementary File 1).

Attitudes, perceptions, practices, experiences, and behaviours which had helped the individual PwDR-TB to positively adapt and navigate their reported treatment challenges were explored. Probes were also aimed at gaining the perspectives of persons about their familial relations and health care provider's role in navigating the treatment with resilience.

Caregivers and health care providers were interviewed using the same sequence to get their perspectives and experiences with respect to the positive adaptations towards treatment by PwDR-TB and by themselves. Following an initial piloting (2–3 interviews) probes were refined. Further guided by principles of data saturation, interviews were expected to be conducted among 15–20 PwDR-TB, their primary caregivers (n = 15–20) and health care providers (n = 5–8) in both sites. Each interview lasted for approximately 45–60 min.

Quality control

The interviewers were academically qualified and trained social workers and public health researchers (P.M.D., J.B.) representing male and female gender. Data collectors were not involved in patient care in the same health facility to reduce bias. Interviews took place in participant's local languages (Kannada, Tamil,

Telugu, Urdu and Hindi) and were flexible to suit the participant's response pattern, Interviews took place at participants' (PwDR-TB and caregivers) homes (n = 32) and also at health facilities (n = 8) as per their convenience and privacy. Caregivers and health care providers were interviewed separately using separate interview guides. The interviewers took notes in diaries the fine details of the interviewees' responses and was further incorporated into the analysis. Participants were asked for feedback whenever there is a need for additional clarity of quotes and to help arrive at a consensus on themes and subthemes.[14]

Data analysis

The analysis was conducted based on a systematic and multi-step reflexive process which involved data familiarisation, creating initial coding framework, assessing saturation, reviewing and organising themes. Initially interviews were taped, and further notes were transcribed from local language to English. Audio recordings of interviews were transcribed verbatim by data collectors and further translated from English to local language. The transcribing and translation quality was evaluated by considering linguistic nuances. Preliminary analysis was conducted manually (by authors R.B., V.P., K.N.) to identify a preliminary coding framework consisting of first level of child codes. With an understanding of the coding patterns evolving, the transcript files were imported into NVivo 12 (QSR International) software for in-depth thematic analysis using an inductive approach.[20–23] Two researchers independently conducted analysis to ensure reliability (K.N., M.M.). Child codes which reflected the participant perspectives and experiences at granular level were exhaustively developed in an open-ended manner. Top level codes were further evolved based on similarities and overlaps between child codes. Sub-themes were evolved based on conceptual harmony between top-level codes and overarching major themes were developed which encompassed overlapping sub-themes. The analysis team iteratively evaluated the emerging child codes, top codes, sub-themes and major throughout the analysis till saturation was attained. Saturation was attained at the 19th DR-TB person-caregivers interview dyad at which time no additional top-level codes evolved. One additional interview was conducted to ensure gender representativeness among caregivers across both study districts. Distinguishing and categorising of top codes, sub-themes and themes were based on consensus between data analysts and was performed in an iterative manner. Analytical memos, notes, participant's feedback and reflections from study team were used to review and add a broad-based validation of coding process. Health care provider's interviews were analysed separately but using the same coding patterns, as their perspectives and experiences were mostly consistent with that of PwDR-TB and caregivers. Framework matrix and case classification methods were used to differentiate cross-compare and differentiate the codes of PwDR-TB, caregivers, and healthcare providers. Such an approach provided an opportunity to triangulate and validate the mutual perspectives and experiences of PwDR-TB, caregivers and healthcare providers which have not been attempted before. Reporting adheres to Consolidated Criteria for Reporting Qualitative Research guidelines[24] [Supplementary File 2].

Role of the funding source

The funders of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report.

Results

A total of 20 semi-structured in-depth interviews were completed among eligible PwDR-TB (rifampicin resistant with and without isoniazid resistance-20) who completed treatment under the public health facilities of study districts as per the NTEP guidelines during study period. PwDR-TB were mostly male (n = 13, 65%), literates (n = 18, 90%) and middle aged (35 years, range 21–56 years). Majority of the participants were treated for RR-TB (n = 18, 90%) and had initial hospitalisation (n = 12, 60%) whereas few people had re-treatment history (n = 5, 25%).

The interviewed caregivers were mostly female (n = 14/20, 70%) and literates (n = 15/20, 75%) with a median age higher than DR-TB persons (38 years, range 25–60 years). In terms of relationship with persons, most caregivers were spouses (n = 14, 70%) and rest were parents (n = 5, 25%) and a sibling (n = 1, 5%). Interviewed health care providers (n = 10) were mostly male (n = 18, 90%), middle-aged (40 years, range 36–49) and all were educated and employed under NTEP. Sessions averaged 63 min (range 40–90) for persons, averaged 56 (range 35–77) for caregivers, averaged 63 (range 42–88) for health care providers (Table 1). Three DR-TB persons who were eligible and interviewed were not included in analysis as their caregivers were not willing or had withdrawn in between for personal reasons. Replacement interviews were made subsequently.

The perspectival shift adapted by this study using a positive deviance theory resulted in uncovering a wide range of positive adaptions, solutions and resilient experiences of PwDR-TB, their caregivers, and healthcare providers which out looked their barriers and challenges. Of the total 5645 quotes which were coded, 2763 (48.9%) were related to positive adaptions and resilience, 876 (16%) were related to challenges and barriers and 2006 (35.5%) and rest were common details.

PwDR-TB exhibited faith in treatment, sought spiritual strength and engaged in self and peer learning to cope up with their treatment challenges. While consoled by family members, persons also faced compulsion and

Characteristics of people with DR-TB	n (%), N = 20
Male	13 (65%)
Female	7 (35%)
Median age	35 years
Unemployed	5 (25%)
Poor socio-economic status[a]	5 (25%)
Literate	18 (90%)
Newly diagnosed	15 (75%)
Initial hospitalized care	12 (60%)
Resistance to rifampicin	18 (90%)
Resistance to rifampicin + isoniazid	2 (10%)
Characteristics of caregivers	**n (%), N = 20**
Male	6 (30%)
Female	14 (70%)
Median age	38 years
Unemployed	9 (45%)
Poor socio-economic status[a]	5 (25%)
Literate	15 (75%)
Spouses	14 (70%)
Parents	5 (25%)
Sibling	1 (5%)
Characteristics of healthcare providers	**n (%), N = 10**
Male	8 (80%)
Female	2 (20%)
Median age	40 years

DR-TB: drug-resistant tuberculosis. [a]Poor socio-economic status of family defined by Below Poverty Line criteria used in Indian economic context.

Table 1: **Background demographic characteristics of participants.**

persuasions towards treatment continuation and were aided with resources and livelihood support by caregivers. Healthcare providers ensured routine care, rendered advice and were particularly supportive in ensuring uninterrupted drug supply to PwDR-TB.

Rooted beneath these conventional factors, as we parsed through the narratives, additional insights were attained which were explanatory of positive deviance. PwDR-TB inculcated self-adaptive practices and behaviours which were enabled by the intensive care and participation of their primary caregivers. PwDR-TB acquired treatment related self-efficacy through decisive experiences of attitudinal change, intense sensitisations, and motivations from family members. Consistent engagement and risk mitigation of serious health events by health care providers who ensured the continuity of treatment in face uncertainties (Fig. 1).

Self-adaptation towards treatment challenges and demands

The enormity of dealing with the arduous treatment journey was left to PwDR-TB and their caregivers to deal with it, and healthcare providers played a conventional but minimal role in this context. Hence, self-adaptation towards the adverse side effects and uncertain outcomes was found to be a self-driven phenomenon of the PwDR-TB and their caregivers. Adaptations were tailored to the self-needs and practiced with consistency with the in-delineable participation of care givers (Figs. 1 and 2) (Supplementary Table S1).

Two distinct types of self-adaptive behaviours and practises were adapted by PwDR-TB and caregivers for engaging with the immediate biological consequences of injections and drugs.

Specific self-adaptive practises towards biological adverse consequences of drugs

These included intake of "special adjuvants" by PwDR-TB to improve pill palatability (e.g., swallowing millet-balls with pills inside). Consumption of pills were spaced based on its "size and perceived power" to downplay the consumption burden. Special nutritional intake was practised consistently with the support of caregivers with a belief to fasten cure and improve immunity. Adaptation to injection-induced pain was constantly tried through home-made topical application by the caregivers. Immobility and weakness experienced after injection administration was overcome with resting and person's choice of convenient timing and place for injection use.

Perceptual adaptations to psychological consequences of drugs

Perceptual adaptations were aimed to deal with the perceived burden of pill intake and treatment fatigue. To overcome the treatment fatigue and stress, specific "mind diversion" techniques were nurtured and practised PwDR-TB. It was either passive (listing to music, spiritual contents) or an active engagement (rearing plants, changing ambience, socialisation, creativity, digital entertainment). A personalised medication intake routine was meticulously developed and adapted by persons and caregivers, which helped normalise the drug consumption process. This routinisation involved timing of drug intake (morning or evening), sequencing (before or after food) and choices were made based on the perceived ease or difficulty (taste, size, power, and nausea of pills). Special nutritional intake, weight gain and increase in appetite were considered symbols of hope and it was constantly reinforced and interpreted by persons and care givers throughout treatment.

During daily conversations, "positive labelling" was created for the pills in daily conversations, which were otherwise highly undesirable (e.g., labelling as chocolates). Two types of temporal adaptations were conspicuous in the PwDR-TB narratives. Immediately after the diagnosis, PwDR-TB have adopted "risk aversion" in terms of non-consumption of alcohol and tobacco. Perceptual adaptations toward medication challenges and fatigue were cumulated and were strongly pronounced in the later stages of treatment.

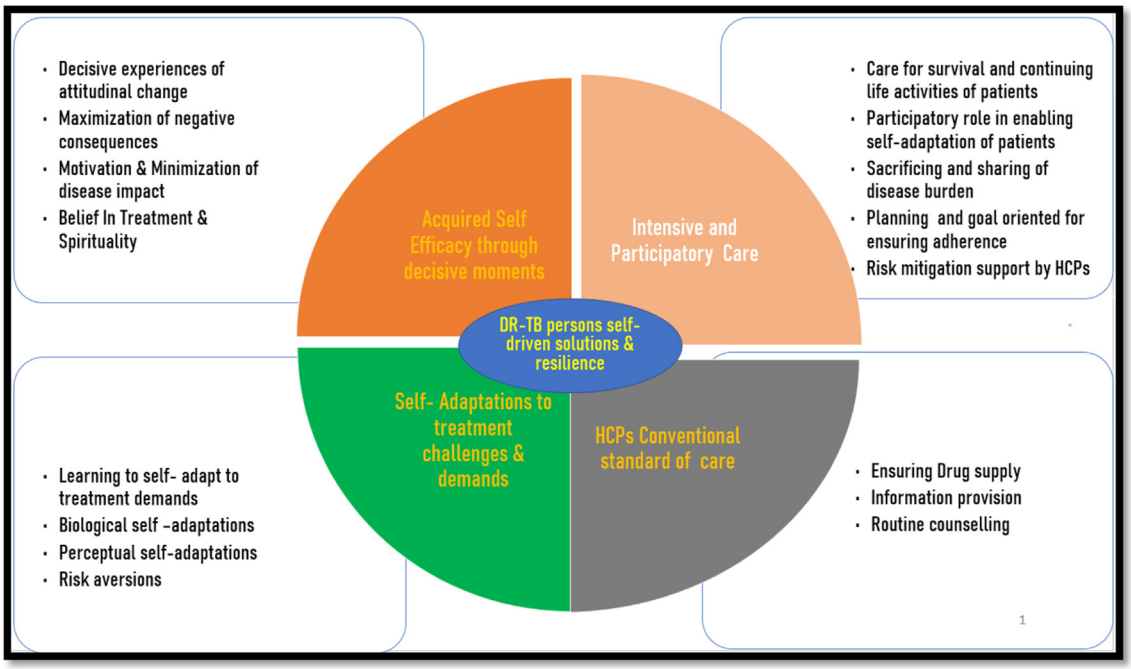

Fig. 1: Themes reflective of self-driven solutions and resilience of persons with DR-TB.

Intensive and participatory caregiving and risk mitigation of healthcare providers

Self-adaptive behaviours and practices of PwDR-TB were intrinsically aligned with the supportive care of caregivers who themselves shared the burden of the illness and made sacrifices. Extreme physical weakness, reduced food intake, respiratory distress, injection induced pain and emotional distress were experienced by the PwDR-TB particularly during initial phase of treatment necessitated a palliative type care. Such intense sort of care demanded commitment, planning, and participation on the part of the family caregiver and was of critical importance for the PwDR-TB survival. Supportive care givers enabled the persons to perform almost all essential life activities which was otherwise seriously disrupted. Caregivers acted in a goal-oriented manner towards PwDR-TB, especially with respect to their medication and food intake. A wide range of personalised nutritional and adjuvant intake were learned by the care giver from peers and were prescribed.

In addition to the conventional care services like counselling, healthcare providers had steps adapted to swiftly and timely mitigate the drug side-effects and other crisis situation's which were experienced and perceived by the PwDR-TB. The role of healthcare providers was that of "risk mitigators" for the PwDR-TB who were in distress and panic and thus ensured treatment continuity (Supplementary Table S2) (Figs. 1 and 2).

Acquired self-efficacy through decisive moments of change in attitude

The in-depth narratives highlighted some "decisive phases" of experience which tide-turned the PwDR-TB's attitude towards medication challenges and had profound impact on their perceived ability (or self-efficacy). Concerns about the disease impact on the lives of their children (e.g., orphanisation in the face of treatment failure), transmission risks and end of life notions were usually the factors which triggered these decisive experiences and subsequent attitudinal change. Family members and healthcare providers maximised the negative impacts of drug discontinuation by invoking fearful references and invoked positive and motivating examples. PwDR-TB sought inspirational contents through online sources. While decisive moments were spontaneous and standalone, sensitisations and motivations were repeatedly availed for and accessed by PwDR-TB which conditioned their self-efficacy levels (Supplementary Table S3) (Figs. 1 and 2).

Belief in treatment and spirituality

While the side effects of drugs and poor progress haunted the PwDR-TB, still they had acquired a strong belief in medication. Contrastingly participants also resorted to spirituality to reinterpret their disease status and provided a moral basis for disease acceptance and pragmatism (Supplementary Table S3) (Figs. 1 and 2).

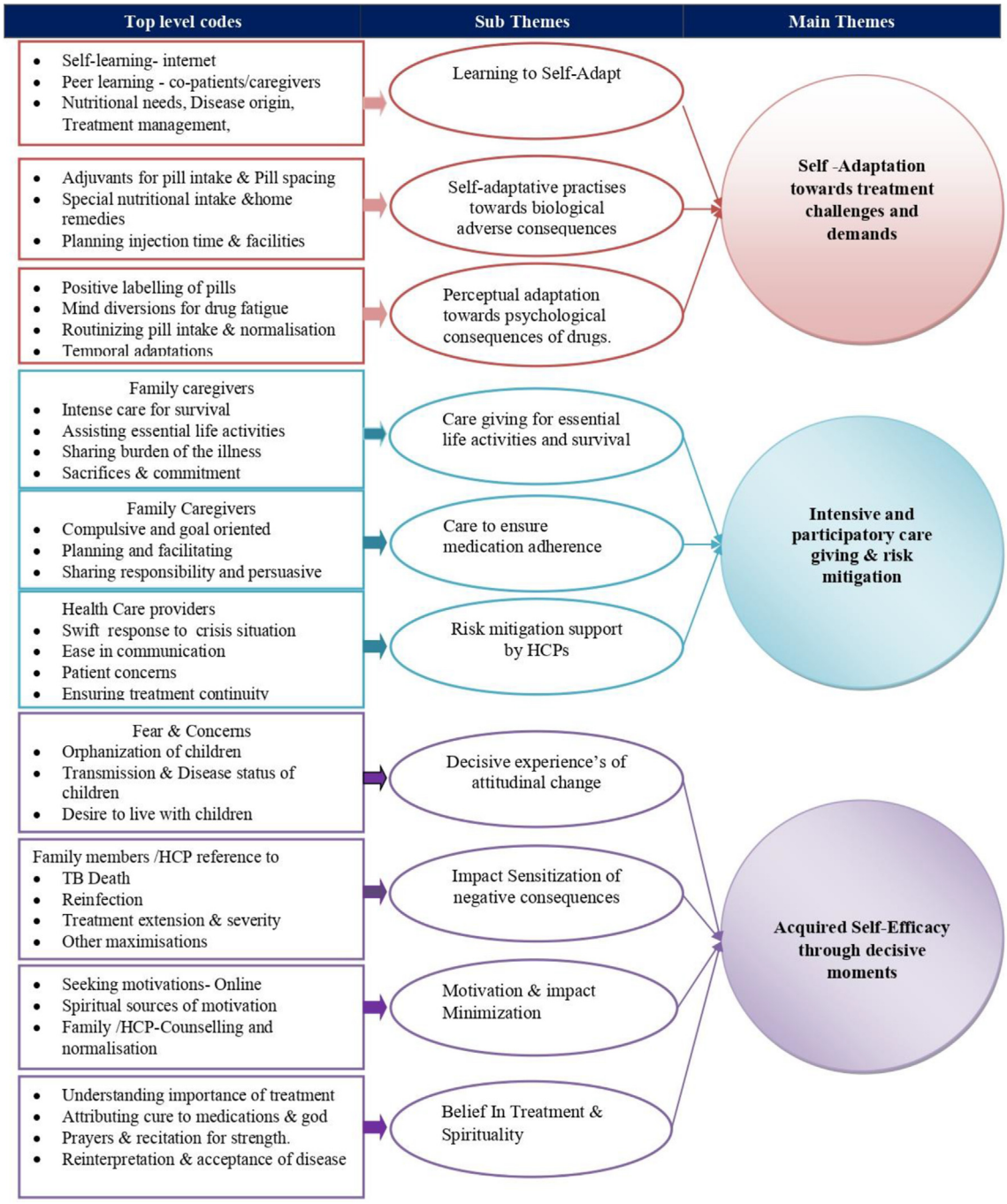

Fig. 2: Hierarchical representation of top level codes, sub-themes and themes reflective of self-driven solutions and resilience of persons with DR-TB treatment.

Discussion

We chronologised the rich experiences and perspectives of PwDR-TB, which were reflective of the self-driven solutions and resilience as compared to their experiences of challenges and barriers.[1] We hence made a notable shift from the problem-centred perspective. We attempted to provide rational explanations for the identified distinct forms of positive deviances: intense and participatory care, self-adaptation and self-efficacy towards treatment challenges, and discussed the

opportunities for translating these positive deviances into implementable solutions.

Underlying rationale and cognitive process of self-adaptive practises

The range of self-adaptive practices of PwDR-TB was found to be of vital importance for their survival and resilience. Self-adaptive practices provided the PwDR-TB with choices to process, reinterpret and confront their painful and inescapable treatment experiences and had a cognitive restructuring effect for them.[25–27]

PwDR-TB and caregivers had cognitively anchored their own collective beliefs and hopes for disease recovery with the special nutritional intake process and its consequent gain in terms of, immunity and weight gain. In addition, special nutritional intake was strongly associated for its curative effects against the microbes as like antibiotics. Such hyped, yet beneficial belief in the curative effect of special nutrition acquires significance from the PwDR-TB's perspective, who seek for promising alternatives and hopes, while trying to navigate a rigid and unpleasant treatment regimen.[28] Signs of incremental physical progress also provided an opportunity for PwDR-TB to reinterpret their debilitated status in a positive manner.[25,29]

Positive labelling of drugs leads to the desirable anchoring effects with "pills", and thus helped PwDR-TB to counter the displeasure associated with pills. Similarly, practises like "adjuvant intake", "pill spacing" and "routinisation of medication intake" helped them turn pill consumption into a routine process and created an opportunity for cognitively[30] normalising the aversion associated with consumption.[31,32] Increased adaption to drugs with progressive treatment stages could be due to the cumulative biological improvements and continuous drug exposure leading to sustained perceptual adaptions and habituation. Distinguishing such adaptive difference during the timeline of treatment could help develop phased psycho-social interventions with varying intensity as compared to pre-determined modules.

Intervention opportunity to address perception burden and treatment fatigue of PwDR-TB

The symbolic importance associated with nutritional intake and physical signs of improvement could help restructure the treatment perceptions of PwDR-TB. In-building intuitive information feedbacks and framing nudges within the person–caregiver interaction process, to reinforce person's perceptions on improvement of their physical health—however trivial—could unease treatment fatigue.[33–38] Gain framing approaches for developing communication messages for PwDR-TB could be a useful way forward.[39] Caregivers could positively reinforce the incremental milestones which persons have achieved through the treatment (e.g., increasing probability of cure, decreasing transmission risk for family members) to help ease their perception burden. Insights from paediatric care and drug marketing research could be of use in repurposing drugs pouches with person friendly design and cues to address drug aversion.[40–43] Interventions like mind and body relaxation therapy, guided imagery and cognitive distraction technique's which have been utilised in addressing cancer and HIV therapy related stress, fatigue and nausea could be of use in DR-TB context.[44–46]

Orienting and skill building for caregivers in adopting person centred communication strategies (involving verbal and non-verbal cues) and to practise motivation, mind diversion and relaxation techniques could help normalise the persons drug intake process.[47–49]

Opportunities to maximise biological self-adaptations to adverse consequences medications

Over the existing personalised nutrition counselling in TB program, healthcare providers could aid and handhold the caregivers and persons with an implementable dietary plan in consideration of their resource limits, traditional food and cultural context. Compilation of dietary practises of PwDR-TB and insights from the traditional system of medicines could be of utmost importance in developing cost-effective and culturally adaptive special nutritional recipes and adjuvants (e.g., pomegranate based products used for chronic nausea and vomiting) to improve drug acceptance and palatability.[50,51] Lessons from paediatric and child care to improve nutrition and pill intake could be of use for improving drug palatability by adjusting the size colour and the aesthetics of the pills and pill covers.[52]

Considering the programmatic shift towards all oral regimens, we restricted our discussion towards the adaptive management of pain and weakness associated with injections. Still the high demands and the complexities which the PwDR-TB and caregivers adapted for, especially regarding the oral drug consumption, underscores its limitation as an all-out saviour from the injection-based regimens for DR-TB.

Intense and participatory care: recognising the enhanced role of caregivers

The granular insights pertaining to the positive adaptations and resilience of PwDR-TB were found rooted in the intense care and participation of caregivers. Past studies have underscored the wider spectrum of the care demands of PwDR-TB and the limitation of health care systems in fulfilling them.[53,54]

While the importance of family care has been realised in previous literature related to DR-TB care,[55] present findings underscore the dyadic relationship and the collective agency between the patient and care giver. Intense commitment, consistent participation, goal setting and shared responsibility were the attributes of this dyadic relationship and the study distinguishes caregivers as active therapeutic partners of the PwDR-TB.[56] The role of care givers in reinforcing biographical

and biological continuity in the lives of PwDR-TB needs more emphasise and mainstreaming.[57–59]

Preparing the caregivers along with PwDR-TB

Providing TB literacy for care givers at the time of diagnosis could have a multiplier effect in addressing the perceived uncertainties, disease denials and suicidal thoughts of PwDR-TB and could sow the seeds of resilience in them in an early stage of disease.[60] Orienting and skill building of the caregivers on aspects of patient management including goal setting, microplanning, problem solving, crisis handling, caregiving, motivational techniques, and person centred communication skills would be of practical value.[57,61–63]

Self-efficacy and decisive moments

Our study population from a resource-poor setting, had acquired notable self-efficacy towards treatment uptake despite being greatly distressed by mental and physical debilitation.[14] While self-efficacy could be attributed to the life-threatening nature of DR-TB and elevated risk perceptions,[64,65] our findings add further insights. PwDR-TB narrated about instantaneous decisive experiences which tide-turned their attitude towards medication challenges. During decisive experiences, the familial role of PwDR-TB and the purpose of their lives were sensationalised in an intense way by the family members.[66] Hence instilling and reinforcing the life purpose notions, family values and purpose of life notions using cognitive approaches could be a potential way to build self-efficacy of PwDR-TB.[25,66,67] Health communication, counselling and therapeutic contents targeted at PwDR-TB needs to be designed with family-centric contents and emphasising the value of life purposes of PwDR-TB. Creating self-reflective patient, family and relationship stories through peer group interaction and innovative digital contents in local languages could be of utmost use in building self-efficacy of PwDR-TB. Choices in using positive motivations and maximisation of the disease consequences during person–provider interactions could help sustain the acquired self-efficacy. The role of healthcare providers in risk mitigation of PwDR-TB at the time of despair could be formalised at the facility level. A rapid response approach to risk mitigation is feasible with the present digital and health platforms being adopted in the national TB programs.[68]

Our study findings need to be interpreted with limitations and opportunities to address them. Our study population excluded children, adolescents, and more severe forms drug resistance (XDR, HIV coinfections) and thus may be limited in generalising the identified DR-TB person's self-driven solutions. Participants' experiences regarding their adaptations and resilience were collected after their treatment completion and thus were retrospective and were subject to recall bias. The interviews of family care providers were strength of this study which provided opportunity to cross-compare and validate the perspectives of PwDR-TB and fill in information gaps which could have resulted from recall bias. Our interviews attained sufficient depth and granularity which is reflected in the richness of quotes of participants. While the adherence level of PwDR-TB (used to define their positive deviance) lacked a standard biological validation, still our verification process was valid, as it was triangulated using a multi-step verification process.

The identified self-driven solutions among positively deviant PwDR-TB may have some limitations in terms of generalisability. However, the findings highlight the existing opportunities for nurturing resilience and enabling caregivers support for another PwDR-TB who may lack it partly or completely. While the positively deviant individuals in this study had faced immense challenges and barriers similar to all other PwDR-TB, still a combination of factors related to individual resilience, care givers and health system support enabled them in coping up. The present study provides an opportunity for developing person-centred interventions for DR-TB which are self-driven and could be easily facilitated by the TB program workers.

The present study provides opportunity to develop implementable self-driven solutions for PwDR-TB based on their positively deviant peers, which could be tested for their effectiveness using quantitative methods. Moving beyond the behavioural change notions, this study emphasises the importance of change in attitude and self-efficacy acquired by PwDR-TB in navigating the multi-dimensional challenges of DR-TB. Attitude change towards medication challenges, acted as a strong mediating factor which in turn was enabled by the intense and participation caregiving process. We found these three deviations (intense and participatory care, self-adaptation and self-efficacy towards treatment challenges) of PwDR-TB, acted in a mutually dependent and reinforcing manner and enabled them to be more resilient. The thematically categorised experiences of PwDR-TB and caregivers provide the opportunity for conceptualising and testing conventional and cognitive science-based interventions to improve the person centred care and outcomes care of PwDR-TB in India and similar resource poor countries with high DR-TB burden.

Contributors

Conceptualisation, K.N., K.K., A.S., R.A., R.B., R.S., A.G., and M.M; methodology, K.N., S.S., M.M., R.B., and V.P; software, K.N., S.A., and M.M; formal analysis, PMD., R.B., VP.,KN.,MM.; investigation, S.S., K.K., V.P., R.R., data collection, PMD, JB data curation, S.S., M.M., K.N., VP., R.B.; writing—original draft preparation, K.N., K.K., S.S., S.A., J.B., and M.M; writing—review and editing, K.N., K.K., V.P., A.S., R.A., R.B., M.M., R.S., J.M., J.B., and A.G; supervision & project administration, K.N., K.K., A.S., R.A., R.B., R.S., J.M., and A.G. resources & funding acquisition, K.N., K.K., R.B., R.S. and A.G. All authors have read and agreed to the published version of the manuscript.

Data sharing statement

All relevant data are included in this publication. Audio files and transcripts of this study contain sensitive and personal information about persons and families and thus will not be shared to maintain participant confidentiality.

Declaration of interests

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Appendix A. Supplementary data

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