

University of Groningen

Tuberculosis Patient-Centred Care

Akkerman, Onno W.; Van der Werf, Tjip S.

Published in:
Essential Tuberculosis

DOI:
[10.1007/978-3-030-66703-0_20](https://doi.org/10.1007/978-3-030-66703-0_20)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2021

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):
Akkerman, O. W., & Van der Werf, T. S. (2021). Tuberculosis Patient-Centred Care. In *Essential Tuberculosis* (pp. 177-183). Springer International Publishing AG. https://doi.org/10.1007/978-3-030-66703-0_20

Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.



Onno W. Akkerman and Tjip S. van der Werf

Abstract

Increasing complexity of tuberculosis (TB) is one of the causes that TB is still the leading cause of death by an infectious disease. Among the complicating factors are increasing drug resistance and comorbidities. Patient-centred care, and even more individualised treatment, would be the way forward. The different aspects of patient-centred care model, including medical, social and supportive care are discussed.

Keywords

Patient-centred care · Holistic approach · Individualised treatment · Pharmacokinetics · Social care · Supportive care · Video-observed treatment

O. W. Akkerman (✉)

Department of Pulmonary Diseases and Tuberculosis, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

TB Center Beatrixoord, University Medical Center Groningen, University of Groningen, Haren, The Netherlands

e-mail: o.w.akkerman@umcg.nl

T. S. van der Werf

Department of Pulmonary Diseases and Tuberculosis, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

Department of Internal Medicine, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

e-mail: t.s.van.der.werf@umcg.nl

20.1 Introduction

The British Medical Research Council (BMRC) trials in the seventies of the last century established a combination of anti-tuberculosis (TB) drugs for 6 months as the standard treatment to cure TB, with more than 97% of TB patients having successful outcome [1]. The strength for national TB programmes to use this combination of anti-TB drugs was its simplicity; the standard TB regimen is the principle of ‘one size fits all’ in relation to the dose of the drugs, and the duration of treatment. If active case finding would be added to this standardized, highly effective treatment, national programs would be enabled to reduce transmission and improve TB control [2]. Since 1994, the principle of directly observed therapy (DOT) was actively promoted to increase compliance with TB treatment, thereby enhancing the efforts to eradicate TB [3]. Based on these principles, national programs have prevented many new cases, including over 50 million TB-related deaths in the past five decades. TB has however not been eradicated; it still leads the cause of death by infection.

The fact that TB is still the most prevalent and deadly infectious disease worldwide [4] can at least partly be explained by the increased complexity of TB; its comorbidities and the ever-increasing drug resistance are just two of several important complicating factors. Emerging drug resistance reflects failure of national TB programs and with increasing drug resistance worldwide, it calls for alternative approaches to improve TB control [2]. With increasing complexity, a programmatic approach falls short to address these new challenges. Patient-centred care would be the way forward [5], as a new strategy [6] adjusting or replacing the DOT strategy that does not necessarily tailor the approach to enhance compliance with therapy, and patient-centred care addresses specific needs of individuals patients to adhere to the scheduled TB treatment. It recognizes the basic rights of people affected with TB to be addressed as a unique human being, with unique needs; the need to be fully informed about the condition they suffer from, and the required medication to obtain cure; the side effects that are possibly met; their preferences with regard to time slots and practical challenges to follow their treatment; the timing, venues and practicalities involved in follow-up visits; financial and time constraints to report at planned follow-up visits; financial and logistic problems involved in the therapy; care in case of adverse events; challenges in disclosure toward family members, beloved ones, friends and acquaintances; issues related to disclosure, in relation to contact and source investigations; pharmaceutical care issues and issues related to school attendance and resuming of work. It starts with including the private sector, where many first contacts with TB patients happen, into the national TB programs [5]. This private sector is diverse, and it is underequipped to both diagnose and manage TB patients.

In summary, there is a need to make patient-centred care a more individualized or holistic approach that pays respect to patients’ unique needs and unique (drug-susceptible, mono- or multi-drug resistant) *M. tuberculosis* isolate; comorbidities, like diabetes mellitus or malnourishment; and co-infections like human immunodeficiency virus (HIV), hepatitis B or C. For the medical challenges, the individual approach uses the principles of treatment guided by pharmacokinetic/

pharmacodynamic (PK/PD) equations, with adequate attention for adverse events and necessary tailoring of treatment. A more holistic approach of the patient also includes attention to their social environment, their vulnerability but also their specific physical, nutritional, social, mental and spiritual needs [7].

20.2 Aim

The aim of this chapter is to provide an overview of different aspects of patient-centred care or an even more holistic approach, including medical, social and supportive care.

20.3 Individualized Care

20.3.1 Medical Care

Management of severe forms of TB, like drug-resistant tuberculosis (DRTB) and central nervous system tuberculosis (CNSTB), is challenging. Treatment of DRTB, compared to drug-susceptible tuberculosis (DSTB), lasts long (from 9 to 24 months), is more toxic, needs centralized care, with longer hospital stays and, due to adverse drug reactions that are more common, result in interruptions or complete cessation of therapy [8].

Starting an adequate treatment regimen with high efficacy and low toxicity is the first step. Although in designing an individualized initial treatment schedule, typically following the international guidelines [9], often, tailor-made solutions are essential to enhance adherence, trust and effectiveness. Knowledge of PK/PD principles is important to improve outcome and it helps to reduce complications. Drug susceptibility testing, using molecular or phenotypical assays—the PD part in the equation—is important to tailor individual treatment regimens. To optimize efficacy and decrease toxicity, therapeutic drug monitoring is essential. Based on the PK/PD results, the treatment regimen can be adjusted, by tailoring the dose. Collaboration with a clinical pharmacologist and microbiologist helps optimizing the adjusted treatment regimen [7]. Monitoring of treatment and follow-up are essential; once the patient is responding to treatment, and no longer infectious, treatment can be continued in a decentralized setting. A shared care model can be used with a local doctor works with the experts in the central facility.

Many patients with TB experience sequelae after the end of treatment. Individualized awareness for these sequelae helps minimizing the complications and tailor the design of individualized rehabilitation programmes [10]. Some patients treated for pulmonary TB benefit from pulmonary rehabilitation, evaluating their pulmonary status, including pulmonary function and exercise tests [10], at the end or after treatment.

Severe forms of extrapulmonary TB (EPTB), like spinal and central nervous system TB, have a high morbidity and mortality as well. Optimizing treatment regimens using the PK/PD principle, including knowledge of, or assessment of drug

penetration in tissues and body fluids like the cerebrospinal fluid may improve outcome [11]. Follow up during treatment and rehabilitation should all be teamwork, including neurologists and rehabilitation specialists, and can be decentralized after well-tolerated, adequately dosed treatment is initiated. A decline in physical function during treatment can be due to treatment failure, but also the result of paradoxical worsening, and should be assessed carefully and managed accordingly.

20.3.2 Social Care

Special attention for the social status is one of the keystones of patient-centred care. Long treatment and hospital stays can lead to stigmatization, family or social isolation and loss of income. To improve adherence and treatment outcome, these issues are important in the centralized as well as in the decentralized treatment centres or TB clinics. Furthermore, patients should be encouraged to take an active role in their treatment, with special attention to denial of disease, lack of hope and their sense of social isolation. Paternalism in healthcare systems can hinder patient's active engagement [12]. Proper communication, including attention for language barriers, is part of the motivation, as is compensation for their economic losses. Specially trained social workers can help and motivate patients in their engagement to treatment [12]. Explaining TB, while taking into account the literacy level of patients, can be done by these social workers as well, but also dedicated TB nurses have an important role.

Some patients experience loss of quality of life during their treatment, but in most patients, we see their overall well-being improve over time during treatment. Patients who do not improve need extra attention, as their treatment outcome may be poor [13]. In every setting, social workers should actively assess quality of life using questionnaires to monitor improvement over time. Extra attention by socializing and connecting with individuals, addressing specific needs, desires, preferences and problems may help, while specific problems may be detected that require specialized care by psychiatrists, psychologists or spiritual counsellors.

In the different setting, including the centralized TB centres, decentralized TB hospitals and TB clinics, nurses play a pivotal role in the treatment of TB. Nurses are trained to interact with patients with various different backgrounds, and their mindset and commitment creates opportunities to effectively interact with patients without barriers that may be present in interactions with medical staff. Therefore, nursing staff are literally the ears and eyes of the medical staff [14]. They can play an important role in education and follow up of video-observed therapy (VOT) at home, which is a preferable option compared to DOT [15]. The next step in patient-centred care is to decide (in different frequencies) for either synchronous VOT, i.e. swallowing the medication in front of a camera while the health care worker watches remotely, or asynchronous, i.e. video record swallowing the medication so the healthcare worker can assess drug intake later [16].

20.3.3 Supportive Care

Nutritional and physical assessment and care are important parts of TB treatment [10]. Malnutrition can be disease related, which is characterized by a loss of free fat mass, resulting in impaired muscle function. Even normal weight, overweight and obese TB patients can have disease-related malnutrition. Loss of physical function leads to dependency and reduced participation in society. Regaining the physical function shortens the time needed for recovery and to resume work.

Malnutrition is an important reversible risk factor for treatment failure and is associated with a twofold higher mortality risk. Malnutrition, next to other comorbidities like diabetes and HIV, can lead to malabsorption of anti-TB drugs, resulting in low drug exposure [10]. Although a gold standard for malnutrition is lacking, the Global Leadership Initiative on Malnutrition provides criteria for uniformity in nutritional assessment. These criteria include assessment of weight loss, low Body Mass Index, reduced muscle mass (phenotypic criteria) and reduced food intake and disease burden/ inflammation condition (etiologic criteria).

If malnutrition is diagnosed, a tailor-made, individualized treatment plan needs to be developed that should consist of a combination of training with sufficient intake of proteins and energy. During and after treatment, when patients follow a rehabilitation program, physical and nutritional counselling and measurements should be repeated regularly [10].

20.4 Global and Country Experiences

Different aspects of patient-centred care have been studied and some have been implemented in TB programs. Performing therapeutic drug monitoring is addressed in the American Thoracic Society (ATS) guidelines for specific groups of TB patients [17]. Furthermore, VOT has been implemented in the TB programme of Belarus, with high patient satisfaction, resulting in time and cost savings, and good appreciation of healthcare workers [18]. A study conducted in the United Kingdom showed higher success rates of VOT versus DOT in treatment completion after the first 2 months of treatment [15].

In a South African study, social workers were specially trained in motivating active engagement of patients in their treatment for DRTB-HIV. Though with a small sample size, this study showed that adequate training for social workers can be a successful strategy for patient-centred care.

20.5 Main Conclusions and Recommendations

To improve outcome and decrease absolute numbers of DRTB or severe EPTB cases, there is an urgent need for more individualized and patient-centred care. Clearly, an effective treatment regimen with the lowest possible toxicity and lowest possible duration is needed. Treatment should be continued at home as soon as

possible using (a)synchronous VOT. Social circumstances, like stigmatization, social isolation and loss of income by expert social workers or TB nurses, are important. Supportive care should be focussed on societal participation, with individual needs, while regaining physical function as fast as possible, by nutritional and physical care. All these aspects enhance treatment adherence and, eventually, improve treatment outcome.

References

1. Mitchinson DA, Davies G. The chemotherapy of tuberculosis: past, presence and future. *Int J Tuberc Lung Dis.* 2012;16(6):724–32.
2. Fox W, Ellard GA, Mitchinson DA. Studies on the treatment of tuberculosis undertaken by the British Medical Research Council Tuberculosis Units, 1946–1986, with relevant subsequent publications. *Int J Tuberc Lung Dis.* 1999;3(S2):S231–79.
3. Chaisson RE, Coberly JS, De Cock KM. DOTS and drug resistance: a silver lining to a darkening cloud. *Int J Tuberc Lung Dis.* 1999 Jan;3(1):1–3.
4. <https://www.who.int/health-topics/tuberculosis>.
5. Jaramillo J, Yadav R, Herrera R. Why every word counts: towards patient- and people-centered tuberculosis care. *Int J Tuberc Lung Dis.* 2019;23(5):547–51.
6. O'Donnell MR, Daftary A, Frick M, Hirsch-Moverman Y, Amico KR, Senthilingam M, Wolf A, Metcalfe JZ, Isaakidis P, Davis JL, Zelnick JR, Brust JC, Naidu N, Garretson M, Bangsberg DR, Padayatchi N, Friedland G. Re-inventing adherence: toward a patient-centered model of care for drug-resistant tuberculosis and HIV. *Int J Tuberc Lung Dis.* 2016;20(4):430–4.
7. Akkerman OW, Grasmeyer F, de Lange WCM, Kerstjens HAM, de Vries G, Bolhuis MS, Alffenaar JW, Frijlink HW, Smith G, Gajraj R, de Zwaan R, Hagedoorn P, Dedicoat M, van Soolingen D, van der Werf TS. Cross border, highly individualised treatment of a patient with challenging extensively drug-resistant tuberculosis. *Eur Respir J.* 2018;51(3):1702490.
8. Collaborative Group for the Meta-Analysis of Individual Patient Data in MDR-TB treatment–2017; Ahmad N, Ahuja SD, Akkerman OW, Alffenaar JC, Anderson LF, Baghaei P, Bang D, Barry PM, Bastos ML, Behera D, Benedetti A, Bisson GP, Boeree MJ, Bonnet M, Brode SK, Brust JCM, Cai Y, Caumes E, Cegielski JP, Centis R, Chan PC, Chan ED, Chang KC, Charles M, Cirule A, Dalcolmo MP, D'Ambrosio L, de Vries G, Dheda K, Esmail A, Flood J, Fox GJ, Fréchet-Jachym M, Fregona G, Gayoso R, Gegia M, Gler MT, Gu S, Guglielmetti L, Holtz TH, Hughes J, Isaakidis P, Jarlsberg L, Kempker RR, Keshavjee S, Khan FA, Kipiani M, Koenig SP, Koh WJ, Kritski A, Kuksa L, Kvasnovsky CL, Kwak N, Lan Z, Lange C, Laniado-Laborín R, Lee M, Leimane V, Leung CC, Leung EC, Li PZ, Lowenthal P, Maciel EL, Marks SM, Mase S, Mbuagbaw L, Migliori GB, Milanov V, Miller AC, Mitnick CD, Modongo C, Mohr E, Monedero I, Nahid P, Ndjeka N, O'Donnell MR, Padayatchi N, Palmero D, Pape JW, Podewils LJ, Reynolds I, Riekstina V, Robert J, Rodriguez M, Seaworth B, Seung KJ, Schnippel K, Shim TS, Singla R, Smith SE, Sotgiu G, Sukhbaatar G, Tabarsi P, Tiberi S, Trajman A, Trieu L, Udwardia ZF, van der Werf TS, Veziris N, Viiklepp P, Vilbrun SC, Walsh K, Westenhouse J, Yew WW, Yim JJ, Zetola NM, Zignol M, Menzies D. Treatment correlates of successful outcomes in pulmonary multidrug-resistant tuberculosis: an individual patient data meta-analysis. *Lancet.* 2018;392(10150):821–34.
9. <https://www.who.int/tb/publications/2019/consolidated-guidelines-drug-resistant-TB--treatment/en/>
10. Akkerman OW, Ter Beek L, Centis R, Maeurer M, Visca D, Muñoz-Torrico M, Tiberi S, Migliori GB. Rehabilitation, optimized nutritional care, and boosting host internal milieu to improve long-term treatment outcomes in tuberculosis patients. *Int J Infect Dis.* 2020;92S:S10–4.

11. Wilkinson RJ, Rohlwink U, Misra UK, van Crevel R, Mai NTH, Dooley KE, Caws M, Figaji A, Savic R, Solomons R, Thwaites GE. Tuberculous meningitis international research consortium. Tuberculous meningitis *Nat Rev Neurol*. 2017;13(10):581–98.
12. Zelnick JR, Seepamore B, Daftary A, Amico KR, Bhengu X, Friedland G, Padayatchi N, Naidoo K, O'Donnell MR. Training social workers to enhance patient-centered care for drug-resistant TB-HIV in South Africa. *Public Health Action*. 2018;8(1):25–7.
13. Dujailli JA, Sulaiman SA, Hassali MA, Awaisu A, Blebil AQ, Bredle JM. Health-related quality of life as a predictor of tuberculosis treatment outcomes in Iraq. *Int J Infect Dis*. 2015;31:4–8.
14. Newell S, Jordan Z. The patient experience of patient-centered communication with nurses in the hospital setting: a qualitative systematic review protocol. *JBIC Database System Rev Implement Rep*. 2015;13(1):76–87.
15. Story A, Aldridge RW, Smith CM, Garber E, Hall J, Ferenando G, Possas L, Hemming S, Wurie F, Luchenski S, Abubakar I, McHugh TD, White PJ, Watson JM, Lipman M, Garfein R, Hayward AC. Smartphone-enabled video-observed versus directly observed treatment for tuberculosis: a multicentre, analyst-blinded, randomised, controlled superiority trial. *Lancet*. 2019;393(10177):1216–24.
16. Garfein RS, Doshi RP. Synchronous and asynchronous video observed therapy (VOT) for tuberculosis treatment adherence monitoring and support. *J Clin Tuberc Other Mycobact Dis*. 2019;17:100098.
17. Nahid P, Dorman SE, Alipanah N, Barry PM, Brozek JL, Cattamanchi A, Chaisson LH, Chaisson RE, Daley CL, Grzemska M, Higashi JM, Ho CS, Hopewell PC, Keshavjee SA, Lienhardt C, Menzies R, Merrifield C, Narita M, O'Brien R, Peloquin CA, Raftery A, Saukkonen J, Schaaf HS, Sotgiu G, Starke JR, Migliori GB, Vernon A. Official American Thoracic Society/Centers for Disease Control and Prevention/Infectious Diseases Society of America Clinical Practice Guidelines: treatment of drug-susceptible tuberculosis. *Clin Infect Dis*. 2016;63(7):e147–95.
18. Sinkou H, Hurevich H, Rusovich V, Zhylevich L, Falzon D, de Colombani P, Dadu A, Dara M, Story A, Skrahina A. Video-observed treatment for tuberculosis patients in Belarus: findings from the first programmatic experience. *Eur Respir J*. 2017;49(3):1602049.