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Long term conditions

Expectations and reality: A survey of UK physiotherapy practice in the management of non-tuberculous mycobacterial pulmonary disease

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Abstract

Introduction

The incidence of non-tuberculous mycobacterial infection and pulmonary disease (NTM-PD) is increasing nationally and globally. This is not only related to enhanced mycobacterial surveillance, but also host and environmental factors. Physiotherapy is a key component of the management strategy for NTM-PD but is not routinely available to all UK patients. NTM Network UK are developing multi-disciplinary national standards of care with the aim of supporting clinicians, promoting health-care provider education, and ensuring that people with NTM can access high-quality services throughout the UK.

Methods

Prior to the development of the national standards of care we undertook the first national survey designed to better understand current physiotherapy management of people with NTM-PD and identify barriers to service provision. This survey was distributed and completed over a two-month period in 2022.

Results

Responses received from 52 experienced physiotherapists caring for people living with NTM-PD identified considerable variation in access to physiotherapy resources, with 33% of respondents not having the capacity to see new patients referred with respiratory symptoms related to their NTM-PD (defined as NTM disease identified within the preceding 6 months), and 40% of respondents unable to offer routine outpatient physiotherapy reviews to people with established NTM. Barriers to service provision included a scarcity of funding for staff and devices for airway clearance, a lack of specific NTM-PD national guidance, and limited experience of personnel in relation to sputum surveillance and overall management of NTM-PD.

Conclusion

Alongside extra financial resources, our results support the need for national quality physiotherapy standards for NTM-PD that can help minimise the identified variation in clinical practice. These should include the provision of training, education and experiential practice and reflection for physiotherapists.

INTRODUCTION

The incidence of non-tuberculous mycobacterial pulmonary infections and disease (NTM-PD) is increasing both in the UK and globally.[1,2] Whilst improved detection methods, greater awareness amongst healthcare professionals, and enhanced surveillance may account for some of this, a number of studies suggest that the underlying incidence is rising.[1-3] Possible explanations for this: include declining rates of *M. tuberculosis* infection potentially reducing population immunity to mycobacteria; increases in environmental exposure to NTM e.g. through the use of energy-conserving lower temperature settings for home water heaters plus greater use of showers leading to more NTM-containing aerosol exposure; increased long-term antibiotic usage in inflammatory lung diseases, potentially creating a more favourable lung niche for NTM as normal bacterial flora are reduced; greater use of medications that might impair usual

host immunity to NTM e.g., immunosuppressive drugs; and the potential impact of person-to-person transmission of certain NTM species in some patient cohorts such as people living with Cystic Fibrosis (CF).[3-6]

In associated conditions such as bronchiectasis, persistent detection of NTM in a patient's sputum is associated with worse outcomes, such as weight loss and increased frequency of pulmonary exacerbation.[7] International guideline-recommended approaches to mitigate these are based on clinical studies and pragmatic expert opinion.[8,9] These include physiotherapy review, advice on sputum clearance, sputum surveillance and lifestyle management. For example, sputum collection, either expectorated or via sputum induction, for microbial culture is recommended every 3-4 months in a person with NTM-PD. Anecdotally, good clinical practice suggests that this is carried out by a respiratory physiotherapist experienced in airway clearance methods and sputum induction techniques that allow adequate sample retrieval. Through this regular surveillance, personalised treatment implementation and monitoring can occur. The wider role of the physiotherapist in NTM-PD can further minimise the consequences of repeated respiratory exacerbations in people with underlying lung disease such as bronchiectasis by educating patients in airway clearance techniques, as well as the use of adjunctive and nebulised therapies.[9]

Despite the potential patient benefits of specialist respiratory physiotherapy in this setting, a recent UK survey of clinicians managing patients with NTM-PD found that less than 50% had access to physiotherapy services that could support sputum retrieval, implementation of appropriate airway clearance or advice on physical activity and lifestyle.[10]

There are no UK data on clinical physiotherapy practices for patients with NTM. We wanted to better understand: 1) the current physiotherapy management of people with NTM-PD, and 2) why the recommendations for physiotherapy in NTM guidelines are not being met by >50% of services.

METHODS

NTM Network UK is a multi-professional grouping with membership from over 200 UK centres with a clinical or research interest in improving care for people affected by NTM. Its Physiotherapy Interest Group, which comprises 18 physiotherapists from 13 UK clinical sites with experience of managing patients with NTM infection, developed a physiotherapy-specific national survey to explore the services available to patients with NTM. This survey contained 23 questions relating to referrals to physiotherapy, airway clearance provision/advice, sputum microbiology surveillance, and current physiotherapy patient management of inpatients and outpatients, as well as people who were and were not on specific treatment for NTM. The survey was initially piloted within the NTM Physiotherapy Interest group and modifications made according to expert opinion, current practices and other feedback received. The second iteration formed the final survey, with questions using phrasing that avoided influencing respondent choice, and the opportunity to submit free-text responses where appropriate. Respondent characteristics were also collected.

The survey was designed to examine physiotherapy involvement in the NTM care pathway across the NHS. For this reason, the inclusion criteria specified UK-based respiratory physiotherapists who identified as being in the care of children and/or adults with NTM.

The survey was distributed electronically via the Associations of Chartered Physiotherapists in Cystic Fibrosis (ACPCF) and Respiratory Care (ACPRC) in an email to their respective members. The survey was open from February to April 2022, with one additional email prompt to respond during this time.

Responses were stored securely and analysed in Microsoft Excel. As this was a survey of practice using professional networks for recruitment with no specific participant interviews, neither formal ethics review nor written consent were required. There was no sharing of confidential personal information or NHS specific data beyond basic numerical statistics of people living with NTM. No independent verification of data/reports from local services was performed.

RESULTS

RESPONDENTS' PLACE OF WORK AND SPECIALIST INTERESTS

Fifty-two responses were received. As shown in Table 1, 80% of respondents were from university hospitals or CF units and 20% District General hospitals. Two-thirds of respondents treated adults, and almost half had a sub-specialty interest in bronchiectasis or CF.

PHYSIOTHERAPY REFERRALS

Most inpatient and outpatient referrals to physiotherapy services were from medical staff (reported by 20/52 (62%) and 38 (82%) of respondents respectively). Nursing and ward staff, including allied health professionals, were identified as responsible for referrals by 19 (35%) of survey participants. Indications for referral are shown in Figure 1 with sputum clearance being the predominant reason in 98% of cases.

FREQUENCY OF PHYSIOTHERAPY REVIEW

One-third of respondents did not have the capacity to see new patients (defined as NTM disease identified within the preceding 6 months) and 40% of respondents were unable to offer routine outpatient physiotherapy review to established NTM patients. Barriers to service provision were highlighted as a scarcity of funding for staff, devices for airway clearance, plus a lack of clinician experience and national guidance.

Where physiotherapy review was available, it was scheduled every 1–3 months for 40% of new NTM patients and most established NTM patients, with an annual review as a minimum. Physiotherapy review took place mainly in hos-

Table 1. Respondent workplace and specialism

	Number of respondents, N=52 (%)
Workplace setting	
University hospital	27 (52%)
District general hospital	10 (19%)
Regional referral centre for NTM	3 (6%)
Community setting	2 (4%)
Other (includes Cardio thoracic, cystic fibrosis and paediatric tertiary centres)	10 (19%)
Specialty	
Adult Respiratory medicine	33 (63%)
Paediatric Respiratory medicine	12 (23%)
Adult General medicine	1 (2%)
Adult Infectious diseases	1 (2%)
Paediatric Infectious diseases	0 (0)
Other (includes adult and paediatric Cystic fibrosis centres)	5 (10%)
Sub-specialty	
Bronchiectasis	25 (48%)
Cystic fibrosis	25 (48%)
No subspeciality	9 (17%)
NTM disease	4 (8%)
Tuberculosis	0 (0)
Other (includes ILD, Home Oxygen service, complex chest, COPD, difficult asthma and breathing pattern disorders)	10 (19%)

COPD, Chronic obstructive pulmonary disease; ILD, Interstitial lung disease

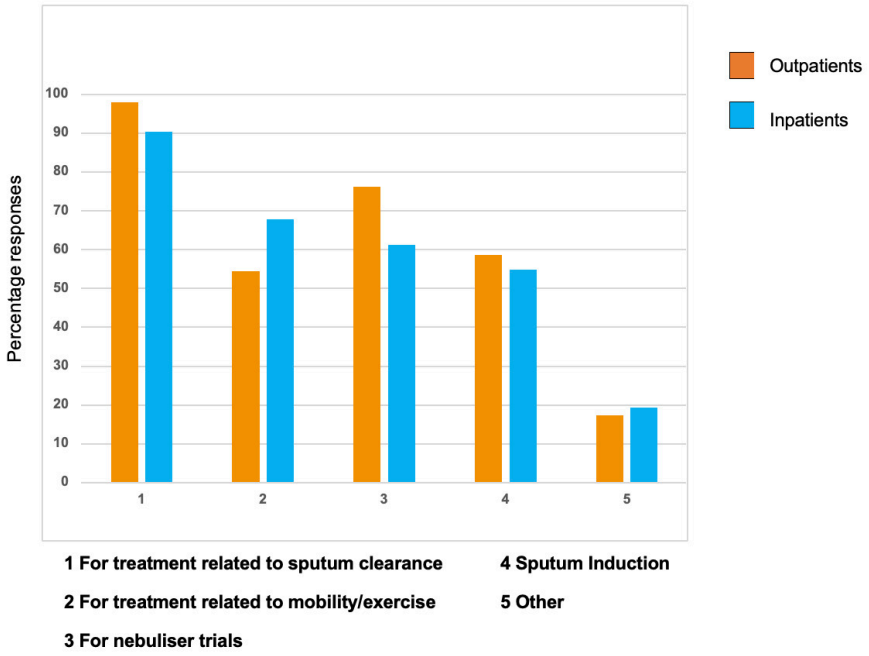

Figure 1. Indications for referral to Physiotherapy.

pital clinics (83%), though there was the occasional opportunity to be seen in the community (22%).

AIRWAY CLEARANCE

Airway clearance techniques plus device provision, depended on the experience of the physiotherapist and funding. Over 40% of survey respondents (21/52) reported experiencing funding issues; these were worse in settings where physiotherapists only reviewed out-patients. Breathing techniques predominated as the technique most frequently taught, followed by Positive Expiratory Pressure (PEP) devices or oscillatory PEP devices.

SPUTUM SAMPLING & NEBULISED ANTIBIOTICS

Sputum surveillance was performed routinely by 75% of respondents (39/52) for both in- and out-patients and included obtaining 2–3 mycobacterial cultures plus bacteriology.

Fifty-two percent (27/52) of physiotherapists were involved in nebulised antibiotic challenges including adherence monitoring.

GUIDELINES ADHERENCE

Where standards of care or guidelines (including for infection prevention and control) were reported as being followed (in 21/52, 40%, responses), lifestyle and management advice was predominantly extrapolated from CF, British Thoracic Society or European Respiratory Society statements.[7-10] These guidelines included room ventilation, decontamination of environments, segregation practices and timing of interventions, however the responses did not specify which guideline components were followed.

DISCUSSION

To our knowledge, this is the first survey of clinical physiotherapy practices used in the management of people with NTM-PD both nationally and internationally. We find that despite being guideline-recommended 15 of 52 (33%) of survey participants reported that their UK physiotherapy service could not routinely assess new patients, and 21/52 (40%) were unable to provide ongoing physiotherapy review to patients established on long-term anti-NTM treatment.[5, 6] Whilst of considerable concern in themselves, these findings disguise the wide variation in what can be offered by specialist respiratory UK physiotherapy services as part of their package of care to people with NTM-PD. When specifically asked about the barriers to providing an appropriate physiotherapy service for people with NTM-PD, this appeared to be largely due to financial and service provision limitations (including staffing and training 15/52, 29%). Based on the high frequency with which patients were referred to physiotherapy from other services, we believe that the value of specialist physiotherapy to patients with NTM-PD is recognised by other members of the multidisciplinary team. However, in the current physiotherapy workforce crisis and funding constraints, the provision of suitable physiotherapy services for this patient cohort is both poorly funded and staffed. If not urgently addressed, we believe that the majority of UK NTM services may soon be unable to offer a basic level of care to the increasing numbers of NTM-PD patients now being managed across the UK and any future standards of care may be unachievable.

We identified several areas of consistent good practice. These included 75% of services providing high-quality sputum sampling for microbiology surveillance (crucial to guide management yet often not performed routinely in a busy medical clinic setting), and the capability to offer nebulised antibiotic assessments in over half of responding services. There was also considerable expertise and support for patients, though it is important to note that many respondents work in specialist units, and so our results may not fully reflect practice where most UK NTM-PD is managed (i.e. outside of these regional or specialist centres). Given the complexities of NTM infections, their associated treatment regimens and options for alternative physiotherapy techniques, we believe that in addition to extra financial resource, the provision of training and education for physiotherapists, plus experiential practice and reflection, are necessary if we are to improve NTM-PD physiotherapy management and develop quality services for the future management of this rapidly expanding patient population.

LIMITATIONS

Although the survey was supported and distributed by both the ACPCF and ACPRC, we cannot accurately determine whether all relevant physiotherapists saw it; and of those who did, the proportion who chose to complete it or their geographical location. The relatively small sample size is likely to be skewed towards specialist units, and hence care needs to be taken when extrapolating the results. Given this, it would be expected that our results are better than the national average as we have targeted respiratory physiotherapists, and hence general medical physiotherapists may not have had the opportunity to respond. To ensure maximal response to this first UK survey our questionnaire was intentionally brief. Detailed information on some aspects of current service delivery was, therefore, limited and could be explored through further studies including single person interviews and more specific questions.

FUTURE WORK

The lack of comparator studies both nationally and internationally argues for similar work to ours to be performed elsewhere. These would provide important information on both global physiotherapy staffing and practice in people with NTM-PD; and support the development of national standards of care for people affected by NTM. Physiotherapy services have a central role within this and the findings from this survey have been instrumental in the delivery of the NTM-PD aspect of these standards.[11] In addition, this survey has highlighted areas where physiotherapy-specific guidance based on best clinical practice (and ultimately good-quality evidence) is needed. With this in mind, we are developing supplementary standards to support physiotherapy practice. These will both complement and enhance the overarching NTM Network standards of care. It should be noted that there is significantly less information on people with NTM-PD reviewed in a community setting for example; how care is delivered, frequency, quality and both positive or negative effects on the patient. This is another important area for future work.

CONCLUSION

Our results highlight considerable practice-pattern variation and argue for national physiotherapy quality standards for NTM-PD, plus the necessary funding to support these. NTM Network UK's work in this area aims to support physiotherapists, promote health-care provider education, and ensure that people with NTM can access high-quality services throughout the UK.

Key Messages

1. There is a wide variation in access to NTM physiotherapy services across the UK. This includes the provision and frequency of review for both new and existing patients.
2. Barriers to NTM physiotherapy service delivery include limited funding for staff and devices for airway clearance, a lack of clinical physiotherapy experience and national guidance on NTM management.
3. National standards of care and physiotherapy-specific guidance based on best clinical practice for people affected by NTM are needed.

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ETHICAL APPROVAL

Not required

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DECLARATION OF INTEREST

LM reports a position as unpaid Chair of the NTM Network UK Physiotherapy Interest Group. ML reports positions as unpaid Chair of NTM Network UK and unpaid Trustee of NTM Patient Care UK. SB reports a position as paid Project Manager for NTM Network UK. JP reports no declaration of interest.

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