



TBeat

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Language in tuberculosis services: can we change to patient-centered terminology and stop the paradigm of blaming the patients?

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SUMMARY

The words ‘defaulter’, ‘suspect’ and ‘control’ have been part of the language of tuberculosis (TB) services for many decades, and they continue to be used in international guidelines and in published literature. From a patient perspective, it is our opinion that these terms are at best inappropriate, coercive and disempowering, and at worst they could be perceived as judgmental and criminalizing, tending to place the blame of the disease or responsibility for adverse treatment outcomes on one side - that of the patients.

In this article, which brings together a wide range of authors and institutions from Africa, Asia, Latin America,

Europe and the Pacific, we discuss the use of the words ‘defaulter’, ‘suspect’ and ‘control’ and argue why it is detrimental to continue using them in the context of TB. We propose that ‘defaulter’ be replaced with ‘person lost to follow-up’; that ‘TB suspect’ be replaced by ‘person with presumptive TB’ or ‘person to be evaluated for TB’; and that the term ‘control’ be replaced with ‘prevention and care’ or simply deleted. These terms are non-judgmental and patient-centred.

We appeal to the global Stop TB Partnership to lead discussions on this issue and to make concrete steps towards changing the current paradigm.

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Heartland National TB Center joins the effort to eliminate stigmatizing language

June 2015 - Heartland National TB Center (HNTC) has joined the effort in eliminating stigmatizing language "and acknowledging ongoing efforts to improve communication, engagement, and inclusion of TB-affected communities in all activities."¹ During the 2015 NTCA conference in Atlanta, HNTC displayed real-life statements and stories as according to actual Texas Center for Infectious Disease (TCID) patients. Display's included 4 varied 2015 calendars, each featuring a different patient with a different statement; and a 12 minute video featuring current and past patients describing a situation that affected them personally during their diagnosis and treatment of TB disease. The calendars are available via the HNTC website (www.heartlandntbc.org/stopthestigma/) or by contacting us. The video is accessible via You-Tube by searching "Stop the Stigma" - Eliminating Stigmatizing Language or by clicking the following link, https://www.youtube.com/watch?v=-zE72y_oB9o.

Where it began: Document links containing information regarding the use of stigmatizing language in TB are listed below. If you are unable to access these, please contact us. The article on the first page is also one of reference.

[Suggested Language and Usage for Tuberculosis \(TB\) care, communications and publications.](#)

[Open letter: Retiring Stigmatizing and criminalizing language from the global TB discourse.](#)

[Civil society calls for the retirement of stigmatizing language from the global TB discourse.](#)

HNTC's commitment: Use language that is patient centered, appropriate and sensitive and represents the dignity of people with TB and their families. **Implement** the use of non-stigmatizing language in the creation of our published material including products, posters, marketing materials and speaking engagements. **Promote** the use of non-stigmatizing language by working with our speakers to ensure all presentations are free of words such as , "suspect", "TB control", "defaulter", "non-compliant", and "TB case".

Our challenge to you: Commit to using language that is patient centered, appropriate and sensitive and represents the dignity of people with TB and their families. **Challenge** others to join you in your commitment. **Promote** the "Eliminating Stigmatizing Language" campaign. **PLEDGE TODAY!**

If you would like to pledge, commit to change and/or challenge others to participate, please contact an HNTC staff member.

During the 2015 NTCA conference, approximately 165 participants pledged to commit and challenge others to eliminate stigmatizing language.

¹Open letter: Retiring stigmatizing and criminalizing language from the global TB discourse.

***Campaign supported by funding from the Treatment Action Group (TAG) (<http://www.treatmentactiongroup.org/>)

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#CommitToChange #TB

#StopTheStigma #TB



#LanguageMatters #TB

#SpeakFromTheHeart #TB



Regional and State Highlights, Updates, and Abstract Presentations

TB CONTROLLER OF THE YEAR - Pat Infield was awarded the 2015 TB Controller of the Year at the National TB Conference in Atlanta in June, 2015. Pat started her career as a TB nurse in Omaha in 1975 and transitioned into the TB Program Manager role in 2003 for the Nebraska Department of Health and Human Services. She has spent 40 years in TB prevention and care. She formed the Nebraska TB Advisory Committee, created a LTBI medication system in Nebraska that allows practitioners to distribute “incident to practice,” and has advocated for legislation to allow nurse practitioners to dispense LTBI medication which failed twice in the Nebraska legislature. Pat was awarded the Nebraska Infection Control Network Distinguished Service Award in 2012 for her lifelong contributions to TB. She has been active in NTCA serving as treasurer and on various committees, always advocating in various ways. Pat is planning a retirement in August, 2015 and will be greatly missed.



NEW POSITION - Patrick Ndibe, MA is now the Public Health Investigator Manager with the Bureau of Tuberculosis in Houston, Texas. In this capacity, he oversees the Bureau’s case registry, contact investigation and the African American Project. Congratulations Patrick!



APPOINTMENTS - Dr. Jeffrey Starke was recently appointed to the Advisory Council for the Elimination of Tuberculosis (ACET) for the Centers for Disease Control and Prevention.



COMMITTEES - Deborah Isaacks, RN, BSN (New Mexico) was appointed to chair the planning committee for the past National TB Nurse Committee’s (NTNC) Webinar, January 22 entitled, “It’s never Just TB-Juggling TB and HCV”; Diana Fortune, RN, BSN presented the NTNC members only webinar entitled, “Presenting Nursing Interventions through Poster & Abstract Displays”.

Deborah Isaacks, RN, BSN is incoming President for NTNC.

Diana Fortune RN, BSN chaired the National TB Controllers Association (NTCA) Planning Committee for the 2015 NTCA conference.

Diana Fortune RN, BSN is the incoming secretary of the NTCA board.

Lisa Armitige, MD, PhD is the incoming president for the National Society of TB Clinicians (NSTC).

Rose Bramble, RN, BSN is the New Mexico Liaison for the New Mexico TB & Corrections Advisory Committee Meetings.



NSTC TRAVEL GRANT RECIPIENTS: Wendy Chung (Texas), Margaret Crawford (Texas), Annie Kizilbash (Texas), Gautam Kal-yatanda (Florida), Kavita Prabhakar (Connecticut), Luis Rubio (Connecticut).



TO BE PUBLISHED - Dr. Jeffrey Starke is currently working on a book called *Tuberculosis in Children and Adolescents*, to be published this fall by the Oxford University Press. His co-editor is Peter Donald from the University of Tygerberg in Cape Town, South Africa. The book will have 22 chapters, written by international experts in the field, and will be the first multi-author book on childhood TB to be published in many decades.



EDUCATION TOOLS (In progress) - Diana Fortune, RN, BSN has created a TB & DM educational flipchart based on the Hawaii model. (English and Spanish) Diana presented the challenges on creation of this educational tool at IUATLD. She is preparing to train nurses at the pilot site to provide education to patients co-infected with TB & DM.

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TB observed National Public Health Week

Article from the Health-e-News, a monthly publication from Metropolitan Health, San Antonio, Texas (with permissions)



Dr. Lisa Armitige, MD, PhD (left); Dr. Barbara Seaworth, MD (right)

Metro Health TB staff joined Heartland National TB Training Center folks to celebrate National Public Health Week, April 6-12. Barbara Seaworth, MD and Lisa Armitige, MD provided pizza, salad, and other healthy food choices to honor front line public health employees making a difference in peoples' lives.

Dr. Armitige and Dr. Seaworth praised the boots on the ground staff performing TB-related directly observed therapy, contact investigations, and nursing patient care as examples of public health in action everyday — working steadily, efficiently, and many times unnoticed by the general public. They also praised the excellent work behind the scenes that the Heartland National TB Training Center staff provides each day with consultations, TB expertise, and training provided in a 9 state region they cover. In his Presidential Proclamation for National Public

Health Week, President Obama also recognized public health professionals and all who care for the welfare of others, and recommitted to doing everything within his power to build a world where every child can enjoy the limitless possibilities of a healthy lifestyle.

Tommy Camden, Health Program Manager, Dora Marrufo, Clinical Nursing Supervisor, and Norma Santos, Community Services Supervisor on behalf of all the staff at Metro Health TB commends Dr. Seaworth and Dr. Armitige for their undying professional devotion to our TB Clinic and making a positive difference in the lives of thousands of people impacted by this terrible disease. Find TB. Treat TB. Eliminate TB.

Congratulations to the Core Values Employees of the Month

Article from the Health-e-News, a monthly publication from Metropolitan Health, San Antonio, Texas (with permissions)

Congratulations to our inaugural recipients of the Core Values employee recognition for April. The leadership vote resulted in a tie. Please extend your congratulations to our recipients:

Pete Hernandez (below left) was recognized for teamwork and integrity.

Cara Hausler (below right) was recognized for teamwork and professionalism.

Both were recognized during the May managers meeting and received a certificate and a Metro Health coin.



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Resources

TB Education and Training Network

<http://www.cdc.gov/tb/education/Tbetn/default.htm>

National TB Controllers Association

<http://www.tbcontrollers.org>

Find TB Resources

www.findtbresources.org

Tuberculosis Epidemiologic Studies Consortium (TBESC)

<http://www.cdc.gov/tb/topic/research/TBESC/default.htm>

Regional Training and Medical Consultation Centers' TB Training and Education Products

<https://sntc.medicine.ufl.edu/rtmccproducts.aspx>

Program Collaboration and Service Integration (PCSI)

<http://www.cdc.gov/nchhstp/programintegration/Default.htm>

Centers for Disease Control and Prevention, Division of Tuberculosis Elimination

<http://cdc.gov/tb/>

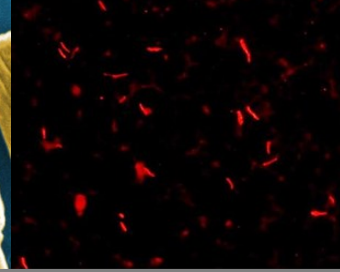
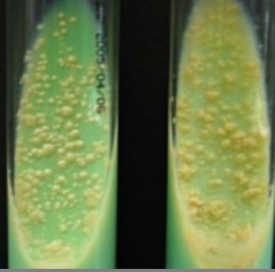
****If your organization has any additional links for TB resources you would like published, please send them to Alysia.Wayne@uthct.edu****

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TBit: Recently Published

- Starke JR and the Committee on Infectious Diseases for the American Academy of Pediatrics: Interferon- γ release assays for diagnosis of tuberculosis infection and disease in children. Epub ahead of print, doi: 10.1542/peds.2008-1536, November 24, 2014. <http://www.ncbi.nlm.nih.gov/pubmed/25422024>
- Nachman S, et al. Towards earlier inclusion of Children in Tuberculosis (TB) drug trials: Consensus statements from an Expert Panel. Lancet Infect Dis, DOI: [http://dx.doi.org/10.1016/S1473-3099\(15\)00007-9](http://dx.doi.org/10.1016/S1473-3099(15)00007-9), 2015. Dr. Starke is on of many co-authors.
- Chiang SS, Swanson DS, Starke JR: New diagnostics for tuberculosis in children. Infect Dis Clin N Am, in press.
- Jakeman B, Gross B, Fortune D, et al. Evaluation of a pharmacist-performed tuberculosis testing initiative in New Mexico. <http://japha.org/article.aspx?articleid=2300225>
- Lessem E, Cox H, Daniels C, Furin J, McKenna L, Mitnick CD, Mosidi T, Reed C, Seaworth B, et al. Access to new medications for the treatment of drug-resistant tuberculosis: patient, provider and community perspectives. Int J Infect Dis. 2015 <http://www.ncbi.nlm.nih.gov/pubmed/25809757>
- Mingote LR, Namutamba D, Seaworth B, et al. Informed use of bedaquiline for tuberculosis - Authors' reply. Lancet. 2015 <http://www.ncbi.nlm.nih.gov/pubmed/25943935>

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Trainings

2015 HNTC Training Calendar

Date(s)	Course	Location
September 22 - 24	TB Nurse Case Management	San Antonio, Texas
September 24	Tuberculin Skin Test Practicum	San Antonio, Texas
October 16	Bi-State Infectious Disease Conference	St. Louis, Missouri
October 21	TB in Corrections	Austin, Texas
October 22 - 23	Beyond Diversity: A Journey to Cultural Proficiency	Austin, Texas
October 29, Nov 5, 12, 19	Introduction to TB Nurse Case Management	Online
November 3 - 4	Four Corners Conference	Denver, Colorado
November 17 -20	TB Intensive	San Antonio, Texas
November 18	TB Intensive Live Presentation	Webcast

****The calendar will be updated in every newsletter as well as on the website to show trainings that have been confirmed****

Please visit our website: <http://www.heartlandntbc.org/training/calendar.php> to find detailed information concerning registration and participation.

Proposed topics are subject to change; check website for the latest updates.

Products from the Heartland National TB Center are available for download at

<http://www.heartlandntbc.org/products/>

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Abstract Presentations



- Fortune D, Struminger B. Managing TB in a Global Society Utilizing ECHO (Extension for Community Healthcare Outcomes)
- Leader C, Horvath L, Mata D, Elkins J, Sanchez R, Farrell D, Acevedo R. The Elastomeric Respirator of Choice in a Tuberculosis (TB) Hospital.
- Mukasa L, Patil N, et al. The Case for Tuberculosis Screening of Arkansans in Birth Cohort Through 1950: A Remote Contact Investigation Strategy.
- Patil N, Beebe A, Seaworth B, Mukasa L. Rifampicin-induced Nephrotoxicity in a Tuberculosis Patient.
- Griffin P, Seaworth B, Armitige L. MDR TB Exposure in a Neonatal Intensive Care Unit.
- Onofre D, Wortmann T, Hadley T, Seaworth B. Enhancing Care Across Distance Through Collaborative MDR-TB Case Management: A Nursing Perspective.
- Kizilbash QF, Jost K, Armitige L, Griffith D, Dunbar DF, Schlenker TL, Seaworth B. Detection of a Cluster of Non-tuberculous Mycobacteria at a Tuberculosis Hospital: A Quality Assurance Intervention.

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The **MISSION** of the Heartland National TB Center is to build capacity with our partners. We will share expertise in the treatment and prevention of tuberculosis by: developing and implementing cutting-edge trainings, delivering expert medical consultation, providing technical assistance, and designing innovative educational and consultative products.

The **VISION** of Heartland National TB Center is to provide *excellence, expertise, innovation* in training, medical consultation, and product development to reduce the impact of tuberculosis in our region.

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