

The ethical imperative to relieve suffering for people with tuberculosis by ensuring access to palliative care

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SUMMARY

Patients diagnosed with tuberculosis (TB) continue to experience clinical uncertainty and high mortality and to bear a high burden of symptoms and other concerns. Additional concerns may be family support needs and stigma, particularly the latter, as TB and human immunodeficiency virus (HIV) coinfection are common. Human rights covenants, global health policy and the End TB Strategy all recommend palliative care as an essential component of care services. As established in the resolution adopted by the World Health Assembly (WHA) on “Strengthening of palliative care as a component of comprehensive care throughout the life course”, there is a “need for palliative care across disease groups (non-communicable diseases, and infectious diseases, including HIV and multidrug-resistant tuberculosis), and across all age groups”. We address the

ethical imperative to respect the dignity and fundamental rights of people with TB by providing palliative care. We review the evidence for the need for person-centred palliative care and highlight novel models that utilise the skills and training functions of specialist palliative care to achieve better care. We outline simple recommendations for the delivery of specialist and generalist palliative care, offer suggestions on how to ensure optimal coverage by enabling access to appropriate good-quality palliative care at all points of the health system, including alongside treatment. Finally, we set out the current priorities for research and policy to ensure that quality care is delivered to all who need it irrespective of treatment outcome, to minimise distress and to optimise engagement in treatment and care.

KEY WORDS: TB; palliative care; mortality; symptoms

THE WORLD HEALTH ORGANIZATION (WHO) 2017 Global TB report highlights the continuing challenge posed by mortality due to tuberculosis (TB).¹ The WHO reports that 4.1% of new cases and 19% of previously treated cases in 2017 had drug-resistant (DR-) or rifampicin-resistant TB, and that there were 1 670 000 deaths from TB (95% confidence interval [CI] 1530–1820). A recent systematic review of clinical trials for pulmonary TB concluded that the majority of reported outcomes are bacteriological, with some radiological and clinical outcomes implied.²

Person-centred outcomes must form primary outcomes in evaluations of treatment and care. Studies aimed to measure person-centred concerns among TB patients have identified significant unmet needs.³ An unpublished study using the WHO Quality of Life BREF Score and qualitative interviews of TB patients and family carers identified the following symptoms among people on TB treatment: lethargy (50%), pain (45%), shortness of breath (35%), anxiety (35%) and weight loss (35%). The interviews highlighted the

great financial burden for TB patients, as well as the poor body image and sexual isolation experienced by TB patients. The change in family dynamics, physical exhaustion and also the fear of contracting TB contribute to partners physically withdrawing from patients, resulting in isolation.⁴

Interestingly, the palliative care-related concerns measured using the African Palliative care Outcome Scale among patients with drug-susceptible TB (DS-TB) admitted to a South African TB ward were higher than those admitted with DR-TB.⁵ presumably due to the then policy of admitting all DR TB patients and DS-TB patients with acute problems while on treatment. The items with the worst scores were worry (60.5%), pain (42.1%), help and advice with planning for the future (35.1%), symptoms (29.0%) and ability to share feelings (25.1%).

Data from a South African community highlighted the emotional and physical burden patients and families face in living with or with someone living with incurable DR-TB.^{6,7} Both studies concluded that

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Article submitted 27 March 2018. Final version accepted 26 July 2019.

sufficient palliative care resources and infection control measures are lacking at primary health care level.

Odell reports that among patients with DR-TB in Cape Town, South Africa, the most significant symptoms were joint pain, shortness of breath, fatigue and feelings of isolation and loneliness.⁸ Fear and guilt associated with infectious risk is described among DR-TB patients, with a depression prevalence of 52.2%.⁹ The cohort in Cape Town reported concerns about infecting their children and regularly had the children tested at the clinic. The study also reports that a diagnosis of TB worsens existing financial difficulties due to loss of employment and the cost of clinic attendance. As TB-HIV co-infection is common, symptom prevalence among people with acquired immune-deficiency syndrome (AIDS) is a useful source of data, given the lack of TB-specific symptom data. A systematic review of symptoms among people with AIDS found high symptom prevalence such as fatigue (43–95%), anorexia (82%), pain (30–98%), breathlessness (43–62%), nausea and vomiting (43–61%) and depression (17–82%).¹⁰ These symptoms are likely to be prevalent among TB patients in area where HIV coinfection is common. Information and clear communication by health care professionals,¹¹ as well as the provision of spiritual care may also be very important to optimise care for TB patients.^{12–14} This more respectful approach involving patients as partners in care enhances self-care and improves adherence to treatment.

To date, palliative care in relation to TB management has focused on DR-TB,¹⁵ which led to a declaration on palliative care for those with little chance of cure.¹⁶ However, people with both DS- and DR-TB face clinical uncertainty, that is treatment, prognosis or recovery are complex or unpredictable.¹⁷ Palliative care should therefore be provided “early in the course of the illness” to ensure that patients and families plan and hope for the best but prepare for the worst, and that unnecessary suffering is avoided.¹⁸

PRINCIPLES AND PRACTICE OF PALLIATIVE CARE

The 2002 WHO definition of palliative care is as follows¹⁹: “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” “Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;

- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”

The specific focus on assessment and management of pain and other distressing symptoms distinguishes palliative from supportive care.²⁰ As breathlessness is a common symptom in TB, it is important that this debilitating and distressing symptom is managed using the best tools available using a multiprofessional approach that includes respiratory medicine, palliative care, rehabilitation and social work to meet the total care needs of the patient and their family.^{21–25}

Components of palliative care are currently delivered by TB care providers. These may include prevention and management of suffering due to adverse TB drug reactions, and provision of social support to enable adherence. These are important and should continue. However, in the 2018 WHO TB report “only one high MDR-TB burden country (Thailand) and three other countries (Algeria, Bhutan and Uganda) reported prescribing morphine to treat pain or terminal dyspnoea in patients for whom second-line TB treatment regimens did not work, suggesting that there are widespread unmet needs in terms of end-of-life care as well as inadequate data gathering on this issue.”²⁶ While acknowledging the strengths of current practice, we must take a more holistic and integrated approach to ensuring that palliative care needs are routinely assessed and met.

EVIDENCE OF EFFECTIVENESS AND COST-EFFECTIVENESS

Palliative care reduces symptom burden, physical and psychological suffering, in-hospital mortality and costs.^{27–29} Use of advance care plans can also improve outcomes for patients families and health services, but must be adapted to local cultural preferences.³⁰ Newer models of early integrated palliative care have found the person-centred, symptom controlling, holistic approach to be of benefit in

terms of patient and caregiver satisfaction, survival, family depression and costs.^{31–35} These studies have evaluated multiprofessional palliative care consultancy for better management of patient and family concerns—physical, psychological, social and spiritual. Effect sizes of early palliative care may be greater in parts of the world with a high prevalence of comorbidity.³⁶

A systematic review in HIV literature concluded that palliative care significantly improved outcomes of pain and symptom control, anxiety, insight and spiritual wellbeing.³⁷ In addition to the need for expertise in infectious diseases, similarities between HIV and TB management include lack of specialist expertise at end of life, lack of death discussions, stigma, and potentially palliative/curative dual approaches.³⁸ This means that barriers to access to appropriate palliative and end-of-life care for both infectious conditions are also similar.³⁹

THE SOUTH AFRICAN EXPERIENCE

South Africa is one of the countries with the highest burden of TB; according to the WHO 2017 report the country had an estimated 438 000 incident cases of TB,¹ of which 258 000 were among people living with HIV and 19 000 had DR-TB. In 2014, 8.4% of deaths in South Africa were due to TB.⁴⁰ The mortality rate due to multidrug-resistant (MDR-) and extensively drug-resistant TB (XDR-TB) was 40% and 60% respectively.⁷

In 2008, the Hospice Palliative Care Association, Cape Town, South Africa, initiated an active TB programme and produced “Guidelines for Providing Palliative Care to Patients with Tuberculosis” in 2011 (<http://www.hpca.co.za/category/tb.html>). These guidelines are currently under review by the Vulnerable Populations Task Team of the National Palliative Care Steering Committee. The Guidelines identify processes and TB control measures for the palliative care setting; and palliative care knowledge and skills to be implemented in the TB setting. They cover infection control, preventive therapy, intensified case finding and management of TB patient at home and in in-patient facilities. DR-TB is a particular focus, as is the management of children with TB.

The Guidelines also provide information on ethical considerations, symptom management, nutritional support, support of family carers, end-of-life care and bereavement support, integration of TB aspects into risk management and “Care for the Caregiver” programmes and advice on promoting optimal health among healthcare staff and implementing a good workplace policy so as to create a nurturing environment that encourages staff to know and disclose their own HIV and TB status.

ETHICAL POLICY CONTEXT OF PALLIATIVE CARE

Palliative care is a global human right⁴¹ and its provision is recommended “throughout the illness course”.⁴² The WHA Resolution 67.19 calls for palliative care “integrated throughout the life course”.⁴³ The most recent iteration of the WHO Universal Health Coverage goals calls for the “full spectrum of essential, quality health services, from health promotion to prevention, treatment, rehabilitation, and palliative care”.⁴⁴ However, despite the high need for palliative care, coverage is at best patchy; the WHO Global Atlas concludes that one third of countries have no known activity.⁴⁵ There is also a huge inequality in access to quality palliative care with respect to country income, as indicated by the Economist’s Death Ranking, which found gross domestic product to be a good indicator of quality of death.⁴⁶ Despite the need to reduce this inequality, palliative care is currently only mentioned once in the WHO’s 2017 End TB Strategy (and only in relation to DR-TB).

Palliative care is inexpensive and can be delivered across conditions and settings, and many countries have made exemplary progress.^{47,48} Underpinning this success is the requirement for high-quality research to determine feasible, acceptable, accessible and effective local palliative care models and interventions in line with the WHO’s public health palliative care strategy.⁴⁹ Much research in palliative care has been catalysed by the development, validation and implementation of outcome measures that reflect the concerns and symptoms of patients and families with advanced illness. An example is the POS, which is currently used in over 100 countries to inform assessment, guide and evaluate care, and conduct outcomes-focused research (www.pos-pal.org). Findings from have shown that POS is valid and measures consistently across time, individuals and situations, and is commonly used to inform research and care where *Patient Reported Outcome Measures* could be used to improve communication and care outcomes.^{50–52}

Given that palliative care is effective in terms of outcomes and costs, is indicated in policy documents, and is a relatively inexpensive intervention, the poor global access to palliative care is a curious phenomenon. Evidence increasingly suggests that stigma operates to prevent clinicians, patients and their families from acknowledging the likelihood of death.⁵³ The stigma of death and dying is compounded by the erroneous belief that palliative care must replace any potentially disease-modifying treatments. This does not reflect the modern practice of palliative care, which can be provided from the point of diagnosis alongside potentially curative treatment in case of clinical uncertainty. This is best described by the “bowtie” model of palliative care (Figure).¹⁸ Disease management begins as the main component of care, and this can be delivered alongside palliative

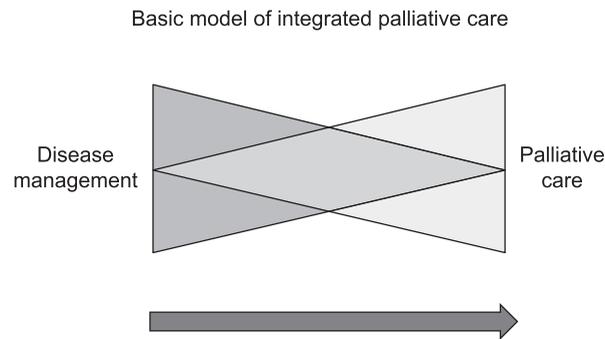


Figure Hawley's "bowtie" model of palliative care.

care; palliative care can become the main modality of care if death approaches. Individual decisions must be made at the end of life when treatment is deemed futile and burdensome to the patient.

The WHO considers engaging, educating and supporting TB patients an ethical responsibility of health care workers; this directly relates to positive treatment outcomes.⁵⁴ Palliative care addresses the ethical issues associated with treating TB patients, such as respect for the patient's basic individual right to decide their treatment options with full disclosure and good communication, advocating for effective, free curative measures and symptom management (beneficence) to limit the decline in the patient's functioning and family responsibilities, and reduce financial outlay (non-maleficence). Palliative care recognises that TB patients experience unnecessary suffering due to physical, social, psychological and spiritual symptoms and concerns, and stigmatisation. It might also be true to say that directly observed therapy is only ethically justifiable if palliative care is available.

In the interests of social justice, palliative care should be based on sound ethical practice, observation of human rights, and equitable distribution of governmental and international resources. It is a recognition of the fact that TB care should begin from the time of diagnosis, and continue throughout the treatment process, regardless of treatment outcome. Patients should not be abandoned when cure is not possible, or the patient remains infectious. This patient-centred approach is crucial to win the trust and co-operation of TB patients and their families, ensuring a successful TB programme. Inclusion of the family within palliative care provision protects the health of the community.

PRIORITIES FOR RESEARCH AND CARE

Research

In terms of palliative care, the following are important research priorities:

- Well-designed epidemiological studies that measure person-centred concerns and symptoms

- More qualitative studies to understand the experience of advanced TB care, main TB concerns, TB impact on physical, psychological, social and spiritual domains, and family support needs
- Studies in understanding death, not only as a failure endpoint but also how people die
- Clinical trials to measure the effectiveness of novel models of integrated palliative care developed to fit diverse contexts
- Care of household contacts where a TB/DR-TB death has occurred as it is now known how new cases from these households may be impacted
- Bereavement care packages and how TB screening can be factored into such packages.

Care

Important features of palliative care are as follows:

- All TB care services should have access to local specialist palliative care teams
- Routine assessment of pain and symptoms should be central to care
- All TB care team members should be skilled in basic palliative care
- Communication skills should be trained to ensure that clinical uncertainty and advanced care planning can be managed
- Palliative care outcomes should be routinely measured using *Patient Reported Outcome Measures*
- A good death should be an articulated goal of care for all services
- Infection control is a component of care that is essential, especially if patients are managed in their homes
- Drugs for the control of pain and symptoms should be reliably available throughout the health system.

CONCLUSION

People living with TB face a high burden of physical, psychological, social and spiritual concerns. In addition, families face the burden of providing informal care for a stigmatised infectious condition. Given the high mortality rates and the clinical uncertainty faced by patients, families and professionals, palliative care must be a core component of all TB care services.

Research must ensure that person-centred outcomes, and the quality of care and of death, are primary outcomes of research. Given the evidence of cheap and effective management of symptoms and concerns, palliative care must be part of a humane health system response alongside maximum efforts to cure.

Conflicts of interest: none declared.

References

- World Health Organisation. World Tuberculosis Report, 2017. WHO/HTM/TB/2017.23. Geneva, Switzerland: WHO, 2017.
- Bonnett L J, Ken-Dror G, Davies G R. Quality of reporting of outcomes in phase III studies of pulmonary tuberculosis: a systematic review. *Trials* 2018; 19(1): 134.
- Harding R, Defilippi K, Cameron D. What palliative care-related problems do patients with drug-resistant or drug-susceptible tuberculosis experience on admission to hospital? A cross-sectional self-report study. *Palliat Med* 2016; 30(9): 862–8.
- Krause R. An evaluation to assess the holistic care of Tuberculosis patients with palliative care needs in the Western Cape, South Africa. Cape Town, South Africa: University of Cape Town, 2010.
- Harding R, et al. Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale. *Health Qual Life Outcomes* 2010; 8: 10.
- Senthilingam M, et al. Lifestyle, attitudes and needs of uncured XDR-TB patients living in the communities of South Africa: a qualitative study. *Trop Med Int Health* 2015; 20(9): 1155–1161.
- Dheda K, et al. The epidemiology, pathogenesis, transmission, diagnosis, and management of multidrug-resistant, extensively drug-resistant, and incurable tuberculosis. *Lancet Respir Med* 2017; 5(4): P291–360.
- Odell. A study to determine the palliative care needs of patients with drug resistant tuberculosis in the southern sub-district of Cape Town. Cape Town, South Africa: University of Cape Town, 2018.
- Vega P, et al. Psychiatric issues in the management of patients with multidrug-resistant tuberculosis. *Int J Tuberc Lung Dis* 2004; 8(6): 749–759.
- Moens K, et al. Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review. *J Pain Symptom Manage* 2014.
- Selman L, et al. Meeting information needs of patients with incurable progressive disease and their families in South Africa and Uganda: multicentre qualitative study. *BMJ* 2009; 338: b1326.
- Selman L E, et al. Quality of life among patients receiving palliative care in South Africa and Uganda: a multi-centred study. *Health and Quality of Life Outcomes* 2011; 9(1): 21.
- Selman L, et al. The MVQOLI successfully captured quality of life in African palliative care: a factor analysis. *J Clin Epidemiol* 2011; 64(8): 913–924.
- Selman L, et al. The “Spirit 8” successfully captured spiritual well-being in African palliative care: factor and Rasch analysis. *J Clin Epidemiol* 2012; 65(4): 434–443.
- Harding R, Foley K M, Connor S R, Jaramillo E. Palliative and end-of-life care in the global response to multidrug-resistant tuberculosis. *Lancet Infect Dis* 2012; 12(8): 643–646.
- Connor S, Foley K, Harding R, Jaramillo E. Declaration on palliative care and MDR/XDR-TB. *Int J Tuberc Lung Dis* 2012; 16(6): 712–713.
- Bristowe K, et al. Patient and carer experiences of clinical uncertainty and deterioration, in the face of limited reversibility: a comparative observational study of the AMBER care bundle. *Palliat Med* 2015; 29(9): 797–807.
- Hawley P H. The bow tie model of 21st century palliative care. *J Pain Symptom Manage* 2014; 47(1): e2–5.
- World Health Organization. WHO Definition of Palliative Care. Geneva, Switzerland: WHO, 2013. <http://www.who.int/cancer/palliative/definition/en/>. Accessed February 2020.
- Gysels M, Higginson I J. Improving supportive and palliative care for adults with cancer: research evidence. London, UK: National Institute for Clinical Excellence, 2004.
- Farquhar M C, et al. The clinical and cost effectiveness of a Breathlessness Intervention Service for patients with advanced non-malignant disease and their informal carers: mixed findings of a mixed method randomised controlled trial. *Trials* 2016; 17: 185.
- Farquhar M C, et al. Is a specialist breathlessness service more effective and cost-effective for patients with advanced cancer and their carers than standard care? Findings of a mixed-method randomised controlled trial. *BMC Med* 2014; 12: 194.
- Higginson I J, et al. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. *Lancet Respir Med* 2014; 2(12): 979–987.
- Malik F A, Gysels M, Higginson I J. Living with breathlessness: a survey of caregivers of breathless patients with lung cancer or heart failure. *Palliat Med* 2013; 27(7): 647–656.
- Simon S T, et al. Episodic breathlessness in patients with advanced disease: a systematic review. *J Pain Symptom Manage* 2013; 45(3): 561–578
- World Health Organization. Global Tuberculosis Report, 2018. WHO/CDS/TB/2018.20. Geneva, Switzerland: WHO, 2018.
- Kassianos A P, et al. The impact of specialized palliative care on cancer patients’ health-related quality of life: a systematic review and meta-analysis. *Support Care Cancer* 2017.
- Liu X, et al. Effects of hospital palliative care on health, length of stay, and in-hospital mortality across intensive and non-intensive-care units: A systematic review and metaanalysis. *Palliat Support Care* 2017: 1–12.
- Smith S, et al. Evidence on the cost and cost-effectiveness of palliative care: a literature review. *Palliat Med*. 2014; 28(2): 130–150.
- Lin C P, et al. The conceptual models and mechanisms of action that underpin advance care planning for cancer patients: a systematic review of randomised controlled trials. *Palliat Med* 2019; 33(1): 5–23.
- Temel J S, et al. Effects of early integrated palliative care in patients with lung and gi cancer: a randomized clinical trial. *J Clin Oncol* 2017; 35(8): 834–841.
- Temel J S, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010; 363(8): 733–742.
- Zimmermann C, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *Lancet* 2014; 383(9930): 1721–1730.
- Dionne-Odom J N, et al. Translating and testing the ENABLE: CHF-PC concurrent palliative care model for older adults with heart failure and their family caregivers. *J Palliat Med* 2014; 17(9): 995–1004.
- Bakitas M A, et al. Early versus delayed initiation of concurrent palliative oncology care: patient outcomes in the ENABLE III randomized controlled trial. *J Clin Oncol* 2015; 33(13): 1438–1445.
- Hirschhorn L R, et al. Cancer and the ‘other’ noncommunicable chronic diseases in older people living with HIV/AIDS in resource-limited settings: a challenge to success. *AIDS* 2012; 26 (Suppl 1): S65–S75.
- Harding R, et al. Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence. *Sex Transm Infect* 2005; 81(1): 5–14.
- Harding R. Palliative care as an essential component of the HIV care continuum. *Lancet HIV* 2018; 5(9): e524–e530.
- Harding R, et al. Access and equity in HIV/AIDS palliative care: a review of the evidence and responses. *Palliat Med* 2005; 19(3): 251–258.
- Statistics South Africa. Mortality and causes of death in South Africa 2014. Findings from death notifications. Pretoria, South Africa: SSA, 2015. <https://www.datafirst.uct.ac.za/dataportal/index.php/catalog/566>

- 41 Gwyther L, Brennan F, Harding R. Advancing palliative care as a human right. *J Pain Symptom Manage* 2009; 38(5): 767–774.
- 42 Gelband H, et al. Costs, affordability, and feasibility of an essential package of cancer control interventions in low-income and middle-income countries: key messages from Disease Control Priorities. 3rd ed. *Lancet* 2016; 387(10033): 2133–2144.
- 43 World Health Organization. Strengthening of palliative care as a component of comprehensive care throughout the life course. WHA67.19. Geneva, Switzerland: WHO, 2014. http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf Accessed February 2020.
- 44 World Health Organisation. Universal Health Coverage. Geneva, Switzerland: WHO, 2020. <http://www.who.int/mediacentre/factsheets/fs395/en/> Accessed February 2020.
- 45 World Health Organisation. Global Atlas of Palliative Care at the End of Life. London, UK: World Palliative Care Alliance, 2014. https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf Accessed February 2020.
- 46 The Economist. Quality of Death Index 2015. <https://eiu Perspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf> Accessed February 2020.
- 47 Merriman A, Harding R. Pain control in the African context: the Ugandan introduction of affordable morphine to relieve suffering at the end of life. *Philos Ethics Humanit Med* 2010; 5: 10.
- 48 Jagwe J, Merriman A. Uganda: delivering analgesia in rural Africa: opioid availability and nurse prescribing. *J Pain Symptom Manage* 2007; 33(5): 547–551.
- 49 Harding R, et al. Research into palliative care in sub-Saharan Africa. *Lancet Oncol* 2013; 14(4): 183–188.
- 50 Bausewein C, et al. EAPC White Paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services—Recommendations from the European Association for Palliative Care (EAPC) Task Force on Outcome Measurement. *Palliat Med* 2016; 30(1): 6–22.
- 51 Collins E S, et al. A systematic review of the use of the palliative care outcome scale and the support team assessment schedule in palliative care. *J Pain Symptom Manage* 2015; 50(6): 842–53. e19.
- 52 Etkind S N, et al. Capture, transfer, and feedback of patient-centered outcomes data in palliative care populations: does it make a difference? A systematic review. *J Pain Symptom Manage* 2015; 49(3): 611–624.
- 53 Harding R, Nair S, Ekstrand M. Multilevel model of stigma and barriers to cancer palliative care in India: a qualitative study. *BMJ Open* 2019; 9(3): e024248.
- 54 World Health Organisation. Ethical issues in tuberculosis prevention treatment and care. Geneva, Switzerland: WHO, 2017. https://www.who.int/tb/publications/ethics_in_tb_factsheet_28jan11rev.pdf?ua=1 Accessed February 2020.

R É S U M É

Les patients qui reçoivent un diagnostic de TB supportent toujours un lourd fardeau de symptômes et d'autres soucis, une incertitude de leur évolution clinique et une mortalité élevée. Les autres soucis peuvent être un besoin de soutien familial et une stigmatisation, notamment parce que la coinfection TB et VIH est fréquente. Les conventions des droits de l'Homme, la politique sanitaire mondiale et la stratégie Mettre fin à la TB stipulent toutes que les soins palliatifs sont un élément essentiel des services de soin. Comme l'a établi la résolution adoptée par l'Assemblée Mondiale de la Santé relative au "Renforcement des soins palliatifs en tant qu'élément du traitement intégré à toutes les étapes de la vie", il existe un "besoin de soins palliatifs dans tous les groupes de maladie (non transmissibles et infectieuses, dont le VIH et la tuberculose multirésistante) et dans tous les groupes d'âge". Nous nous penchons sur l'impératif éthique de respecter la

dignité et les droits fondamentaux des personnes atteintes de TB en leur offrant des soins palliatifs. Nous revoyons les preuves du besoin de soins palliatifs centrés sur la personne et mettons en lumière de nouveaux modèles qui utilisent les compétences et les fonctions de formation en soins palliatifs spécialisés pour améliorer la prise en charge. Nous présentons des recommandations simples pour la prestation de soins palliatifs spécialisés et généralistes, suggérons comment assurer une couverture optimale en facilitant l'accès à des soins palliatifs de bonne qualité et appropriés à tous les niveaux du système de santé, notamment en parallèle au traitement. Enfin, nous fixons les priorités actuelles en matière de recherche et de politiques afin d'assurer que des soins de qualité soient prodigués à tous ceux qui en ont besoin quel que soit le résultat du traitement afin de minimiser la détresse et d'optimiser l'engagement dans le traitement et les soins.

R E S U M E N

En los pacientes con diagnóstico de tuberculosis (TB) persiste una alta carga de síntomas y otras preocupaciones, incertidumbres clínicas y alta mortalidad. Otras fuentes de inquietud pueden ser las necesidades de apoyo familiar y la estigmatización, sobre todo esta última dada la frecuencia de coinfección por el virus de la inmunodeficiencia humana (VIH). Los pactos en derechos humanos, las políticas de salud mundial y la Estrategia Fin a la Tuberculosis todos estipulan que los cuidados paliativos son un aspecto primordial de los servicios de atención. Según lo establece la resolución aprobada por la Asamblea Mundial de la Salud sobre "Fortalecimiento de los cuidados paliativos como parte del tratamiento integral a lo largo de la vida", se reconoce "la necesidad de cuidados paliativos en relación con los distintos grupos de enfermedades (no transmisibles e infecciosas, incluidas la infección por el VIH y la TB polifarmacorresistente) y en todos los grupos de edad". En el presente artículo se aborda la exigencia ética de

respetar la dignidad y los derechos fundamentales de las personas con TB, mediante la prestación de cuidados paliativos. Se analiza la evidencia sobre la necesidad de un cuidado paliativo centrado en las personas y se destacan los nuevos modelos que utilizan las aptitudes y las funciones de capacitación del cuidado paliativo especializado, con el fin de lograr una mejor atención. Se describen recomendaciones sencillas para la prestación de cuidados paliativos especializados y generalistas, se formulan sugerencias sobre la forma de lograr una cobertura óptima al facilitar el acceso a cuidados paliativos de buena calidad en todos los puntos del sistema de salud, incluso al mismo tiempo que el tratamiento. Por último, se fijan las prioridades actuales de la investigación y las políticas con el objeto de garantizar que se preste una atención de calidad a todas las personas que lo necesiten, sea cual fuere el desenlace terapéutico, a fin de reducir al mínimo el sufrimiento y optimizar la participación en el tratamiento y la atención.