Palliative Care for Tuberculosis

Stephen R. Connor, PhD
Worldwide Hospice Palliative Care Alliance, Fairfax Station, Virginia, USA

Abstract
In 2014, 1.5 million people died of tuberculosis (TB) worldwide including 400,000 co-infected with HIV. TB remains a major cause of death and suffering globally, in spite of the fact that it is supposed to be a curable disease. Drug resistant forms of TB have developed as a result of poor treatment compliance including multi-drug and extreme drug resistant forms that take longer to treat and have higher likelihoods of treatment failure. In 2010, at the initiation of the TB community, a partnership was formed between the World Health Organization Stop TB Program, the Worldwide Hospice Palliative Care Alliance, and the Open Society Foundation’s International Palliative Care Initiative to explore how to improve the ability of TB professionals to deliver palliative care (PC) to their patients. This article describes the progress made in the last six years and the barriers remaining. A training curriculum was developed, courses conducted at major TB conferences (Union Lung Health), several publications produced, model programs identified, and comprehensive clinical guidelines developed. There remain significant barriers including lack of awareness and a major need for resources to deliver PC education to the TB workforce and the PC community to realize World Health Organization’s goal of zero suffering for TB patients.

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Key Words
Palliative care, hospice, TB, MDR-TB, Worldwide Hospice Palliative Care Alliance, WHO Stop TB

Background
Palliative care (PC) for tuberculosis (TB) patients is a relatively new form of care. TB is and should be a curable disease. However, each year an increasing number of TB patients acquire or develop drug-resistant TB (DR-TB). DR-TB can be multi-drug resistant (MDR-TB) or may be extensively drug resistant (XDR-TB). Five-year survival rates for XDR-TB are only 23%. Treatment for DR-TB is improving as is testing and PC may even contribute to improved compliance with TB treatments.

The World Health Organization (WHO) Global TB program has called for zero new infections, zero deaths, and zero suffering for people with TB. In 2014, 1.5 million people died of TB including 400,000 co-infected with HIV and 140,000 children. There were an estimated 9.6 million new cases of TB in 2014 including one million children. More than 10 million children were orphaned as a result of their parents’ death from TB. There were also an estimated 480,000 new cases of MDR-TB and 190,000 deaths from MDR-TB in 2014. South-East Asia and Africa have the highest burden of TB particularly India, Indonesia, Nigeria, Bangladesh, DR Congo, and South Africa. Over 95% of TB deaths occur in low- and middle-income countries.

The main target groups needing PC are those with DR-TB, both MDR-TB and XDR-TB. However, TB experts also note that there are some drug susceptible patients who may also need PC. These include those co-infected with HIV and extra-pulmonary TB patients.

In 2010, following a lunch seminar at WHO headquarters, Dr. Ernesto Jaramillo, medical officer in the Stop TB program, acknowledged that there is a serious problem globally with the lack of PC for those suffering with TB. He requested assistance in bridging this gap. This was discussed with staff from Open

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Address correspondence to: Stephen R. Connor, PhD, Worldwide Hospice Palliative Care Alliance, 10990 Rice Field Place, Fairfax Station, VA 20039, USA. E-mail: sconnor@thewhpca.org

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Society Foundation’s International Palliative Care Initiative (OSF/IPCI), and we agreed that a partnership between WHO, OSF/IPCI, and the Worldwide Hospice Palliative Care Alliance to work on PC for TB was needed.

**Declaration on PC for MDR- and XDR-TB**

As a first step, it was decided to bring together experts in PC and TB to explore needs and opportunities. OSF agreed to fund a meeting (Palliative Care and MDR/XDR-TB Integration Meeting, November 18–19, 2010, which was organized by OSF/IPCI, Worldwide Hospice Palliative Care Alliance, and WHO Stop TB, and held in Geneva, Switzerland.). 37 experts attended from most major TB and PC organizations. There was unanimous agreement that PC needs to be included in the global response to TB, and a declaration was drafted that all attendees agreed to. The Declaration is as follows:

“As a group of experts in PC and MDR/XDR-TB, we declare that:

1. access to PC for individuals (adults and children) with MDR/XDR-TB is a human right and promotes dignity.
2. PC is an essential component of the provision of care for individuals (adults and children) with MDR/XDR-TB, wherever in the world that they are receiving care.
3. PC should be strengthened where being provided, and integrated alongside the prevention and treatment of MDR/XDR-TB.
4. PC in the context of MDR/XDR-TB should be integrated into the management of MDR/XDR-TB from the time of diagnosis until the patient reaches cure or the end of life. The problems faced by MDR/XDR-TB patients and families span multiple physical, psychological, social, and spiritual dimensions. We believe that the existing WHO definition of PC is highly appropriate for patients with DR-TB.
5. PC strengthens the Stop TB strategy.
6. as experts on MDR/XDR-TB and PC, we are keen to learn from each other.
7. we are committed to developing the agenda on PC in MDR/XDR-TB, and improving access to care, medications, training and capacity building, and collaborating to improve the knowledge base through research.”

Following publication of the “Declaration” in the *International Journal of Tuberculosis and Lung Disease*, an exchange occurred with letters to the editor. In response to the Declaration, a letter criticizing PC in TB was published. The letter essentially said that as TB was a curable disease, it would be unethical to provide PC. This afforded the PC experts and opportunity to correct this misconception. Following this exchange, a special article was published in *Lancet Infectious Disease* making the case for the need for PC for TB patients.

**Education**

Following the joint meeting, a number of initiatives were undertaken to begin to develop education about PC for TB workers. These included development and launch of a basic course on PC for TB, several workshops held at the Union World Conference on Lung Health, which is the pre-eminent conference on TB and lung health annually, and trainings held in target countries. In addition, considerable work has been performed to develop evidence-based clinical guidelines for PC in TB and to identify model programs.

**Salzburg Seminar**

OSF’s Open Medical Institute, the American Austria Foundation and OSF/IPCI sponsored the development of a one week course on PC for TB, which was developed by PC experts with expertise in TB. The course was taught to key TB leaders as part of the Salzburg Seminar courses in Austria on February 27 to March 3, 2012. Contact the corresponding author if interested in obtaining slides from the course. The course used many studies and included the following modules:

- WHO policies on PC and TB, epidemiology of TB, challenges in DR-TB
- PC and human rights
- Ethics and communication
- Breaking bad news
- Assessment and treatment of TB and TB side effects
- Pain principles, assessment and treatment, and side effects, including opioid use disorder
- Dyspnea, hemoptysis, constipation and/or diarrhea, nausea, end-stage renal disease, and dermatology treatment
- Depression, delirium, and anxiety treatment
- Grief and loss, bereavement support, burnout prevention
- Gastrointestinal care, infection control, HIV co-infection
- Models of care in hospital and community, PC education and training resources.

The course was repeated for TB professionals in Tajikistan in June 2014.

**Union World Conference on Lung Health**

The Union Conference is the preeminent conference on TB worldwide. Attendees from all over the world meet to discuss the latest development in TB. Following the 2010 joint meeting it was decided that
seminars and courses on PC should be held at the Union Conference. OSF again agreed to help sponsor these events, the first of which was at the union meeting in Kuala Lumpur in 2012. This was followed by UNION meetings in Paris in 2013, Barcelona in 2014, and Cape Town, and with support from University Research Corporation, South Africa in 2015. These workshops and postgraduate courses kept the profile of PC in the TB community and were performed in cooperation with the WHO Stop TB Program.

Clinical Guideline Development

Of the curricular materials and early guidelines developed by the Hospice and Palliative Association of South Africa, a first effort to do clinical guidelines for PC for DR-TB was developed by the KNCV Tuberculosis Foundation in the Netherlands in 2014 with funding from the United States Agency for International Development (USAID) TB Care I program and with support from OSF/IPCI.

Following this, a more comprehensive set of Guidelines for TB and DR-TB Palliative Care and Support for South Africa were drafted in 2015 by University Research Corporation with funding from USAID TB Care II program. These guidelines are the most up to date guidelines on PC for TB available.

Models

A number of exemplary models of integration of PC into mainstream TB treatment exist. These include a PC service in the main TB hospital at Riga East University Hospital in Latvia (https://www.aslimnica.lv/en/saturs/department-palliative-care). A home care program (Sputnik) piloted in Tomsk for non-adherent TB patients that includes palliation of side effects and co-morbidities. A number of successful PC programs are operating in South Africa with support of the Ministry of Health and the Hospice and Palliative Care Association of South Africa. The Care & Support for Improved Patient Outcomes program, funded by USAID, and run by Hospice and Palliative Care Association of South Africa is designed to improve the provision of PC with a major focus on TB patients. These models include inpatient care when needed, but emphasize care delivered in the home setting when possible with good infection control practices.

Current Challenges

PC for TB patients and their families remains under developed. There are two main barriers to advancing the availability of PC for TB. The first is that TB should be a curable illness and DR-TB is the result of ineffective treatment. There is some inherent resistance to the idea of PC for TB patients because of lack of awareness of the benefits of PC for TB patients and, like HIV, its role in helping manage comorbidities, improving treatment compliance through symptom relief, effective infection control, and ensuring a dignified end of life for those whose treatment has failed.

The second main barrier is simply lack of knowledge of PC principles and practice. Efforts to increase collaboration between PC providers and TB professionals have been described, but the vast majority of TB workers have no PC knowledge and skills. Ideally, all TB workers would have a basic knowledge of PC to help their patients, especially with DR-TB and access to specialist PC for the most difficult cases. We remain a long way from that reality. In addition, very few TB care facilities have any access to opioids for relief of shortness of breath and pain.

Conclusion

The TB community has reached out to the PC community for support in improving TB patient outcomes, especially for patients with DR-TB. Both specialties can benefit from each other’s expertise to improve care. A number of important resources have been generated to advance PC for TB patients until all patients with TB are cured. These include a training curriculum, sets of clinical guidelines, and model programs that can be replicated. Resources are needed and barriers need to be overcome to reach the WHO’s goal of zero new infections, zero deaths, and zero suffering for those living with TB.

References