Non-Stigmatizing Language for TB Care: words count!

by Julia Lechner, RN

Everyone talks about TB Stigma, and how it is linked to greater social isolation, poor health outcomes, and limits people from accessing care. Yet it still exists. If we're ever going to meet our goal of TB Elimination, we need to take steps towards breaking down the stigmas associated with TB. One thing that can easily be done - and that's entirely on us - is to stop using stigmatizing language in TB care.

We all want to provide respectful and supportive care for our patients, and may not even realize the harmful words we use. We need to consider the actual meaning of the words we say, and how they are interpreted, to ensure we don't unintentionally cause harm to our patients and undo the good we do. Something as simple as using the word 'care' instead of 'control', or completely eliminating the use of the word 'control' in TB care, can eliminate the inference that patients are going be controlled by health care workers when they seek care and create a less intimidating and more respectful environment. Instead of calling a patient a 'Suspect TB', referring to them as a person being evaluated for TB. Instead of a 'non-compliant' patient, as a person who missed doses. Not a 'TB contact', a person exposed to TB; not a 'homeless patient', rather someone experiencing homelessness. What about 'Directly Supportive Care' instead of Directly Observed Therapy'? Let's stop suggesting that we are about controlling our patients. Let's stop labelling and blaming the patient and start using non-judgemental words that respect the dignity of people with TB - to help empower, rather than isolate, the patients we care for.
UN High-Level Meeting on Tuberculosis
by Elizabeth Rea

TB Advocates around the world are preparing for the United Nations General Assembly High-Level Meeting on Tuberculosis to be held in September 2018, in New York. This will be the most significant political meeting ever held on tuberculosis - moving it beyond ministries of health to the forefront of the global political agenda. A High-Level Meeting is a very specific, formal type of meeting on a specialized topic, convened under exceptional circumstances through a UN resolution and vote - in this case, following a campaign launched by the Stop TB Partnership and others in September 2016. The goal is to reach agreement on cooperation measures and solutions on important global issues among Heads of State and governments. This is only the fifth high-level meeting held on a health issue. The hope is that an ambitious Political Declaration on TB will be endorsed by Heads of State. Declarations like this will mean commitment from Heads of State and governments for a coordinated global response, along with substantial increases in financial resources for TB prevention, care, and research, and lead to millions of lives saved. A Declaration will also likely endorse measurable targets and commitments from governments and key stakeholders for 2020 and 2025. This is critically important because it means counties can be monitored and held politically accountable through regular public reporting.

The High-Level Meeting is an interesting opportunity for Canada - both internationally and nationally. Canada has historically been a strong supported of international TB efforts, as a founding funder of the Global Drug Facility (the world’s largest supplier of quality-assured TB medications), TB REACH, and the Global Fund to Fight AIDS, TB, and Malaria. This will be a key opportunity for Canada to renew these commitments to ending the world’s worse infectious disease killer. Closer to home, while Canada is a low-burden country for TB, our own progress has stalled. There has been no real decline for over a decade in the TB rate or the number of Canadians falling ill from TB - about 1,600 every year. Worse, the number actually increased substantially in 2016, by an additional 100 people (according to the most recent WHO Global TB Report - table A4.4 “notified TB cases” in Annex 4 here http://www.who.int/tb/publications/global_report/en/ - detailed 2016 numbers for Canada are due to be published in the spring). This is an opportunity for Canada - the federal government and the provinces and territories all working together - to commit publicly, politically, to real and substantial targets for TB elimination in our country. It will mean committing resources and policy effort - for improved access to IGRA testing, rifapentine and other short course LTBI treatments, for bench and operational research - and for collaborative, co-ordinated work on TB policy issues that affect us all. This should also be a wake-up call on the need for developing detailed program metrics and targets for TB care and prevention, for each of the TB programs in Canada, as part of our existing TB surveillance system.
The Nunatsiavut Government's Department of Health and Social Development (DHSD) launched a tuberculosis (TB) awareness campaign on Wednesday, March 22, 2017. The launch was held in advance of World TB Day, celebrated on March 24 each year, and was in response to outbreaks involving teens and young adults in the communities of Nain and Hopedale over the past couple of years.

TB is typically transmitted by older adults to family members within their home or close living arrangements. The recent outbreaks, however, appeared to be related to high risk behavior, such as sharing of smoking devices (e.g. third lungs, bongs and cigarettes).

Planning for the campaign began fall of 2016 in collaboration with Labrador-Grenfell Health Authority and youth. The idea for the campaign came from a community consultation meeting held in Hopedale Labrador, in November, after which a committee was formed to begin the initial planning stages.

A logo contest – held in January to brand the campaign – engaged youth between 12 to 25 years of age. After the winning logo was chosen, promotional items were purchased based on youth recommendations. In addition to the winning logo, there were some great submissions that were used to develop posters to help raise TB awareness.

The campaign was rolled out in all of Labrador Inuit communities. The event consisted of a TB education session by DHSD Public Health Nurses with the help of the department’s Home Care Nurse, Community Health Aides and other staff. The education session provided information about TB, and gave the public the opportunity to ask questions and have open dialogue about this risk of infection. Media outlets covered events on the day of the launch, promoting awareness of the campaign and providing information about safe health practices in an effort to reduce the risk of TB transmission.

The campaign was months in the planning phase, but was very well received at the community level and across the province. Based on this success, plans are in the works to build on the campaign in the future.
The Global TB Report 2017 - a summary
by Geetika Verma

The 2017 Global Tuberculosis Report was released by the World Health Organization a few months ago.

The report indicates, not surprisingly, that we are not on track to reduce the number of TB deaths by 90% and overall incidence by 80% by 2030. TB remains the 9th leading cause of mortality and the number one single infectious agent cause of death (exceeding HIV/AIDS).

The number of deaths among HIV negative TB patients has declined from 1.7 million per year in 2000 to 1.3 million in 2016. The mortality rate from TB has decline 37% from 2000 to 2016. The incidence is falling by 3% per year globally. The fastest decline in TB incidence and mortality has been seen in the WHO European region. Greater than 4% per year decline in incidence has been seen since 2010 among in the following high-incidence countries: Ethiopia, Lesotho, Zambia, Zimbabwe, Russian Federation, Kenya.

The countries that contribute the most TB cases annually are India, Indonesia, China, Philippines, and Pakistan. India alone is the source of 33% of TB deaths per year among HIV negative patients. There has been a 37% increase in case notification rate in India from 2013-2016.

There were 490,000 cases of MDRTB in 2016. Of those, 50% originate from India, China or the Russian Federation. Treatment success rates remain low at 54%. Thirty-five countries have introduced shorter regimens for MDRTB, 85 countries have used Bedaquiline and 54 have used Delaminid by June 2017.

No major changes in TB incidence, MDRTB treatment rates or initiation of ARV in HIV positive patients with TB between 2015 and 2016.

In 2017 the WHO developed a monitoring framework that includes 14 indicators (including proportion of people living below the poverty line, comorbidities like smoking and diabetes, etc).

No new technology or drugs have been launched in 2017, but there are several vaccines and drugs in Phase 2 and 3 trials.

Funding for Global TB control increased from 6.3 billion US to 6.9 billion USD from 2016-2017. India has made the biggest change in their budget for TB control nearly doubling it from 2016 to 2017, following a commitment from their government to work towards TB Elimination by 2015. Globally, however, there remains a funding gap and persistent lack of access to adequate health care that impedes the goal of TB elimination.

Read the full 2017 WHO Global TB Report here:

For nearly 100 years, the mission of the International Union against TB and Lung Disease (IUATLD, sometimes referred to as ‘The Union’) has been to improve health among people living in poverty. The Union works toward its mission in many ways, including conducting scientific research, working with governments and other agencies to translate research into better health for people around the world, and delivering projects directly in the field. It also convenes an annual conference – the World Conference on Lung Health (WCLH).

The Union describes the WCLH as ‘the largest gathering of clinicians and public health workers, health programme managers, policymakers, researchers and advocates working to end the suffering caused by lung disease, with a focus specifically on the challenges faced by the low- and middle-income countries.’ I describe it as an amazing experience and one I wish everyone who serves in lung health, and especially in TB, could experience at least once.

The 2017 WCLH took place November 11th to 14th at the massive Expo Guadalajara conference centre in Guadalajara, Mexico. A few quick facts to help put the scope, depth and reach of the conference into perspective:

• Thousands of delegates from more than 125 countries;
• 150 sessions, including plenaries, post-graduate courses and workshops, symposia, oral abstract sessions, poster discussion sessions, e-poster discussions, and ‘Meet the Expert’ sessions;
• A community space - Encuentro – where local people could attend free sessions alongside conference delegates on a variety of lung health topic areas;
• A student networking forum; and
• An exhibition area full of interesting displays, including (my personal favourite) two booths dedicated to TB education and training materials.

Although the majority of us were at the WCLH to ‘talk TB’, the scientific programme also featured sessions dedicated to other lung diseases, tobacco use and air pollution. Many were held in Spanish, with translation available.

Administrative meetings of The Union occur at the WCLH, as do annual meetings for The Union’s scientific sections, working groups and Regions (such as the North America Region, or ‘NAR’). As an active member of NAR and the Global Indigenous Stop TB Initiative, and incoming Chair for the Nursing and Allied Health Professionals Sub-Section of The Union (NAPS), it was a challenge to meet my responsibilities, attend meetings, and still find time to attend sessions!

For many, the WCLH provides a forum to connect and reconnect with colleagues from near and far and to meet and welcome new people into the TB community. For me personally, it is also (continued…)

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(continued…) an opportunity to be inspired by the many contributions Canada and Canadians continue to make to the Union and its efforts toward ending TB such as:

- The Canadians I serve with in The Union: Xiaolin Wei (Secretary General and Individual Member Representative, Board of Directors), Pam Orr (Individual Member Representative, Board of Directors), Kevin Schwartzman (Vice-Chair, TB Section), Wendy Wobeser (Programme Secretary, TB Section), Anne Fanning (Stop TB Initiative), and Diego Silva (TB and Ethics Working Group).


- The Canadians who contributed this year to opening and closing plenary sessions (Grand Chief Wilton Littlechild, Madhu Pai), to post-graduate courses and workshops (Madhu Pai, Stephanie Law, Amrita Daftary, Rich Lester and Kevin Schwartzman), to Diego Silva and colleagues on hosting the inaugural meeting of the TB and Ethics work group; and to Wendy Wobeser, Malcolm King, Grand Chief Littlechild and their colleagues for a powerful symposia on eradicating TB through building positive relationships between TB programs and indigenous populations. You can view Madhu Pai’s presentation during the final plenary session of the conference – Time for a quality revolution in TB care - here: https://www.youtube.com/watch?v=zXLuP5jWx8w&t=5m11s

The 2018 WLHC will be held 24-27 Oct in The Hague, The Netherlands, with the theme: ‘Declaring our Rights: Social and Political Solutions’. Trust me, it will be worth the effort to get there – and not just for the stroopwafels! For more info: http://thehague.worldlunghealth.org/

Call for articles from TB Survivors

Have you or someone you know had TB, or a family member with TB? We would love to include pieces written by people who know firsthand what it’s like to have TB and go through TB treatment. Have your say on what it’s really like, and what it’s meant for you. Articles do not need to have your name if you aren’t comfortable. Contact elizabeth.rea@toronto.ca

SAVE THE DATE: UPCOMING CONFERENCES

Union North American Region Conference 27 February - 3 March 2018, Chicago, USA

49th Union World Conference on Lung Health  24-27 October 2018, The Hague, Netherlands

Ontario Lung Association TB Conference,  20-21 November 2018, Toronto, Canada
Canada takes part in the Global TB Caucus Americas TB Summit

by Shelley Graham

Brenda Shanahan, MP (Chateauguay-Lacolle) and Co-Chair of Canada’s All-Party Parliamentary Global Health Caucus on HIV/AIDS, TB and Malaria, represented Canada at the Americas TB Summit, held in Guadalajara, Mexico in lead up to the Union Conference on Lung Health. The summit was hosted by the Global TB Caucus Secretariat and was attended by 12 parliamentary TB champions from across the Americas region. Ms. Shanahan and her fellow MPs heard from academics, researchers, patients and civil society members and worked with one another to develop parliamentary strategies on including TB in national agendas. The summit concluded with three concrete outcomes from the summit:

• A position statement for the Americas region on the Global Ministerial Conference (November 2017, Moscow) and the United Nations High Level Meeting on TB (September, 2018, New York),
• A work plan guiding MPs in their next steps for these meetings, and
• A strategic agenda to prioritize TB in the region.

Photo: Brenda Shanahan and other delegates looking at the classic Mexican-style murals of the Guadalajara Civil Hospital in Mexico.

Has your MP joined the Global TB Caucus? The Global TB Caucus is a network of parliamentarians around the world who have committed to fight TB in the real world of budget allocation and government policies. Many Canadian MPs from all parties have signed, including Brenda Shanahan above - has yours? For World TB Day this year on March 24, ask your MP to join, and send a message of support to your MP who already has.

More information on the Global Caucus here: https://www.globaltbcaucus.org/
Find your MP here: https://www.ourcommons.ca/Parliamentarians/en/members

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Sign up for email news from the global Stop TB Partnership at http://www.stoptb.org/mailinglist.asp

follow on twitter at https://twitter.com/StopTB

World TB Day is March 24th - what are you doing to mark the day? let us know! send your news and photos to dina.fisher@albertahealthservices.ca

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