Nontuberculous mycobacteria (NTM), also often referred to as environmental or atypical mycobacteria, are mycobacteria that do not cause mycobacterium tuberculosis (MTB). However, NTM can cause pulmonary diseases that resemble MTB, making it difficult to diagnose.

Nontuberculous mycobacterium pulmonary disease (NTM-PD) is more common in patients with pre-existing lung conditions that resemble MTB, making it difficult to diagnose.

The disease requires significant specialist nurse input and a standardised approach to care.

NTM-PD is difficult to treat and can exacerbate pre-existing conditions. It increases morbidity and mortality, and accelerates lung function decline (Diel et al, 2018; Floto et al, 2016). Its symptoms are often non-specific and associated with pre-existing lung conditions, such as chronic cough, increased sputum production, haemoptysis, dyspnoea, and low-grade fever, malaise and weight loss.

Treatment is complex; it is often open-ended, of uncertain efficacy, and the regimes can be difficult for patients to tolerate. Duration is typically 18-24 months, but can be longer if the infection recurs. Due to the possibility of recurrence, the goal of treatment is not necessarily to cure the disease but, rather, to stabilise symptoms, prevent disease progression and, most importantly, improve the patient’s quality of life.

Decisions to treat should be made in the appropriate clinical context and based on the potential risks versus benefits for each individual patient (Titmarsh, 2017). A successful patient response to therapy should include radiographic and microbiologic, as well as clinical improvement (Griffith et al, 2007).
Epidemiology
Between 2006 and 2016, the average annual prevalence of NTM in patients with respiratory disease was 27.7 per 100,000 (Haworth et al, 2017). NTM is a slow-growing organism that can take up to six weeks to culture and be identified by the national mycobacterium reference laboratory. There are over 150 species of mycobacterium; not all are pathogenic but the most commonly isolated species that are pathogenic are:
- The Mycobacterium avium complex group, which comprises Mycobacterium avium, Mycobacterium chimaera and Mycobacterium intracellulare;
- Mycobacterium kansasii;
- Mycobacterium xenopi;
- Mycobacterium abscessus (Lake et al, 2016).
It is important to establish the species’ clinical relevance when making treatment decisions. NTM are being isolated more frequently, meaning NTM-PD is a growing concern whose effects on the future health economy are likely to be considerable (Henkle et al, 2017). Possible explanations for its increasing incidence include:
- More people with structural lung damage who are, therefore, more susceptible to mycobacterial infection;
- More mycobacteria in the environment;
- Improved laboratory detection techniques;
- A greater awareness of mycobacteria’s potential relevance, resulting in more frequent mycobacterial culture being performed;
- An increase in investigations to exclude MTB (Henkle et al, 2017).

Diagnosis
Diagnosis of NTM-PD is difficult, particularly as the symptoms can be masked by other respiratory conditions. As NTM exists in the environment (especially in water and soil), its presence in a single spontaneously produced sputum sample does not indicate disease or the need for treatment and could, instead, be a contaminant. Repeated sputum sampling or taking a sample from a sterile area reduces the risk of any misleading source contamination, so diagnosis is confirmed by three separate culture-positive spontaneously produced sputum samples or by one positive bronchial wash (lavage).

A positive culture from a biopsy and compatible radiological features are also indicative of a diagnosis. Imaging is imperative when NTM-PD is suspected because it has a broad range of radiological patterns (Haworth et al, 2017). As a result, deterioration from normal symptoms or failure to respond to antibiotics should prompt a request for mycobacterial culture from three separate sputum samples taken on different days, and a chest X-ray.

Management and prognosis
Treatment consists of a combination of antibiotics, based on sensitivity and resistance patterns of the NTM. However, there are limited therapeutic options (Diel et al, 2018). The most common combination of antibiotics used is rifampicin, ethambutol and clarithromycin/azithromycin. In severe disease, amikacin or streptomycin are also considered.

At the start of treatment, it is important that the patient’s views are considered and that the potential risks and benefits of treatment are explained in contrast to the observation-only option. Side-effects, allergic reactions and toxicity are commonly caused by treatment for NTM-PD, which can result in poor outcomes and the premature discontinuation of treatment. Patients with NTM-PD have higher mortality rates and experience increased rates of hospital admissions than the general population (Diel et al, 2018). A study conducted in Korea by Park et al (2019) found that mortality rates of all patients with NTM-PD at one year and five years after diagnosis were 4.7% and 17.8% respectively.

National guidelines produced by the British Thoracic Society – Haworth et al (2017) – state that the goals of treatment should include symptomatic, radiographic and microbiologic improvement. Microbiologic improvement should be documented by negative sputum cultures. Treatment should be continued for 12 months following the first negative culture; requesting regular sputum sampling is, therefore, essential to provide both the patient and the clinician with a timeframe for treatment duration.

The role of the specialist nurse
There is no standardised approach in place to support patients with NTM-PD through treatment, monitor adverse effects (such as vision or hearing loss), or provide drug monitoring. As tuberculosis (TB) nurses with a background in respiratory medicine, we were familiar with the management of respiratory symptoms and the drugs prescribed, and experienced in managing the adverse side-effects of similar treatment. We, therefore, felt in a position to support patients with NTM-PD by using the specific aspects of the model of care we have for patients with MTB, which focus on treatment, care and compliance. This meant we could establish a relationship with these patients and provide them with much-needed continuity, support and education through their diagnosis and treatment.

Adapting guidance
In the absence of agreed standards of care for patients with NTM-PD, the Royal College of Nursing’s (2019) guidance for the management and care of MTB provided a framework we could adapt and use for these patients. The framework ensured we provided safe, standardised care, as detailed below.

Drugs used to treat NTM-PD are highly toxic; patients need to be fully aware of what is involved, including the:
- Likely side-effects;
- Benefits and drawbacks of treatment (Titmarsh, 2017);
- Interactions with existing drug therapy.

Drug-monitoring guidance that was developed by Potter et al (2015) to support the monitoring and safe use of anti-TB drugs also advocates baseline assessment to identify the potential for drug toxicity and adverse effects at the start of treatment; the drugs used to treat NTM-PD are included in this guidance. The recommendations include the following tests:
- A full blood count, liver function test and urea and electrolytes test at baseline, repeated after two weeks and again if the patient is symptomatic;
- Visual acuity and colour-discrimination testing at baseline, then every six months – or more frequently if the patient is symptomatic;
- Audiometry testing at baseline and repeated if the patient is symptomatic;
- An electrocardiogram (ECG) at baseline, repeated after two weeks, then every three months and after the addition of any new medication known to prolong the QT interval, as this increases the risk of cardiac arrhythmia.

There is currently no dedicated specialist nursing resource for patients with NTM-PD; however, it is clear from the recommendations on drug monitoring that efficient coordination and continuity of care are essential to ensure patient safety.

Locally, we support these patients by using a combination of specialist nursing resources from the TB and bronchiectasis
services, following the above guidance. This works for us because of the proximity between these services’ locations, but this may be difficult to replicate in other areas. The adaptation we follow is shown in Table 1.

In a climate of nursing shortages and constrained public spending, specialist nurses are increasingly facing organisational and funding challenges that can make it difficult to meet the growing needs of this complex group of patients in addition to the demands of their existing case-load. However, there is evidence to support the vital role that specialist nurses and allied health professionals (AHPs) can play in improving patient outcomes, especially by helping patients manage treatment side-effects, which reduces the rate of hospital admissions and the risk of adverse events (RCN, 2010).

Clinical guidelines for the treatment of NTM-PD – Haworth et al (2017) – recommend care by a physician with specialist knowledge of the disease but not specialist nurse support. This contrasts with clinical guidance from the National Institute for Health and Care Excellence for other long-term respiratory conditions (including interstitial lung disease, lung cancer, bronchiectasis and TB), which advocates the need for specialist nurse input.

**Responsibility for care**

It is unclear where the responsibility should lie in terms of nursing support for patients with NTM-PD. The disease is more common in people with pre-existing lung conditions or those who are immunosuppressed. Specialist nurse resources are usually already available for patients who have a pre-existing condition, while this may not be the case for those who do not; as a result, follow-up arrangements and standards of care and support for patients starting NTM-PD treatment are variable. In light of this, we recommend a nationally agreed care pathway is created, adapted from the RCN’s (2019) practice guidance for the management of MTB, from which specialist nurses and AHPs can work.

There are many challenges to consider when managing a patient with NTM-PD and a multidisciplinary approach to care that specifically involves specialist nurse support is likely to improve the patient experience, reduce hospital admissions and improve outcomes for these patients.

The RCN’s (2019) guidance defines the level of staffing required to manage complex patients with MTB and this can also be applied to the management of patients with NTM-PD. It states: “Patients who require regular follow-up, have complex side-effects and have a single pattern of drug resistance, whose care is coordinated by a named case manager working alongside a specialist multidisciplinary team providing expert care, should be classified as requiring at least level-2 enhanced case management”. Patients undergoing treatment for NTM-PD fulfil these criteria.

The guidance also suggests that patients who are defined as having higher levels of case management require a higher staffing ratio; this could be difficult for specialist nurses to deliver in addition to an existing caseload and there are significant geographical variations in the specialist services provided across the UK. However, the guidance could be used to direct nurses or AHPs who encounter patients with NTM-PD, to improve their patient’s experience and safety.

As the incidence of NTM-PD increases and the number of patients requiring treatment grows, the approach to care and support needs to be standardised. NT

| Table 1 | The practice guidance we created for NTM-PD patients |
| Time | Practice required |
| Start of treatment | ◆ Counsel patient about the potential side-effects of treatment and discuss potential drug-to-drug interaction ◆ Record baseline full blood count, LFT, U&E, colour discrimination, visual acuity, ECG and audiometry ◆ Give patient contact details to report adverse effects and seek treatment advice |
| Two-week follow-up | ◆ Repeat LFT, U&E, colour discrimination and visual-acuity tests; arrange to repeat every six months or sooner if there are visual disturbances ◆ Repeat ECG; arrange to repeat every three months and after the addition of new drugs known to prolong the QT interval to assess for cardiac arrhythmia ◆ Arrange further follow-up until patient is established on treatment |
| Eight-week follow-up | ◆ Check for adverse effects, compliance and medication supply ◆ Request regular sputum samples for mycobacterial culture (every 4 to 12 weeks during treatment and 12 months after treatment complete) |
| Three-month follow-up | ◆ Consultant review: undertake chest X-ray and ECG, assess adverse effects ◆ Provide sputum culture results to assess efficacy of treatment and request further sputum samples ◆ Check medication supply and ensure patient still has contact details |
| Further follow-up | ◆ Consultant reviews every 3-4 months ◆ Nurse-led reviews and support dependent on individual patient acuity |
| Source: Adapted from Royal College of Nursing (2019) |

ECG = electrocardiogram; LFT = liver function test; U&E = urea and electrolytes.

The practice guidance we created for NTM-PD patients


References


Foundation and European Cystic Fibrosis Society consensus recommendations for the management of non-tuberculous mycobacteria in individuals with cystic fibrosis. Thorax; 71: Suppl 1, i1-i22.