

Structure of a Bronchiectasis and Nontuberculous Mycobacteria Care Center

A Position Statement by the Bronchiectasis & NTM Association



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BACKGROUND: The Bronchiectasis & NTM Association established a network of specialized care centers with unique skills in the diagnosis and management of patients with bronchiectasis (BE) and/or infection with nontuberculous mycobacteria (NTM). The mission of the network is to reduce the time to diagnosis and support high-quality care for patients affected by these conditions. This was intended to address the rising incidence and prevalence of people with BE and/or NTM infection.

RESEARCH QUESTION: What is the ideal structure of a care center, including the members of a multidisciplinary core team, essential partners for more common complications of disease, and the necessary support staff to provide comprehensive care for patients with BE and/or NTM infection?

STUDY DESIGN AND METHODS: Thorough review of the literature and expert consensus was used to develop guidance for center structure.

RESULTS: Recommendations for the core team, essential partners, services and programs, and a support team are offered. These are recommended to provide comprehensive care for people affected by bronchiectasis and/or NTM disease.

INTERPRETATION: This guidance is intended to support the development and improvement of bronchiectasis and NTM care centers.

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KEY WORDS: bronchiectasis; center; guidelines; mycobacteria; team

The incidence and prevalence of bronchiectasis (BE) and/or infection with nontuberculous mycobacteria (NTM) have

been increasing.¹ In response, there has been a similar increase in medical centers dedicated to the care of people with these conditions,

ABBREVIATIONS: BE = bronchiectasis; CCN = Care Center Network; CF = cystic fibrosis; GERD = gastroesophageal reflux disease; ID = infectious diseases; NTM = nontuberculous mycobacteria; PT = physiotherapist; RT = respiratory therapist

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including the development of a Care Center Network (CCN) established by the newly formed Bronchiectasis & NTM Association.² The mission of the CCN is to establish a network of centers across the country, reduce the time to diagnosis, and support high-quality care for patients with BE and/or NTM infection (hereafter referred to as “patients”).

A recent survey of patients found a general dissatisfaction in their care with a low rate of support services offered,³ suggesting that patients might be better served by an interdisciplinary team within a specialized care center. Such centers are associated with improved health outcomes for patients with other complex chronic conditions (eg, sickle cell disease, HIV, cancer).^{4,5} In pulmonary medicine, the cystic fibrosis (CF) care model has been associated with better clinical outcomes⁶ and increased survival⁷; lung transplantation outcomes for people with CF are better when performed at hospitals that have a CF center.⁸ The

specialized centers within the CCN offer expertise in the diagnosis, evaluation, and treatment of BE and NTM infections.

The Cystic Fibrosis Foundation recently updated recommendations for the structure of a CF care team,⁹ and it serves as a template for defining the ideal composition of a BE and NTM center, adjusting and refining for the unique needs and challenges of this overlapping but also distinct patient population. Here we offer guidance for the interdisciplinary team structure based on available evidence and expert consensus opinion with the intent to guide the development and improvement of care centers. We have defined the members of the team, their roles and responsibilities, and suggestions on the optimal team size by discipline. This position statement defines a standard of care that we believe is appropriate and necessary for high-quality management of patients.

Study Design and Methods

The Steering Committee for the Bronchiectasis & NTM Association convened an interdisciplinary working group representing key disciplines, including clinicians (ie, physicians and advanced practice providers [eg, nurse practitioners, physician assistants]), nursing, respiratory care, nutrition, social work, pharmacy, mental health, and genetic counseling, all with considerable expertise in the BE and NTM clinical space; the group also included patients. This working group reviewed literature relevant to the diagnosis, evaluation, and treatment of patients with the goal of defining health care team members and ancillary services essential to optimal care delivery to this population. The final draft was ultimately endorsed by the Steering Committee for the Bronchiectasis & NTM Association.

The working group adapted the CF Team Structure guidance⁹ in its recommendations. Similar to that guidance, we are recommending a multifaceted team structure (Fig 1) including the Core Team, which consists of

members who are primarily responsible for monitoring and treating BE and NTM-related health issues for all patients seen at the center; the Essential Partners, who offer expertise in relatively common complications seen in BE and NTM disease; and the Services & Programs, which offer important contributions that some patients will need because of the severity of their condition. The Programmatic Support Team provides the essential services needed for both a clinical and a research program. These elements are necessary to ensure comprehensive, evidence-based care that can adapt to individual patient needs as well as a changing treatment landscape. We have tried to define the roles essential to the care of patients, but we also recognize that health systems may vary in resources available as well as the training and credentialing required to fulfill that role. Therefore, some of these roles may be fulfilled by more than 1 discipline, but we acknowledge that in some jurisdictions, certain responsibilities must be performed by individuals with specific licensure.

Core Team

Leadership

The operation of a center requires leadership and governance responsible for managing the daily activities of the center. Leadership will develop and implement strategies, optimize processes, and oversee performance to ensure operational excellence where goals are met

efficiently and effectively. This will typically consist of a physician and nurse coordinator who will ensure there is clear communication and collaboration among team members. They will develop standard operating procedures based on existing evidence and a quality improvement framework to ensure they are implemented and updated regularly. The aims of center leadership should align with the stated goals of the

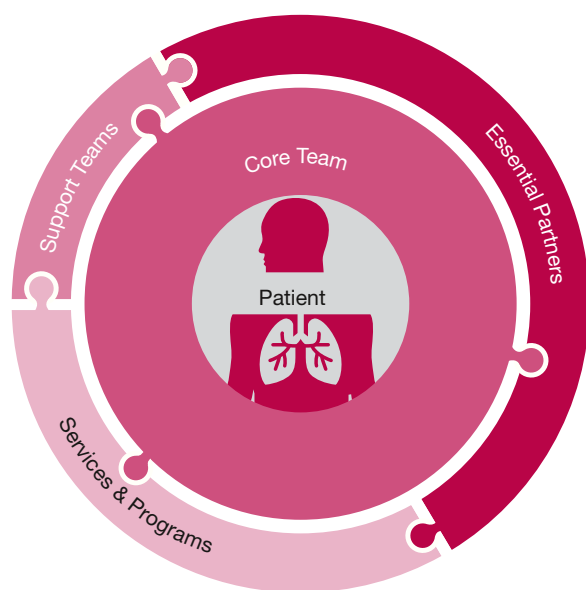


Figure 1 – Structure of a bronchiectasis and nontuberculous mycobacteria center.

Bronchiectasis & NTM Association with an emphasis on timely diagnosis of disease and providing high-quality care.

Clinicians

The clinicians caring for patients should have expertise in BE and NTM infection and will typically include physicians trained in pulmonology or infectious diseases (IDs). A pulmonologist has specialized training and familiarity with BE and airways infections and can offer a sound diagnostic evaluation and evidence-based management plan.¹⁰⁻¹² The ID specialist brings expertise in evaluating whether organisms identified in cultures are truly pathogenic and warrant treatment and develops an appropriate antibiotic regimen.¹³ Some center models will promote full co-management, wherein all patients see both pulmonology and ID; other centers may employ physicians in each discipline who are highly trained and able to manage both the structural lung disease and the infectious complications independently, regardless of their area of specialization. Cross-collaboration and communication between the 2 disciplines is highly encouraged, whether the patient is seen by both specialists or managed under a single specialist, as BE and NTM lung disease can require expertise from both specialties. Advanced practice providers can be highly productive in the center, developing expertise in the conditions, implementing high-quality care, and enabling more frequent follow-

up appointments, which can be essential in preventing hospitalization among more chronically ill patients.¹⁴

Program Coordinator

The program coordinator serves as the key contact between patients and their provider. Their responsibilities include coordinating care, providing education about disease and self-management, coordinating testing, tracking test results, obtaining outside records, triaging clinical concerns, and facilitating communication between the patient and core team, doing so in a compassionate, patient-centered manner to promote health and well-being. In many health systems, this role is provided by someone with nursing training and licensure but could be filled by people with other backgrounds. Successful utilization of the program coordinator requires that centers provide adequate training, standardized protocols, and clear communication pathways with the core team, and ensure that responsibilities are sustainable and keep pace with the growth of a center. Incorporating program coordinators into medical teams also improves clinical outcomes and reduces institutional financial burdens.¹⁵ Coordination of care for patients can include a high volume of responsibilities, where program coordinators may benefit from training and incorporating the help of medical assistants in their daily tasks (eg, obtaining records, placing durable medical equipment orders, coordinating testing).

Respiratory Therapy

Respiratory therapy is an essential component of disease management. The respiratory therapist (RT) or specialized respiratory physiotherapist (PT) plays an important role in the care of patients. They gather important diagnostic data for patients (eg, pulmonary function testing and sputum induction) and assist with bronchoscopy. Airway clearance therapies are a key component in the management of BE and NTM lung disease, and techniques should be taught and reinforced to confirm effectiveness.^{16,17} The RT or PT has advanced and specialized training in airway clearance therapy and can provide customized regimens that improve clearance, reduce exacerbations, and enhance quality of life.¹⁸ RTs and PTs are uniquely positioned to provide education on the proper use and maintenance of nebulizers, positive expiratory pressure devices, and other chest oscillation devices that patients require for self-care.¹⁹ A credentialed RT or PT can have an enormous impact on how well a patient manages their condition.²⁰

Nutrition

A registered dietitian is essential in addressing the various nutritional needs of patients. These can be consumptive conditions^{21,22} that present nutritional challenges including, but are not limited to, appetite loss, early satiety, gastrointestinal complications (eg, constipation, diarrhea, gastroesophageal reflux disease [GERD], nausea), involuntary weight loss, and nutrient deficiencies.^{23,24} Malnutrition and a low BMI are related to disease severity and mortality^{21,22,25}; therefore, it is essential to address these complications with a dedicated treatment strategy. A registered dietitian can assess nutritional risk, the presence and severity of malnutrition, disordered eating, the need for appetite stimulation, and nutrition support, as well as provide compelling individualized recommendations to maintain or restore health.

Pharmacy

Patients are often administered inhaled therapies, antiinflammatory medications, and multiple antibiotics with the potential for overlapping toxicities and drug-drug interactions. The pharmacist plays a critical role in the care center by providing expertise in drug therapy and medication management to ensure safe and effective medication use; this is done by conducting thorough medication reviews and providing essential patient education.^{26,27} Additionally, when patients are on chronic IV antibiotic therapy, pharmacy input has been shown to reduce complications and improve outcomes.^{28,29} Pharmacists, in collaboration with pharmacy technicians, can be especially valuable in facilitating medication access and navigating insurance challenges.^{27,30} In some locations, the pharmacist's role has expanded to collaborative practice models, prescriptive authority, and contributing directly to clinical decision-making.

Mental Health

Depression and anxiety are widely prevalent among patients; current evidence estimates that as many as 75% experience a negative emotional impact from their disease, which adversely affects quality of life and adherence to treatment.³¹ Patients want their emotional and mental health needs addressed in multidisciplinary care.³² A mental health coordinator, who could be a licensed clinical social worker, psychologist, counselor, advanced practice provider, or psychiatrist, can evaluate and treat depression and anxiety. Their participation in a multidisciplinary team can improve mental and

physical health outcomes in patients with chronic lung diseases.³³ A mental health coordinator can conduct screening for mental health and quality of life concerns; provide psychoeducation, brief interventions, and treatment around results from screening; explore barriers to adherence and other psychosocial or quality of life concerns; and provide referrals and resources needed to obtain support for mental health.

Social Work

A dedicated social worker is uniquely positioned to improve the care and outcomes of patients as part of the multidisciplinary team. Effective BE and/or NTM care requires that treatment teams identify psychosocial barriers, provide patient education especially where educational barriers exist, offer self-management tools, and help patients navigate the health care system.³⁴ Social workers have specialized education and training in identifying and navigating each of these unique barriers to effective care and are, therefore, a core member of an effective BE and NTM team. Randomized clinical trial data indicate that multidisciplinary teams including social workers significantly enhance patient-reported quality of life compared with standard care.³⁵

Essential Partners

Comprehensive BE/NTM care is not complete without a team of other specialists who bring unique skills to the management of frequent comorbidities or complications (Table 1). The center should identify these key consultants and engage them longitudinally in the care of their patients.

Primary care providers play a critical role in maintaining a patient's overall health and offering a holistic approach to care through age-appropriate preventive care (eg, cancer screening) and management of common comorbidities (eg, hypertension) for which their foundation of knowledge is greater than that of a subspecialty physician. Since BE and NTM care is often located at tertiary or quaternary care centers where patients may travel long distances for care, collaboration and co-management with local pulmonologist or ID physician should be considered.

The expertise of a *chest radiologist* with formal subspecialty training in thoracic radiology offers invaluable insights into the care of patients with BE and NTM lung disease.^{36,37} High-resolution CT imaging of the chest is the gold standard for confirming the diagnosis of BE and suspicion of NTM lung disease and plays a key role in determining appropriate treatment

TABLE 1] Components of a Comprehensive BE/NTM Center

Core Team
• Leadership
• Clinicians (Pulmonary, Infectious Disease, Advanced Practice Providers)
• Program coordinator/nursing
• Respiratory therapist
• Registered dietitian
• Pharmacist
• Mental health coordinator
• Social worker
Essential Partners
• Primary care provider
• Chest radiologist
• Genetic counselor
• Otolaryngology
• Thoracic surgery
• Gastroenterologist
• Allergy/immunology
• Local pulmonary/infectious diseases physician
Services & Programs
• Pulmonary function laboratory
• Pulmonary rehabilitation
• Interventional Radiology
• Lung transplantation
• Ophthalmology
• Audiology
• Specialty Pharmacy
• Palliative care
Support Team
• Administrative support
• Patient registry
• Microbiology laboratory
• Clinical laboratory
• Research coordinator
• Pharmacy technician

BE = bronchiectasis; NTM = nontuberculous mycobacteria.

plans.³⁸ Both conditions are defined by the presence of radiographic findings of disease as well as the exclusion of alternative diagnoses that may be distinguished based on imaging findings.^{37,39}

Genetic counselors bring expertise to the center and can recommend proper testing, provide interpretation of the results, and counsel patients and their family members. BE occurs in several known Mendelian conditions, including CF, primary ciliary dyskinesia,

and alpha₁-antitrypsin deficiency; additional genetic risk factors and etiologies are likely to be elucidated as genetic testing technology and accessibility expand. Detecting genetic contributions to patient phenotypes can aid prognostication, treatment, and familial risk assessment.^{40,41} Choosing, coordinating, and interpreting genetic tests require advanced genetics understanding and discernment of the multiple available methods.

There is a high prevalence of rhinosinusitis and nasal polyps in patients with BE and can contribute to exacerbations of lower airways disease; engagement with *otolaryngology* can be helpful in disease management.⁴² In addition, some treatments for BE and NTM can affect hearing for which close audiology monitoring is recommended.

Gastroenterologists are often needed in the management of complications related to BE and NTM. There is an association of BE with inflammatory bowel diseases⁴³; also, it is estimated that GERD occurs in up to 75% of patients with BE, and GERD has been associated with increased mortality and severity.⁴⁴

Similarly, immune deficiencies and autoimmune diseases have been identified as a cause of BE as well as a complicating co-morbidity for those with NTM infections; referral to an *allergist/immunologist* or *rheumatologist* may optimize management.⁴⁵

Some patients may be candidates for surgical treatment, where focal disease burden could be removed to improve overall management; a *thoracic surgeon* who is skilled in such cases is essential.^{46,47}

Services & Programs

In addition, there are services and programs needed for some patients that are essential for a comprehensive center. A *pulmonary function laboratory* is needed as part of the baseline evaluation and monitoring of people with BE. Hemoptysis is a common complication and may be severe enough to consider bronchial arterial embolization, performed by a skilled *interventional radiologist*.⁴⁸ *Pulmonary rehabilitation* coordinators (often RT or PT) assist patients by offering education, disease management strategies, and foundational exercises to help improve strength and endurance.⁴⁹ There is clinical evidence that patients participating in pulmonary rehabilitation show increased exercise capacity, improved quality of life, and reduced frequency of acute exacerbations within 1 year.⁵⁰ The benefits of pulmonary rehabilitation are substantial;

TABLE 2] Essential Tasks Performed by the BE/NTM Core Team Outside of Clinic Visits

Medical
• Review laboratory and radiology results
• Triage sick calls
• Coordinate post-hospitalization follow-up visits
• Initiate and manage home IV antibiotics
• Manage prescriptions and communicate with pharmacies and insurance providers
• Adverse effect management
• Communicate with referring providers
• Coordinate and identify resources for dietary needs
• Respond to patient requests and needs in between visits related to food insecurity and dietary needs
• Coordinate insurance challenges and refer patients toward resources
• Coordinate and run support groups
• Respond to patient requests and needs in between visits related to mental health
• Ordering and managing durable medical equipment (supplemental oxygen, aerosol devices, airway clearance devices)
• Obtaining signatures (Certificates of Medical Necessity, insurance documentation)
Administrative
• Organize and participate in team meetings (pre-visit and post-visit)
• Organize and participate in educational activities (eg, case conferences)
• In-box (emails, telephone calls, faxes, EHR messages)
• Coordinate community engagement activities
• Place referrals (pulmonary rehabilitation, counseling/psychotherapy)
• Complete paperwork for prior authorizations, appeals, patient assistance, etc
• Prepare for site visits
• Creation and distribution of patient educational materials
Research
• Plan and conduct clinical trials
• Quality improvement projects
• Maintain patient registry
Financial
• Manage budgets

BE = bronchiectasis; EHR = electronic health record; NTM = nontuberculous mycobacteria.

current guidelines and clinical reviews recommend including pulmonary rehabilitation or exercise training as part of treatment and management plans.¹⁶

Patients who are treated with certain medications will need access to a *specialty pharmacy* as these medications may not be carried by local pharmacies. Some medications have specific toxicity that will warrant monitoring. Treatment with macrolides and aminoglycosides may warrant evaluation by *audiology*. People with NTM infection who are treated with ethambutol are at increased risk for optic neuropathy, a rare but serious complication, and referral to an *ophthalmologist* is advised for new visual signs or symptoms.⁵¹

Those with advanced stage lung disease may benefit from a *palliative care* specialist or even be eligible for *lung transplantation*.

Programmatic Support Team

Additional resources and services improve the care of patients with patients, although they may not be directly involved in patient care (Fig 1). *Administrative support* is needed to manage scheduling and collection of clinical data to ensure an early and thorough evaluation. The core team will partner with the *microbiology laboratory*, including those with mycobacteria speciation and sensitivity testing capability beyond TB, as well as the *clinical laboratory* for diagnostic testing and monitoring

TABLE 3] Staffing Recommendations for the Core Team at a BE/NTM Center

Position	FTE ^a	Per No. of Patients
Clinician ^b	1.0	500
Nurse coordinator	1.0	350
Respiratory therapist	1.0	750
Registered dietitian	1.0	1,000
Social worker	1.0	1,000
Mental health coordinator ^c	1.0	1,000
Pharmacist	1.0	750

BE = bronchiectasis; FTE = full-time equivalent; NTM = nontuberculous mycobacteria.

^aFTE could be distributed among more than 1 person.

^bThe total FTE could be distributed between physicians and advanced practice providers.

^cThis number would increase if the center adopts mental health screening. Full description justifying these numbers are provided in e-Appendix 1.

(eg, sweat testing). The center may contribute to a Patient Registry, critical for planning clinical trials, developing care guidelines, and improving quality of care^{7,52}; a *registry coordinator* can ensure appropriate informed consent and accurate data entry into the registry.⁵² The center is likely to be involved in clinical research and clinical trials; *research coordinators* screen and discuss clinical trial enrollment opportunities with the care team and eligible patients and are responsible for regulatory approvals and study conduct. A *pharmacy technician* can be helpful with medication histories, medication refills, and mitigating cost-related barriers.^{53,54}

Staffing Recommendations

There are numerous factors that will inform how many clinicians and team members are needed for the center. The number of patients at the center will determine how many clinic days and panels should be available to permit prompt evaluation of new referrals, as well as to see those patients who need closer evaluation and monitoring. It is expected that patients referred to centers are likely to have more complicated health issues. Not all patients will need to see all members of the core team at each visit, and some may not require the full range of services; however, since BE is a chronic, and often progressive, condition, many patients will need evaluation and intermittent reinforcement of education by team members. It is important to note that much of the work done by the members of the core team will happen outside of the clinic (Table 2). There are frequent contacts from patients, other clinicians,

pharmacies, and others, through the telephone, electronic health record portals, email, and fax. Some of these tasks are outlined in Table 2, and we have offered some guidance as to staffing in Table 3 with justification in e-Appendix 1.

Team Meetings

Center team meetings are a core component of providing comprehensive, coordinated, and multidisciplinary care for patients. These meetings ensure all members of the core team are aligned on goals, treatments, and the patients' overall health and well-being. The core team should meet frequently (eg, weekly) to conduct clinic planning and follow up of clinic findings. Quarterly or annual meetings may focus on quality improvement and center-wide policies. Case conferences, with the inclusion of essential partners, may be held for the purpose of education or to review complex patient care.

Conclusions

BE and NTM infections are increasingly prevalent conditions in the United States and around the world, and optimal management of this complex and heterogeneous patient population requires a comprehensive care model. Although resources will differ by region or center, we have defined here a set of core team members, key consultants, and support team members that are essential to a center that ensures high-quality, patient-centered, and state-of-the-art care is delivered to patients.

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