

## A notable anniversary for the Nightingale effect

**Rosalind Stanwell-Smith**

Honorary Editor

*'It was impossible to ignore Flo Nightingale'*<sup>1</sup>

Two centuries after Florence Nightingale was born, the influence of her work continues. She has the unusual distinction of being an icon both of nursing and public health: still less common, she experienced the associated respect well before her death. As Lytton Strachey observed in his waspish essay, *'She was a legend in her lifetime and she knew it'*. By this he meant she used this and the authority from her society status to drive through what she felt had to be done, whether this was ordering supplies for a hospital or making sure her carefully compiled statistical evidence was acted upon. Along with admiration for her accomplishments in the Crimean War, army reform and establishing the training of nurses, the Nightingale of Strachey's essay comes across as a tyrant, giving orders from a couch to her 'cabinet' of influential politicians, allowing them neither rest nor disobedience. This was an unfair exaggeration, criticised at the time: Strachey, part of the Bloomsbury set, was doubtless reacting to the anodyne saintly image of the lady with the lamp, also an inaccurate portrayal. For how could she have achieved so much without immense willpower and determination, along with the analytical precision of what Strachey described as her *'fierce pen'*. Victorians were not accustomed to seeing any of this in well brought up ladies. The career options for young Flo were narrow indeed, confined to marriage and running a household. Her parents had no sons and she received an education equal to any wealthy boy, albeit without a college degree, since women were barred from universities. At an early age, she felt religiously inspired to find a higher purpose. Her family members were horrified when she proposed nursing, characterised for Victorians by the drunken Mrs. Gamp in Dickens' *Martin Chuzzlewit* (1843) but she pursued this aim relentlessly, becoming the superintendent of a small hospital in Harley Street in 1853.

In 1854, the Soho cholera outbreak occurred and Florence volunteered her services at the Middlesex Hospital, going without sleep as she tended to prostitutes and other victims. The hospital was a short walk from where Dr John Snow was investigating the cause of the outbreak: sadly there is no record that they met, despite Nightingale's wide acquaintance with influential figures of the day. It would have been an interesting meeting: both strongly believed in the power of empirical evidence, although Florence was reluctant to support evidence other than that she had personally observed. Hence, her dismissal of micro-organisms as the 'germ-fetish': she considered measures against contagion of much lower importance than fresh air and cleanliness. For example, she believed that smallpox, long established as contagious, could be bred in the stagnant air of a closed room.<sup>2</sup> During her time in Crimea, 1854–1856, she observed and documented the improvements brought about by ventilation, sanitation and clean wards, along with a better diet. The mortality fell by half, reinforcing her belief in these measures, particularly attending to drains. She lived long enough to see the germ theory scientifically established, but worried that complacency would distract public health authorities from the impact of bad sanitation.<sup>2</sup>

In this issue, Lynn McDonald pays tribute to Nightingale's influence on public health and Kate Frazer analyses the global system influence of her concern for the poor and homeless.<sup>3,4</sup> Florence observed that it was not medicine, but nature that cures<sup>2</sup> and despite her lack of interest in microbes, the growing interest in the interaction between the human microbiome and the environment might have intrigued her.<sup>5</sup> One of Nightingale's adages was that *'the first possibility of rural cleanliness lies in water supply'*<sup>6</sup> and she would certainly have been interested in the critical analysis of use of orthophosphoric acid in our winning student essay.<sup>7</sup> Similarly, she would have supported government action on unhealthy products<sup>8</sup> and the benefit of exercise, if not Tai Chi, for wellbeing.<sup>9</sup> She would have deplored the current epidemic of obesity<sup>10</sup> and would no doubt have written much on the subject. Florence understood that good care of patients involves social contact and amusement, including combating loneliness or isolation.<sup>11</sup> Clever, sarcastic and driven by deep religious belief, Florence was a challenging figure as well as an icon. Of the many ways in which her outstanding



Florence Nightingale has just been added to the names engraved on the walls of the London School of Hygiene and Tropical Medicine, together with two other notable women health pioneers, Marie Skłodowska-Curie and Alice Ball. Photo credit: London School of Tropical Hygiene and Medicine

achievements have been commemorated, I like the Victorian alphabet primer that awarded N to Nightingale,<sup>12</sup> a tribute that no other public health hero has ever received.

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## Hope in a time of calamity

### **Shirley Cramer CBE**

Chief Executive, Royal Society for Public Health

It is hard to believe that just a few weeks ago we were rushing from pillar to post to get to our next meeting, enjoying a restaurant meal with friends, taking children to football or dance practice, or participating in our community choir or the local yoga session in the church hall. Each one of us has a different tale to tell about our experiences of this global lockdown in the time of COVID-19. As many have said, this pandemic is the biggest threat in living memory to health and wellbeing, social welfare and the global economy.

For many of us it is difficult to feel positive with, at the time of writing, thousands of our fellow citizens dead from coronavirus and many more severely ill in hospital or self-isolating at home with virus symptoms. People are frightened for themselves, their families, friends and colleagues. For those of us involved in the public's health and wellbeing in whatever aspect, we need to consider what the pandemic might mean for the future and one thing is certain; the global public health community is likely to be more influential, more visible and more prominent than before.

Both our readers and contributors to *Perspectives in Public Health* are international and this pandemic has shown, yet again, the importance of sharing information and knowledge across countries and learning from each other. Once the crisis has passed, as it will, the experiences and evidence from the pandemic will help us to be better prepared and scientists are already working across borders to develop a vaccination. International solidarity and strengthening multilateral institutions has never seemed more vital.

One of the most uplifting aspects of the pandemic is that it has highlighted the bravery, skill and humanity of all staff in the NHS, public health and social care who are at the coal face each day. It has been acknowledged too that those working in local government, supermarkets, corner stores, pharmacies, postal workers, refuse collectors, delivery drivers and volunteers, are all essential to our lives as we cope with the virus. Our view of which roles are important has changed for the better.

At RSPH we are playing our part by supporting Government key messages and producing a range of films, blogs and other resources which are on the website and disseminated by social media. These highlight the importance of our mental health, sleep and exercise among other issues. We are conducting surveys to understand the views and experiences of the public at this time and trying to support our members and partners.

All these years of austerity for public health, prevention and social infrastructure have taken their toll, as evidenced by Sir Michael Marmot's February report on our widening health inequalities, but with the funding finally unleashed by Government in response to this crisis, will the tide turn and will the public be unwilling to return to a nation without support systems and social safety nets? I hope, along with many others, that lessons are learned from the bad policy choices taken after the global financial crisis and that we will invest to make sure that we really do 'level up' in every aspect of society.

What is clear now is that health has been prioritised over everything and that 'health means wealth' has never felt so true.

To all our readers and contributors, thank you for all you do to protect and improve the public's health and do stay safe during this challenging time.



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# Fairy Tales and Myths in Public Health

*The use of orthophosphoric acid is a practice used by the water industry to safeguard customers from ingestion of lead but phosphate is a non-renewable resource that has no current practical alternatives. The current dose of 0.5-2mg/l is proven to provide protection of public health, but there is limited published evidence for the use of these concentrations and there could be scope for optimisation.*

Lead exposure can have serious consequences on human health, particularly on the mental development of children, but this is not the only impact. High lead exposure can be responsible for coma, convulsions and death, and even low levels can result in anaemia, hypertension, renal impairment, immunotoxicity and toxicity to the reproductive organs [1].

People are generally aware of lead toxicity, particularly from well publicised sources such as paint and petrol, but do not often associate lead risk from drinking water. In the past, lead was used extensively in industrialised nations because of its durability, malleability and strength, making it a perfect material for the distribution of water from the point of treatment to the consumers of water [2]. Although laying new lead pipes was banned in 1969 in the UK, old lead pipe is still present, especially in houses built before this date. Approximately 40% of UK homes (~17 million people) are still supplied by lead pipes [3]. This is mainly because water utilities own the pipes from the treatment works to the property boundary but the homeowners have responsibility for the pipes from this boundary. Without treatment, lead would be present in tap water because of the corrosive effects of water on household plumbing systems that contain lead pipes, solder or fittings. Although water utilities do not have responsibility for all lead pipes, they work hard to minimise the risk of lead at the tap to ensure water quality is maintained and drinking water is safe to consume.

To ensure lead concentrations are beneath than the strict EU Guideline of 10µg/l, UK water utilities randomly sample customer taps within designated water supply zones, with increased frequency in higher risk areas. They control the lead concentration at the customer tap by dosing phosphate, orthophosphoric acid, which forms an insoluble layer of lead phosphate over the soluble carbonate deposits on the pipe wall, preventing lead leaching. The phosphate dose used is 0.5-2mg/l as it is said that a dose <0.5mg/l has no impact on lead at the customer tap and that a dose >2mg/l does not contribute any additional benefit. The dose used needs to adequately form this barrier while also not delivering too much residual phosphate. This is because phosphate rock is a non-renewable resource with <67,500 million tonnes remaining globally, currently enough for the next 50-100 years, although global phosphate demand is growing at 2.1% every year [4] [5].

Having an optimal dose of phosphate is difficult because of the nature of distribution systems and treatment. Distribution networks are highly complex environments that consist of a wide variety of infrastructure and water characteristics; each individual water source has its own risks and challenges requiring mitigation. Determining the optimised phosphate dose to use within a specific supply zone is difficult, despite intensive local operational testing, as centralised water treatment works dose chemicals for a large area. Therefore if one property within a zone has a risk of lead contamination, phosphate has to be dosed for the entire area to alleviate that risk. Furthermore, risk changes over time as changes occur on a households, network and treatment level, meaning that localised tests should be repeated. If this lead risk presents itself at a consumer tap, phosphate dose will likely increase for a supply zone but it is less apparent when a risk of lead leaching has been reduced and so phosphate dose can be decreased.

Phosphate dose could be further optimised if evidence-based industry best practices were to be shared or if quantities of chemicals dosed were dictated by regulations. An investigation into legislation found that phosphate limits were not mentioned at a worldwide level, an EU level or at a UK level. Thorough examination of literature was completed to find the specific evidence that

suggests a phosphate dose of 0.5-2mg/l is the most optimal range to use. Only one source alluded to the 0.5-2mg/l value, The "IWA [6] Best Practise Guide on the Control of Lead in Drinking Water". This report referenced laboratory tests that found a phosphate dose of 0.9-2.0mg/l successfully reduced lead levels when doses above and below this value did not. Relying on laboratory test results for wider industry practice is challenging as the full environment complexity cannot be accounted for. For example, the laboratory trial used a 30 minute contact time and 25°C when the actual network can have a residence time of > 10 days and be 4-14°C [7]. The original referenced source of this information was a conference proceedings, further details of which could not be found [8]. The intensive local operational testing that UK utilities actually do but do not publish using universally accessible channels, means the depth of detailing surrounding the dose used may be lost.

Therefore, in the utility's best intentions to safeguard human health, it could be that phosphate is overdosed. It is difficult to find published evidence on the best dose to use and validation of the 0.5-2mg/l phosphate dose used by the water industry currently has not been possible. This is an opportunity to further improve the sustainability of this practice by better optimising this dose, reducing treatment costs and protecting dwindling phosphate supplies, or by investing future research efforts in alternatives to phosphate dosing. Identifying common practise and conducting a thorough investigation of them is one way in which to drive efficiency in all industries. The case of the 0.5-2mg/l optimal phosphate dose is just one example of this.

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# Learning from Nightingale’s engagement with complex systems: 21st-century public health issues of homelessness and achieving Sustainable Development Goals

*As an advocate for the poor, much of Florence Nightingale’s work would align with the Sustainable Development Goals we are working towards today. Kate Frazer discusses Nightingale’s person centred work, health inequalities found in homeless populations and the contributions of nurses and midwives to the lives of society.*

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Internationally 2020 is the year of celebrating nurses and midwives in remembrance of the 200th anniversary of the birth of Florence Nightingale. Nightingale was a renowned leader and reformer who was

**Nightingale was a renowned leader and reformer who was highly accomplished in nursing, public health and policy making**

highly accomplished in nursing, public health and policy making.<sup>1,2</sup> Her leadership and advocacy in establishing training and education programmes for nurses recognised their professional role and its importance and impact on population health. She valued public health, sharing her knowledge of sanitation, hand hygiene, reducing risk of infection, nutrition and impact of living conditions with social reformers and policy makers.<sup>3,4</sup>

As a pioneer statistician she collected and used data for change, recognising the influence of statistics in her role as an advocate for the poor. She understood that reform could only be achieved by using irrefutable data to persuade those with entrenched views.<sup>1,2</sup> As an educator she wrote prodigiously disseminating her work and outcomes; she identified nurses ‘as agents of societal and individual reform in advocating to reduce poverty’.<sup>4</sup> Of



importance Nightingale acknowledged the role of *health nurses*, with additional training, to work outside of hospitals and in communities supporting families; changing society’s view of the role.<sup>4,5</sup>

Person centredness was at the heart of her work and is echoed in the contemporary values and strategies of the International Council of Nurses (ICN) and World Health Organization (WHO).<sup>5-7</sup> The World Health Assembly designated 2020 as the *International Year of the Nurse and Midwives* to celebrate their contributions to healthcare. This includes raising the global profile and status of nurses and midwives in workforce planning to deliver universal health provision and to support Sustainable Development Goals (SDGs).<sup>7,8</sup>

The programme of SDGs identifies 17 goals and 169 targets to ‘end poverty, protect the planet and ensure prosperity for all’ by 2030, signed by all 193 member

countries.<sup>8</sup> The SDGs address global challenges including poverty, inequality, climate change, environmental degradation, peace and justice,<sup>8</sup> and nurses working in all sectors of society are ideally positioned to advocate and contribute in a meaningful way.<sup>7</sup> Global action is sought on three levels: leadership, local action and people action. Nurses and midwives in leadership roles can influence policies and reforms: in their practice with individuals, families and communities, they can empower citizens and stakeholders in collaborative partnerships to reduce inequalities and improve health and wellbeing, ensuring no one is left behind.<sup>8,9</sup> The time when academic and professionals could develop research and practice without involving the public and its patients is over. The public and patient voice demands to be heard and the patient to be meaningfully involved in research and care planning. Nurses and midwives hold a key position as knowledge brokers and coordinators in this process.

What can be learnt from Nightingale's legacy of navigating complex health systems to improve health outcomes for the poorest in society and address the wider determinants? Despite attempts to navigate complex health systems, improve health and reduce inequalities, public health problems persist. Evidence and responses to address public health issues require an adoption of a wider set of approaches, recognising a complex systems model of public health with

interdependent and interconnected elements.<sup>10</sup> Concentrating on distinct variables as solvable at a 'micro' individual level ignores complexity and multicausal factors at 'meso' and 'macro' levels for populations and the effect in real-world contexts.<sup>10</sup> It also ignores the dynamic nature of how systems change, or ought to change over time, to be fit-for-purpose to address complex challenges of the 21st century reflected in the SDGs. For many developed countries, for example, the growing number of homeless people concerns public health authorities and practitioners as well as housing officials acknowledging Article 25 of Declaration of Human Rights.<sup>11</sup>

Homelessness is a complex systems issue involving children, adults, and families. Fazel et al.<sup>12</sup> reported in 2014 an estimated 4.1-million people in the EU have a homeless episode annually; however, no single definition of homelessness exists, and data on homeless populations remain underreported and incomplete in 2020.<sup>12,13</sup> Marmot and Bell<sup>14</sup> report that health disparities and inequalities are evident in homeless populations. Homeless adults have reduced life expectancy and poorer health outcomes associated with a multitude of factors.<sup>12,13,15</sup> Hewett and Halligan<sup>13</sup> identified homelessness as not solely a housing and social care issue, but an issue of health, and characterised chronic homelessness as 'tri morbidity' encompassing addiction, and physical and mental health.

Nurses working with homeless populations engage in roles comprising supporting, advocating, navigating and caring – underpinning the ethos of Nightingale. Hewett and Halligan<sup>13</sup> recognised the work of practitioners engaged in supporting homeless populations explaining the 'creativity and ingenuity that arises on the edge of chaos' to seek solutions with multi-tasking to improve healthcare for a marginalised group. A decade later, the value of nurses in building relationships based on trust, such as empathising with clients in their role as homeless links nurses in the community, is pivotal in connecting and advocating for marginalised clients with primary, secondary and specialist care services.<sup>16,17</sup> Unfortunately, the significance of public health and community nurses remains underappreciated and underutilised in many jurisdictions.

To conclude, realising the contributions of nurses to the lives of society will celebrate outstanding practitioners, acknowledge public health practice and highlight inequalities for homeless populations, thus providing a platform for all to contribute to the SDGs.<sup>18</sup> The legacy of Nightingale continues in the importance of collecting and using data to seek reforms of complex public health systems, especially for those living in poverty.

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**Tai chi Movements for Wellbeing – evaluation of a British Lung Foundation pilot**

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## ABSTRACT

**Aims:** In breathless individuals with respiratory disease, pulmonary rehabilitation (PR) can improve exercise capacity, symptoms and ability to cope with their condition. However, access is often limited, and adherence can be poor. Thus there is interest in developing alternative and complementary forms of exercise intervention and tai chi may be effective in this context.

**Method:** The British Lung Foundation worked in collaboration with Tai Chi Movements for Wellbeing Training to train leaders to run community based tai chi groups in the UK. Leaders received funding to run three months of once weekly classes consisting of a 12 movement sequence of tai chi. Participants completed a questionnaire survey to evaluate the service at the start of their first session and again after 3 months.

**Results:** Ten tai chi groups recruited 128 participants, 65% women, mean(SD) age 70.1(7.4) years at baseline. Seventy individuals completed the second questionnaire. Participants demonstrated an improvement in MRC Dyspnoea Score pre 3 (IQR 1.8), post 2 (IQR 1)  $p=0.013$  and symptoms; COPD Assessment Test score pre 19.4(8.7), post 17.9(9.4), mean change -1.5 (CI -2.89 to -0.127)  $p =0.033$ . Those who completed the program had a worse baseline CAT score and were more likely to have participated in maintenance exercise previously. Qualitative feedback suggested that participants felt the classes had helped with breathlessness and relaxation.

**Conclusion:** Establishing a tai chi for wellbeing programme for people with respiratory disease is feasible, with a reasonable level of compliance, and is perceived to be helpful by participants.

## INTRODUCTION

Respiratory diseases are amongst the largest causes of morbidity and mortality(1) and conditions such as Asthma and Chronic Obstructive Pulmonary Disease (COPD) lead to a considerable healthcare burden (2) with considerable unmet need(3). Physical activity limitation is a key feature of COPD (4) and other lung diseases associated with breathlessness. There is a need for effective strategies to reverse this both to improve quality of life and because of the impact of physical inactivity on the development of multimorbidity and mortality rates (5).

Pulmonary rehabilitation (PR) is “a comprehensive intervention based on a thorough patient assessment followed by patient tailored therapies, which include, but are not limited to, exercise training, education, and behaviour change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long-term adherence to health-enhancing behaviours.” (6) Pulmonary Rehabilitation is a highly effective approach, but access can be limited by resources, and even when people are able to participate, approaches to sustain the benefits of rehabilitation are needed(7). PR provides benefits including physical training, education, confidence in managing breathlessness and a reduction in social isolation through taking part in a group activity. It is likely that a range of interventions, which could be complementary or alternative to traditional pulmonary rehabilitation, might be beneficial. These include follow on exercise programs(8), the use of telecoaching(9), and Singing For Lung Health(10-12).

Another possible approach is tai chi, a traditional form of exercise training developed in China (13-15). This may be a more enjoyable activity than a formal exercise class and thus more likely to produce sustained adherence. A Cochrane review of 12 randomised controlled trials of tai chi in COPD found that it improved exercise capacity [increased six minute walking distance by 29.6m (CI:10.52 – 48.77m)], and lung function [increase in Forced Expiratory Volume in 1 second of 110ml (CI: 20-200mls)] compared to control interventions (16). A more recent randomised controlled trial found

that, in treatment-naïve COPD patients, tai chi achieved similar quality of life benefits to pulmonary rehabilitation, with better health related quality of life 12 weeks later(17).

In light of this evidence the British Lung Foundation, developing its current focus on increasing activity participation for those with respiratory disease, is working to establish a network of tai chi groups around the UK. An evaluation of this pilot project is presented here. Compared to previous work in this field we explore the feasibility of offering a simple 12 sequence version of Tai-Chi, to individuals with a broader range of respiratory conditions than previously investigated in one cohort, with clinical outcomes which have not previously been explored in this population in the UK.

### **Aims**

We aimed to find out if it is feasible to set up and deliver ‘Tai Chi for Wellbeing’ groups specifically for people living with respiratory disease and which are run by British Lung Foundation supported leaders. We evaluated feasibility based on numbers of groups that were set up after the training was delivered, the numbers of participants attending the groups, and participant experience feedback. As a secondary aim of this feasibility assessment we investigated whether demographic data and outcome data could be collected from individuals without a professional clinical qualification.

## **THE PROGRAM**

### **Background of establishing tai chi groups**

Tai chi Movements for Wellbeing was developed in 2009 by Richard Farmer, Founder and Principal Instructor of the Rising Dragon Tai Chi School, as a movement sequence based on the principles of tai chi which anyone could do, regardless of their physical capability. It was thought at this time that traditional tai chi could have widespread health and wellbeing benefits but a large percentage of the population were excluded from participation due to its complexity.

A pilot study was carried out with a group of patients with acquired brain injury, and following its success, funding was obtained to train a range of healthcare practitioners in the NHS in Hereford. Since then 'TMW Training' has trained individuals and organisations across the UK and in Europe to deliver TMW in a diverse range of settings. Currently, it is being offered for the general public, through community wellbeing, mental health and rehabilitation schemes, in hospices, care homes, leisure centres and classes for people with long term health conditions. Public Health Wales has funded training for their Exercise Referral Specialists who offer TMW across the country through the GP Referral Scheme. TMW Training is recognised by the Register of Exercise Professionals (REPs).

TMW may be more suitable for the management of COPD and breathlessness than formal or traditional tai chi chuan due to its simplicity. Traditional Tai Chi is a very complex series of movements, (up to 185), that can take a long time to learn. TMW places a strong emphasis on being 'grounded', focusing on the base of support provided by the feet and legs. This focus, together with the principles of TMW which are based around being present and graceful as you move, and the gestures based on an expansion and release, avoid specific focus on the breath yet may encourage a more rhythmical flow of the breath. If appropriate, focus can be brought to the breath and the student is encouraged to follow their natural breathing rhythm so that breathing is not being constrained.

With the support of pamphlets and DVDs, students can go home after their first class and begin a daily practice. They are encouraged to take what they learn into their lives, helping them to cope with stress by knowing how to relax and ground themselves on a day-to-day basis. Further information about the programme can be found at <https://www.tmwtraining.com/about/what-is-tmw/>

### **Tai chi leader training**

The BLF trained 11 TMW instructors. They attended six days of training spread out over three weekends in three consecutive months. They then had homework in between and a final assessment. Level 4 exercise instructor registration was required for applicants. This means that they had expertise working with people who have a long term health condition in exercise classes. Further information about the trainer application process can be found in the online supplement.

The BLF provided trainers with 14 weeks of seed funding: £30 per week for their professional fee and up to £30 per week for their overheads. They received a poster to use for marketing and the BLF used paid marketing on Facebook to promote the groups. In order to be eligible the trainers had to have run exercise classes involving people with long term health problems and therefore they already had experience in how to set-up groups and recruit participants.

The trainers received a one hour session at their training course about the evaluation programme and how to deliver it. The trainers were responsible for handing out and collecting the questionnaires from participants. The trainers were sent all the evaluation paperwork in advance from the BLF project executive.

In each weekly tai chi session the BLF TMW Trainers delivered a 12-move sequence of tai chi Movements for Wellbeing that can be done seated or standing. These movements are based on the principles of tai chi and Chi Kung:

The first principle is that the 'body reflects the mind': mental tension manifests as physical tension in the body, and the use of simple mindful gestures to release tension and 'reflect atmospheres of wholeness' back to the mind, invites a sense of wellbeing.

The second principle is the understanding of 'Soft Limit', the body's natural limit i.e. not overstraining or under reaching, which improves one's ability to come back into balance. This includes moving to support a less restricted limb, by 'mirroring' it with the more-able limb, as opposed to forcing it past its soft limit. Further details of the intervention can be found in the online supplement.



## **METHODS**

### **Evaluation questionnaire survey and patient experience questions**

The evaluation is based on questionnaires administered to participants by the TMW group leaders in 10 groups set up by the BLF around the UK. Leaders were asked to administer the questionnaire survey to participants in the TMW groups at the beginning of the first session and again after 3 months of participation. This provided information about the participants and about the effect of participation.

All the participants who took part in the evaluation completed a consent form which can be found in the online supplement. The BLF sent 4 reminder emails to tai chi leaders during the roll out period of groups, and 4 reminder emails were sent to leaders after 3 months of participation to encourage the receipt of completed questionnaires.

The baseline survey included questions about age, sex, smoking status, how participants had found out about the group, respiratory and other diagnoses, previous participation in pulmonary rehabilitation (PR) and/or exercise groups and breathlessness (MRC dyspnoea score). Questions also included average use of inhaler (regardless of diagnosis), and GP visits and admissions to hospital in the preceding six months. Open ended questions were also provided in order to gain feedback on participant experiences of participation in TMW.

Four patient reported outcome measures were also included:

The COPD Assessment Test (CAT) (18) is a widely used respiratory health related quality of life measure. The CAT is scored from 0-40 with higher scores representing greater disease burden. The minimal clinically important difference (MCID) of the CAT score has been established for Pulmonary Rehabilitation as between two and three points, and the questionnaire has been validated in other respiratory disease (19)

The General Anxiety Disorder-7 (GAD-7)(20) is a measure of anxiety and was developed for use in Primary Care. A score of five or more indicates anxiety and 10 or more indicates that a referral to specialist services is warranted.

The EuroQOL (EQ-5D-3L) is a generic health related quality of life measure containing five question dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) in different domains with three limits per question. A utility score can be calculated which can be used to estimate the health value of an intervention in regard to quality adjusted life years(21).

The fourth questionnaire was designed by the BLF specifically to pilot for use in a Tai-Chi context for global quality of life measurement. All available data were anonymised by the BLF and sent to the authors for analysis. The questionnaire survey is provided with this article.

In addition to the patient reported outcome questionnaire survey, Individuals were given the opportunity to comment on their experiences of tai chi movements for wellbeing on a form with questions and open ended boxes provided for their free text responses. These questions were developed based on previous pilot programmes run by the BLF. The questions are provided in the appendix.

### **Data analysis**

Statistical analysis was performed using SPSS 24. Change following participation in TMW was evaluated for categorical/ordinal grouped data and non-normally distributed data using the Wilcoxon signed rank test, and sign test. Paired t-tests were used to analyse normally distributed data. Baseline differences between participants with and without 3 month follow up data, and participants with and without prior PR participation were evaluated using t-test, chi squared test or Mann-Whitney tests as appropriate. Free text data were analysed by AL who coded and re-coded the data. Codes were grouped into related concepts which were then re-examined in the context of the overall patient

experience. Themes were established based on the relationships of concepts, the researcher's reflexive practice in their experience of running pulmonary rehabilitation for individuals with respiratory disease, and the researcher's interpretation of what participation in TMW means for individuals living with lung disease.

## **RESULTS**

### **Characteristics of population at baseline**

One hundred and twenty eight participants completed the baseline questionnaire survey (Table 1) from ten groups. There was an average of 12.8 participants per group (SD 5.4) and a majority (65.1%) were female. Obstructive lung diseases were most common, reflecting their relative prevalence. Approximately a third (33.6%) of participants had been referred to TMW from PR groups. The majority of participants had completed PR and attended maintenance exercise for at least a year previously. Not all questions were completed by individual participants so there are missing data.

**Table 1: Baseline Characteristics**

<b>Demographic (n)</b>	
<b>Age (n=123) mean(SD)</b>	70.1 (7.4)
<b>Gender M/F (n=126) (%)</b>	34.9/65.1
<b>Current smoker Y/N (n=128) (%)</b>	5.5/94.5
<b>Never smoker Y/N (n=113) (%)</b>	33.6/66.4
<b>Recruitment method (n=116) n(%)</b>	
GP	4 (3.4)
Respiratory Consultant	4 (3.4)
Friend	7 (6.0)
Poster	3 (2.6)
Breathe Easy Group	6 (5.2)
Pulmonary Rehabilitation	39 (33.6)
BLF Website	8 (6.9)
TMW Trainer	38 (32.8)
Other	7 (6)
<b>Attended PR Y/N (n=127) (%)</b>	62.2/37.8
<b>Attended maintenance exercise class Y/N (n=113) (%)</b>	68.0/32.0
Participation in maintenance duration (months)	18(30)
<b>Respiratory diagnosis (123) n (%)</b>	
COPD	88 (57.1)
Bronchiectasis	17 (11.0)
Interstitial Lung Disease	3 (1.9)
Asthma	36 (23.4)
Lung Cancer	2 (1.3)
Pulmonary Fibrosis	8 (5.2)
<b>Comorbidities (94) n(%)</b>	
Heart disease	27 (18.4)
Diabetes	19 (12.9)
Depression	12 (8.2)
Osteoarthritis	34 (23.1)
Anxiety	17 (11.6)
PVD	2 (1.4)
Chronic Pain	13 (8.8)
Sleep disturbance	23 (15.6)

*M/F = Male/Female, Y/N = yes/no, GP = General Practitioner, TMW = Tai Chi Movements for Wellbeing, PR = Pulmonary Rehabilitation, COPD = Chronic Obstructive Pulmonary Disease, PVD = Peripheral Vascular Disease. All diagnoses and comorbidities per participant are reported. Therefore total numbers in 'Respiratory diagnosis' and 'Comorbidities' columns are higher than participant numbers. Data are presented with percentages representing the total of participants who completed the respective questions or questionnaires in the survey.*

### **Response to 3 months of Tai Chi Movements for Wellbeing**

Seventy participants (54.6%) completed the evaluation at 3 months. Fifty eight participants did not return the questionnaire at 3 months. Ten group leaders returned the questionnaire surveys from their group participants at the end of the evaluation. No data was received from TMW group leaders regarding reasons for drop out. The British Lung Foundation contacted group leaders after TMW programme completion regarding numbers of patients approached to enter TMW groups. Two leaders responded and information is provided in the online supplement.

There were statistically significant improvements in the CAT score and MRC score in participants who completed the evaluation at 3 months. Participants reported reduced breathlessness according to the MRC Dyspnoea scale (median change from 3 to 2 Interquartile range 1 p: 0.013) (Table 2). This was associated with a mean improvement in CAT score of -1.5 points (p= 0.033) (Table 3). Inhaler use, number of hospital admissions or GP visits, GAD-7, Euroqol utility score, or BLF QOL questionnaire did not significantly change as a result of 3 months of participation in TMW

**Table 2: Categorical outcome changes from Tai Chi Movements for Wellbeing participation.**

	All	Completers		p value
		Baseline n (%)	Post TMW n(%)	
<b>Inhaler use (105)</b>	<b>Baseline n(%)</b>	<b>Baseline n (%)</b>	<b>Post TMW n(%)</b>	
Hardly ever	20(19.0)	11(18.0)	9(8.1)	
Once or twice a week	6(5.7)	3(4.9)	6(9.7)	
Once or twice a day	45(42.9)	25(41.0)	27(43.5)	
3 to 5 times a week	26(24.8)	14(26.2)	14(22.6)	
More than 5 times a day	8(7.6)	6(9.8)	6(9.7)	1 (sign)
<b>Hospital Admissions in last 6 months (119)</b>				
0	98(82.4)	56(88.9)	63(90.0)	
1-3	18(15.1)	7(11.1)	7(10.0)	
4-7	2(1.6)	0(0.0)	0(0.0)	
7+	1(0.8)	0(0.0)	0(0.0)	0.527 (Wilcoxon -632)
<b>GP visits in last 6 months (105)</b>				
0	21(17.8)	12(19.4)	25(35.2)	
1-3	77(65.3)	41(66.1)	35(49.3)	
4-7	15(12.7)	6(9.7)	9(12.7)	
7+	5(4.2)	3(4.8)	2(2.8)	0.054 (sign z - 1.925)
<b>MRC Dyspnoea score (119)</b>				0.013* (Wilcoxon z - 2.491)
	2(1.0)	3(1.8)	2(1.0)	

*GP = General Practitioner, MRC = Medical Research Council*

**Table 3: Quality of life outcome changes from Tai Chi participation**

	Baseline population Mean(SD)/Median (IQR)	Pre (SD/IQR)	Post (SD/IQR)	Change (95% CI)	p value
<b>CAT (124)</b>	17.3(8.5)	19.4(8.7)	17.9(9.4)	-1.5 (-2.89, -0.127)	0.033* (t-test t = 2.187)
<b>GAD-7 (127)</b>	5.0(5.50)	5.2(5.9)	3.9(4.8)	-1.3 (-2.39, -0.20)	0.360 (sign z = -.915)
<b>EQ-5D-3L utility (122)</b>	0.76(0.80)	0.67(.28)	0.66(0.29)	-0.1(-0.759, 0.534)	0.767 (Wilcoxon z = -.296)
<b>BLF QOL (112)</b>	95.71(44.75)	97.3(48.3)	97.8(53.5)	0.5 (-4.80, 5.73)	0.648 (Wilcoxon z = -.456)

*CAT = COPD Assessment Test, GAD-7 = General Anxiety Disorder – 7, EQ-5D-3L = Euroqol five dimension three limits, BLF QOL = BLF quality of life questionnaire.*

### SENSITIVITY ANALYSIS

Participants who completed 3 months of tai chi were more likely to have a higher (worse) CAT score at baseline (19.2 vs 14.9 p: 0.003), more likely to have completed maintenance exercise programmes post PR (79.7% vs 59.3% p: 0.020) and had fewer hospital admissions (p:0.040). A comparison of baseline demographics between completers and non-completers is provided in the online supplement. Furthermore, participants who had previously completed pulmonary rehabilitation were more likely to improve their MRC dyspnoea score (40% vs 10.5% p: 0.018).





## **Patient experience**

The three month survey provided participants with the opportunity to comment about their experience of TMW. Free text responses to survey questions have been coded and four themes describe the participant experience of TMW of being relaxed and calm.

### **1. Controlling the Breath**

Participants appreciated being taught how to breathe:

*'learning to breathe correctly during the movement does help me to think about my breathing during every day activities.'*

*'It gives calmness to help control shortness of breath.'*

*'I found it helped to control my breathing and taught me the best way to fill my lungs.'*

These techniques appeared to work for patients because of the pace and intensity in which the movement sequences were delivered:

*'Taking everything slowly and controlling your breathing.'*

*'The gentle exercises have enabled me to relieve stress, calming my mind which helps with my breathing.'*

Breathing control was possible once participants learned to relax:

*'The harmony and relaxation to coordinate the function of breathing with that of the movements of Tai Chi.'*

*'Attending Tai Chi has helped me to relax and concentrate. It is so relaxing and being able to focus on my breathing.'*

## 2. Transcendence of physical benefits

The physical benefits of TMW became meaningful for patient spirituality:

*'I found the experience very moving and spiritual when we had mastered the technique and mood in one.'*

This spiritual awakening enabled reflection on the role for TMW for individuals:

*'It has been a rewarding experience physically and mentally, from a firm base enabled us to achieve an inner peacefulness from within that helped to overcome the physical weakness that we endure.'*

*'The slow movements bring a sense of calm and wellbeing that makes me feel peaceful yet gives me energy.'*

## 3. Suitability for those with frailty or more severe disease

The intensity of exercise in TMW enabled individuals with comorbidities and severe respiratory disease to participate and get significant perceived benefit:

*'I can manage without using oxygen but yet still feel I have exercised. The movements are mostly graceful. I particularly enjoy the wild goose and open the day.'*

*'The fact that people with limited mobility can also take part while seated.'*

Participants reported benefit as a form of exercise that is possible when experiencing an exacerbation:

*'I think TMW would be good for all respiratory patients as it is something you can do even when feeling unwell. From my experience it helped me to recover quicker.'*

*'I found it very helpful even with a chest infection as I was still able to do TMW.'*

However, some felt that the level of exercise provided was not at a sufficient intensity.

*'Although I have COPD I am very well and quite fit. I found the style of the Tai Chi was not for me as I prefer more active exercise.'*

#### 4. Sustained benefits following participation

The benefits of participating in TMW were maintained after completion of a session:

*'Going in tense and coming out relaxed and able to take on the world and all its trouble. Thank you.'*

*'I always leave feeling refreshed and ready to get back to everything I have to do.'*

*'The feeling of relaxation and calm following the sessions.'*

The benefits were transferrable to activities of daily living:

*'I can walk much longer distances and not feel out of breath. I can walk my dog again. I've got enough energy to help me cope with housework, gardening and shopping etc. though I still get tired sometimes.'*

## **DISCUSSION**

The results presented here represent the first evaluation of a national TMW program for people with respiratory diseases. Out of 11 leaders trained, 10 groups were set up with approximately 13 participants in each group, and over half participants completed sessions for 3 months providing clinical data. This suggests that establishing community tai chi groups is feasible, with evidence that patients felt that participation had been beneficial. However, although only two trained leaders provided comments about their experience after the evaluation ended, these suggest that caution is needed before TMW is offered with the level of resources allocated to the programme in this evaluation. Participant recruitment to groups is hard work and the sustainability of programmes may be an issue. Our results indicate that the 'Tai Chi movements for wellbeing' programme is more than a programme for generic wellbeing, as TMW is associated with improvements in other clinical outcomes applicable to individuals living with respiratory disease, with statistically significant improvements in participant respiratory health-related quality of life and functional breathlessness. Although these data are uncontrolled they are encouraging and add to the positive outcome data from clinical trials.

### **Breathlessness**

The main perceived benefits of TMW for participants were an improvement in their ability to control their breathing in association with an ability to relax more effectively. These qualitative descriptions of improvement were reflected in improvements in the MRC dyspnoea score. This reflects a central concept of tai chi being mindfulness and associating the flow of movements with the flow of breath. Of note, these findings were not associated with any significant change in self-reported inhaler use. A shared relationship between reduced breathlessness and inhaler use may not be apparent for a number of reasons. It might have been better to use puffs per day of short acting bronchodilator as a more sensitive and specific measure rather than the broad categories used without any indication of inhaler type. Furthermore not all patients with respiratory disease use inhalers. The categorical

sensitivity and specificity of the breathlessness questionnaire could also be improved. For example, future evaluations could use a more discriminative measure of breathlessness such as the dyspnoea 12 questionnaire (22) or the multidimensional dyspnoea scale (23) in order to further understand the mechanisms of improved breathlessness as a result of this intervention and would provide novel data, matching this with more detailed physiology. Interestingly, those participants who previously completed PR showed greater improvements in their breathlessness following tai-chi according to the MRC Dyspnoea scale. This raises the possibility that tai chi may offer clinical benefit additional to PR via an alternate method of exercise and adds to the dose response of exercise given in PR. These patients may have been more likely to benefit from an alternate exercise intervention as they were more likely to be doing regular exercise already, enjoyed it and were familiar with exercise routines. The effect of maintenance exercise classes may reach a plateau effect and a change in type of exercise may test the body differently, and sufficiently to gain additional benefit. Furthermore, those who have received education on ways to manage breathlessness during PR may have been better prepared to use these strategies during tai chi. However, Tai Chi Movements for Wellbeing was designed as a simpler version of traditional forms of tai chi because of a perception that the traditional form may be too difficult for individuals with COPD. However, this may not be the case for some individuals, as illustrated by some of the subjective feedback received and further indicates that TMW is a significantly different intervention to PR, offering improvements in breathlessness management at a reduced physical exertion intensity. Therefore, TMW may also be appropriate for patients who are unsuitable for, or decline conventional PR.

### **Change in Health Status**

Respiratory related health status improved following participation in TMW, although the change in CAT score did not meet the MCID seen among people who note an improvement following pulmonary rehabilitation. PR is normally delivered by a multi-disciplinary team with at least twice weekly sessions(24). There is likely to be a trade-off between the “dose” of intervention delivered, in this case

TMW, and the cost and inconvenience of taking part more frequently. A previous RCT of tai chi in COPD found a 12.4 point improvement in the St Georges Respiratory Questionnaire (SGRQ), over 3 times the defined minimum clinically important difference of 4 points, after 3 months (17). However, the tai chi programme provided in this Chinese study was delivered 5 times per week, a much more intensive intervention. Future tai chi pilots may require at least twice weekly sessions, perhaps over a more intensive initial period, to provide clinically significant improvements in health related quality of life.

### **Methodological issues and limitations**

Since the aim of the program was to establish feasibility and patient acceptability we did not have a control group. This is a limitation because we are unable to know the magnitude of change in a matched group of people living with respiratory disease receiving an alternate intervention of usual care. In future research, a control group is recommended in order to provide a more precise estimate of the effect of TMW in respiratory disease care. Only 2 out of 10 TMW leaders provided comments about their experiences of group set up and delivery. We are unable to comment on leader experiences overall but the comments provided by leaders enable a more moderate interpretation of other results in the evaluation.

A high proportion of the participants had already engaged in other physical activities in the past including pulmonary rehabilitation and maintenance exercise programs. The fact that additional benefit occurred in disease burden and breathlessness encouraging.

Data collection was incomplete, though participation at three months was similar to that observed for pulmonary rehabilitation courses. As with any intervention a proportion of patients will find that it does not suit them and can be encouraged to consider different options. No data were available as to why individuals had not completed their 3 month questionnaire when they were posted back to the BLF.

There were differences in baseline demographics between completers and non-completers of TMW. It may be that those who have previously completed maintenance exercise are likely to continue a similar intervention which may offer similar benefits. However those who completed TMW also had poorer quality of life at baseline. This may suggest that tai chi may be an intervention more appropriate for patients with a high disease burden or that the intervention was not sufficiently tailored to those individuals with a better quality of life at baseline.

### **Summary of findings and recommendations**

The TMW programme we describe here successfully trained tai chi leaders who were able to establish community tai chi groups. Improvements were noted in breathlessness and quality of life. However, the mechanisms of action of TMW remain unclear and data collection was incomplete.

More nuanced measures of inhaler use and breathlessness may be helpful in future research. Further controlled trial data are needed regarding the scale and duration of effects of tai chi in respiratory disease, and further work to understand the benefits may help refine treatments. Additional resources need to be committed to ensure evaluation is as complete as possible, but we would recommend that it is feasible to offer TMW to people with respiratory disease.

### **CONCLUSION**

Recent trial data suggest that tai chi may be an appropriate intervention for individuals with respiratory disease. This service evaluation included a national sample of individuals with respiratory disease who had participated in three months of once weekly TMW sessions, the intervention was feasible and improved participants' breathlessness and health related quality of life. Therefore TMW is a group based physical activity that could be offered to individuals with respiratory disease should sufficient resources be available. Longer term evaluations are needed to address the effects, and a balance between the likely dose response effect and the resource implications for delivering a more frequent intervention will need to be reached.



## **AUTHOR STATEMENT**

The authors have no conflicts of interest related to the work described.

Ethical approval was not sought for this analysis because data obtained were for a BLF internal service evaluation.

TMW leaders received funding to run three months of weekly classes consisting of a 12 movement sequence of tai chi.

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