

ORIGINAL ARTICLE - PUBLIC HEALTH

WINGS OF SUPPORT (UDHAVUM SIRAGUGAL) : A HOLISTIC PSYCHO-SOCIAL INTERVENTION FOR TB PERSONS AND CAREGIVERS IN A TERTIARY CARE FACILITY IN TAMIL NADU, AN IMPLEMENTATION RESEARCH APPROACH

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Abstract

CONTEXT: Patient-centric care recognizes the psycho-social needs of Tuberculosis (TB) patients. Integrating psycho-social interventions to improve the resilience of persons with TB and their caregivers during the TB care cascade is a need.

AIMS : We share the field experiences and outcomes of implementing a participatory patient-centric psycho-social intervention for persons with TB in a selected tertiary TB care facility in Tamil Nadu.

SETTINGS AND DESIGN : We used co-creation methods to develop a psycho-social intervention module based on the self-efficacy constructs used in chronic disease management. Participants consisted of persons with TB admitted to the Government Hospital of Thoracic Medicine, Tambaram, and their family caregivers.

METHODS AND MATERIAL: Participatory and game-based intervention (designated as Wings of Support sessions) was conducted in group mode (n =10-12) (both patients and caregivers) for 45-60 minutes once weekly. Each session focused on TB stigma, medication adherence, nutritional issues, unhealthy behaviors like alcoholism, stress, anxiety, and other related issues. Each session employed specific concepts and techniques involving motivation, goal setting, psycho-education, problem-solving, mindfulness, normalization, behavioral activation, and cognitive coping.

RESULTS : Between March 2023 to January 2024, 44 sessions were conducted by healthcare providers and social workers on different themes related to TB disease, medication, and its management. A total of 450 persons with TB and their caregivers attended. Group Sessions related to TB stigma, nutrition, medication adherence, and family caregiving were co-created and implemented in an iterative and tailored manner by the study team, making it more adaptable and flexible. The intervention was found more receptive, and was perceived as highly relevant and useful by the participants, and in terms of techniques employed in the sessions, game-based activities, artistic recreation, and mindfulness techniques had the most acceptance and participation.

CONCLUSIONS : Post-intervention feedback highlighted the usefulness of Wings of Support sessions in improving their treatment resilience and helped identify potential TB champions. The intervention led to demand generation among other TB persons, caregivers, and healthcare workers in the same facility. Group-based participatory psycho-social interventions hold the potential to address a range of psycho-social and treatment needs of the person with TB and their caregivers in an efficient and program-friendly manner. The intervention is being proposed for evaluation in NTEP program settings using an experimental study design to test its efficacy

KEYWORDS : person-centric, psycho-social, wings of support, motivation, TB persons, caregivers, treatment

INTRODUCTION

TB patients experience a range of physical and psycho-social challenges which are complex. While the disease's status deteriorates the patient's physical and mental health status, on the other hand, TB treatment-related difficulties themselves amplify their existing challenges and adherence to TB medications.^{1,2} Patients and caregivers suffer fear, emotional distress, and anxiety, due to disease denial, perceived fear of death, and infection risk.³ Patients suffer stigma, hopelessness, and suicidal thoughts at diagnosis

and early treatment phase.⁴ Further, at the time of treatment, the patient's negative psycho-social (including depression, anxiety, stress, and low self-esteem) and life experiences get compounded by treatment burden, medication intolerance,

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physical deterioration, and other concerns.⁵ The perceived burden of treatment and infection risk-related concerns affect the mental health of patients and intolerance towards caregivers.⁶

Significant psycho-social and economic burden of the disease and treatment of the patient is shared by family caregivers who also face the risk of infection during the caring process.^{7,8} Such a wide spectrum of issues that prospectively arise for TB patients and caregivers, which in turn affects their treatment adherence and outcomes remains unaddressed to date. TB elimination goals to achieve a 92% treatment success rate by 2025 require an effective patient-centric intervention that could improve the treatment uptake self-efficacy and motivation of patients and caregivers to a substantial level. At present there is a lack of psycho-social interventions that would be effective, acceptable, and scalable in improving the treatment self-efficacy and thereby addressing the multi-dimensional challenges and needs faced by TB patients and their caregivers in an integrated and patient-centric way under the TB program conditions.

SUBJECTS AND METHODS

CONCEPTUALIZATION OF INTERVENTION IN THE FORMATIVE PHASE : The proposed intervention is developed based on the past research findings which were conducted among DS-TB patients and DR-TB patients by ICMR-NIRT in the past in different states of India including Tamil Nadu, Karnataka, and Telangana in past years. The intervention was developed based on the insights and feedback from TB patients, caregivers, and healthcare care providers' views on the barriers to TB treatment completion and also the positive enabling factors (positive deviance) that enabled them to complete the TB medication and related life barriers. We found the following thematic factors at the individual patient level and caregiver level which defined the resilience of the patients which are, self-efficacy, "self-adaptation," and "learning and motivation , and "Care & support". It was found that of all the driving factors behind the patient's completion of treatment was the construct of "Self -Efficacy" in which the patients attained a belief state or attitude to overcome the barriers he/she experienced which was followed by behaviour change (as defined by Albert Bandura's theory 1977). Thus, intervention to inculcate self-efficacy is required in addition to the routine counselling or Information, Education, and Communication (IEC) interventions which is routinely provided for the patients. Self-efficacy as a trait in this study would be inculcated by exposing the patients to peer experiences, participatory

activities, resilience building, and motivational exercises. In addition, the family caregivers of patients would be involved in the intervention with equal importance to the patients thus making them an active agent of the intervention. The intervention manual was formatively developed and piloted in a TB care hospital in the Kancheepuram district of Tamil Nadu.

We used an implementation research approach to develop a psycho-social intervention module based on the self-efficacy constructs. We have used the PRODUCES framework (Problem, Objective, and Design, (end-) Users, Co-creators) for developing this intervention.⁹

Table 1 : We have used the PRODUCES framework (Problem, Objective, and Design, (end-) Users, Co-creators) for developing this intervention.

| | |
|--------------------|--|
| Problem | Addressing the poor self-efficacy, psycho-social issues, health-seeking gaps, and treatment challenges of patients and caregivers |
| Objective, | Developing a comprehensive intervention to improve self-efficacy toward treatment uptake and infection prevention among patients and family caregivers |
| Design, end-Users, | Co-creation, TB patients, caregivers, program stakeholders' workers, community stakeholders, researchers |
| Co-creators | TB persons, caregivers, program stakeholders, student's community stakeholders, researchers |
| Evaluation | Hybrid implementation study to assess efficacy and implementation issues in different socio-cultural settings where it was co-created |
| Scale up | Will be sustained in the implementation districts based on the study outcomes |

Of the six stages of the production framework, the stage till co-creation has been completed and the evaluation stage is being taken up through the present study. We propose to conduct a two-arm non-randomized cluster intervention study for this objective of evaluation.

We utilized a co-creation exercise among TB patients, caregivers, and healthcare workers based on which a self-efficacy drive intervention manual and operating procedures have been developed.

RESULTS

Participants consisted of persons with TB admitted to the Government Hospital of Thoracic Medicine, Tambaram, and their family caregivers. Participatory and game-based interventions (designated as Wings of Support sessions) were conducted in group mode (n=10-12) for 45-60 minutes weekly. Each session focused on TB stigma, resilience building, mindfulness, medication adherence, nutritional issues, unhealthy behaviour stress, anxiety, and other related issues. Each session employed specific concepts and techniques involving motivations, goal setting, psycho-education, problem-solving, mindfulness, normalization,

behavioral activation, and cognitive coping based on the theory of self-efficacy (Figure 1). The sessions were conducted interactively over 10 months with inputs and participation from TB persons, caregivers, and all stakeholders, and sessions were enriched and tailored to the needs and preferences of the affected population.

Table 1 : Co-created intervention manual content and schedule for improving self-efficacy and treatment outcomes of persons with tuberculosis and their caregivers

| Visit Number | Time Point & Duration | Type of session | Topics to be covered | Methods |
|--------------|--|---------------------------|--|--|
| 1 | Intensive Phase 0-15 Days Max -45 Minutes | Individual Session | <ul style="list-style-type: none"> Introduction and purposes of the session. Understanding about TB Medication adherence, infection control, nutrition Risky behavior related to TB | Individual counseling |
| 2 | 16-30 Days Max -50 Minutes | Individual Session | <ul style="list-style-type: none"> Stigma & Discrimination Mental wellbeing & Life purpose clarification exercise Caregiver roles and responsibilities Recap and follow up on medication adherence | Individual counseling |
| 1 | 16-45 days 45- 60 minutes | Group session | <ul style="list-style-type: none"> Practicing healthy diet and infection control, limiting risky behavior. information on routine medication adherence and continuation | Activity - Co-creation activity using pictures on diet and infection control |
| 2 | 45-60 Days Max -30 Minutes | Group session | <ul style="list-style-type: none"> Peers role model identification for normalization, positive attitude, and building self-efficacy Identifying patient attributes, needs, and preferences | Activity -- Expressions using Emoji to trigger positive attitude and role model generation |
| 3 | Continuation Phase 3rd Month 45- 60 Minutes | Group session | <ul style="list-style-type: none"> lifestyle modification for better TB management Routine medication adherence & continuation | Activity -- Using cognitive anchoring methods & number games |
| 4 | 3rd Month 45- 60 minutes | Group session | <ul style="list-style-type: none"> Appraising the value of life, family, and life purpose clarification overcoming stigma, and building self-efficacy Routine medication adherence & continuation | Activity -- Storytelling and relationship valuing activity |
| 5 | 4th Month 45- 60 minutes | Group session | <ul style="list-style-type: none"> Building problem-solving skills, coping behavior, and self-efficacy Routine Medication adherence & continuation | Activity Collaboration conquest to achieve goals by solving hurdles as teams |
| 6 | 5th Month 45- 60 minutes | Group session | <ul style="list-style-type: none"> Medication adherence & continuation. Stress relaxation | Activity- Mindfulness activity and art (painting) |
| 7 | 6th Month 45- 60 minutes | Group session | <ul style="list-style-type: none"> Building communication between patients and caregivers Routine medication adherence & continuation | Activity -- Converse and connect activity |
| 8 | 6th Month 45- 60 minutes | Group session | <ul style="list-style-type: none"> Building resilience among patients Lifestyle modification Routine medication adherence & continuation | Activity-Resilience wheel activity |

INTERVENTION IMPLEMENTATION & ACCEPTANCE:

Between March 2023 to January 2024, 44 sessions were conducted by healthcare providers and social workers on different themes related to TB diseases, medications, and its management. A total of 450 persons with TB and their caregivers attended. Sessions related to TB stigma, nutrition, medication adherence, and family caregiving were found more receptive and perceived as highly relevant and useful by the participants, and in terms of techniques employed in the sessions, game-based activities, artistic recreation,

and mindfulness techniques had the most acceptance and participation. Post-intervention feedback highlighted the usefulness of Wings of Support sessions in improving their treatment resilience and helped identify potential TB champions. The intervention leads to demand generation among other TB persons, caregivers, and healthcare workers in the same facility. Group-based participatory psycho-social interventions were able to address a range of psycho-social and treatment needs of the person with TB and their caregivers in a program-friendly manner. The evolved intervention has been termed a Self-Efficacy Driven Intervention for TB patients and is given below

DISCUSSION

The self-efficacy-driven intervention is further proposed for evaluating its efficacy in program conditions using an experimental study in program settings. The proposed intervention will be the first integrated, theory-driven, and evidence-based psycho-social intervention for persons with TB patients and is aimed at positively impacting their treatment acceptance and uptake, self-care, and underlying psycho-social issues in a holistic way. Evidence of efficacy from this study may lead to the scaling up of self-efficacy interventions pragmatically under the NTEP program in India. The co-created intervention would generate substantial benefits to the participants as it will provide urgently needed answers to what may be feasible and holistic psycho-social intervention for addressing poor treatment self-efficacy, treatment adherence, and poor mental health status at the level of TB patients. This could lead to advances in care that could eventually improve treatment outcomes for TB patients in India and other low- and middle-income countries. The study will also provide evidence that a targeted intervention at the level of patients and caregivers could help improve infection control self-management which is crucial for cutting the transmission of diseases.

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