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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

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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.

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