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Cystic Fibrosis - Caring for Adults through Tai chi – a Study

Final project report

March 2013

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Executive summary

Aim

The aim of this feasibility study was to develop a tailored tai chi (TC) intervention which took into account the particular needs of people with CF, and to provide feasibility data which could inform the design of a future trial, in particular examining the choice of outcome measures.

Methods

A systematic literature review searched Chinese and English language databases to identify research on TC/yoga/qi gong (meditative movement; MM) and respiratory symptoms/cough/dyspnoea. The TC intervention was developed by experts and was based on the "eternal spring" set. Adults with CF were recruited from the Royal Brompton Hospital. Participants took part in 5 weekly TC sessions in their home, with home practice encouraged in between sessions. Subsequently a DVD of the movements was provided and they were encouraged to practice for a further 5 weeks. Quantitative data was collected by postal questionnaire at baseline, and after 5 and 10 weeks, using the cystic fibrosis questionnaire revised (CFQ-R), hospital anxiety and depression scale (HADS), and brief pain inventory (BPI). The TC instructor also collected data at each taught session on use of healthcare, TC practice and CF symptoms, as well as a visual analogue scale (VAS) for general wellbeing. Clinical data was retrieved from hospital records at baseline and after 10 weeks (demographics, BMI, medication, FEV_1, FVC, and oxygen saturation). Data was analysed using a before and after comparison to identify changes in values between the baseline and 1st and 2nd follow up. Two qualitative online focus groups were held with participants after the 10 week programme to explore their experience of taking part and to obtain feedback on research methods and potential outcome measures. Qualitative data was transcribed verbatim and analysed using Framework Analysis.

NHS ethical approval was granted and a steering group monitored study progress.

Results

In the systematic review, 1648 papers were identified, 50 included. Very few were high quality. MM appeared to improve FEV_1 compared with no treatment/exercise; intervention groups in four studies showed changes from 0.07 to 0.83. MM may reduce the Borg scale. MM did not appear to affect FEV_1/FVC ratio and did not affect VO_2, maximal aerobic capacity or cardio-respiratory fitness index.

Eleven patients were recruited; one dropped out due to illness before commencing TC sessions. Five were male, six female and all were White, average age was 38. Five were either working or studying. At baseline predicted FEV_1 ranged from 26% to 74%, five had pain according to the BPI and the highest scoring CFQ-R domains were digestive and eating disturbances; the lowest were physical function, respiratory symptoms and treatment constraints.

Most participants practiced TC for between 5 and 15mins around 4 times a week. None practiced with another person.

A significant improvement was found for the treatment constraints (baseline to 2nd follow up point) and respiratory symptoms (baseline to first follow up point) domains of the CFQ-R, with scores decreasing on average by 27.78 (p=0.023) and 11.90 (p=0.05) points respectively (scale is from 0 to 100). There were no significant differences in the other quantitative variables.

Participants experienced numerous daily or weekly fluctuations in health and CF exacerbations, which appear to be related to events such as chest infections, changes in medication, vaccinations and holidays, as well as declining health.

Seven participants took part in the focus groups. The most common perceived benefit of TC was its relaxing and calming effect, in particular when experiencing breathlessness, as well as improving sleep. Perceived impact on breathing varied; three felt it helped to control breathing or tight airways, and one cited no effect. TC was described as a "powerful tool" to slow down breathing and calm worry and stress when breathless. Other cited benefits including improved mobility and increased exercise levels. Most enjoyed the TC as something other than a medical treatment and free. Challenges to TC practice were diverse but included hospitalisation and poor health, lack of energy, lack of time and prioritising other treatments and forgetting or being unable to do the movements. The DVD was universally seen as helpful and well-constructed. Participants did not report any problems with taking part in the study, although they highlighted that periods of ill health may have affected the results. Six participants planned to continue TC, one was planning to attend a class.

Discussion

This group of patients appear to have had worse health on average than other CF patients, although health varied widely between individuals and fluctuated during the 10 week period. Anxiety and depression scores appeared similar to those in the general population.

Although the uncontrolled study design limits conclusions regarding the effectiveness of TC, preliminary data suggests TC may help reduce the impact of CF treatments on daily life and improve respiratory symptoms. The perceived impact of TC on self-management/coping is important in CF and may relate to self-efficacy which TC is known to improve. Sleep problems are a common problem for people with CF. The challenges of poor health and competing treatments are also common and problematic, in particular for exercise adherence.

Conclusions regarding feasibility

Recruitment and retention in the study was excellent and participants appeared to enjoy and value taking part. The intervention and home practice was appropriate and achievable and the DVD was very helpful. Few wanted to practice with another person.

The lack of significant results may be due to the small sample, as well as the extreme fluctuations in health of participants. It may also be that some of the outcome measures may not have been the most appropriate. From the results of this study and participants' subsequent feedback on other potential outcome measures, we suggest studies measure quality of life, dypsnoea, self-efficacy, coping, sleep and exercise levels. Suggested outcome measures are the CFQ-R, perceived stress scale, Pittsburgh sleep quality index, five facet mindfulness questionnaire, dypsnoea-12 scale, exercise diary and generalised self-efficacy scale.

Further suggestions to deal with fluctuations in health for future studies are a longer follow up period and frequent assessment.

Background

In addition to physical symptoms of cough, poor lung ventilation, recurrent infections, poor weight gain, diarrhoea, and malnutrition, people with CF may have lower quality of life (QOL) than those without (Pfeffer et al. 2003a; Sawyer et al. 2004). They also suffer stress, frustration, depression, irritability, worry, insomnia, behavioural issues, poor posture and missed school or work (Goss et al. 2009; Pfeffer et al. 2003b; Tattersall et al. 2003; Ward et al. 2009). Carers also experience stress, depression and anxiety and may benefit from psychosocial support (Tipping et al. 2010; Ward et al., 2009). However, CF patients may have a higher educational level be more likely to have skilled jobs than the general population (Laborde-Casterot et al. 2012)

In the USA, research indicates that 65% of children with CF used complementary and alternative medicine (CAM) (excluding prayer), 49% being mind-body approaches. CAM was used particularly for CF symptoms, mucous clearance, anxiety, and general health, and 77% found it useful (Tanase et al. 2008).

Tai chi (TC; also known as taiji) is a Chinese form of mindful exercise which includes qi gong. TC has ancient roots in China as a martial practice, but in recent years its focus is on possible health benefits, with evidence of positive effects for a variety of chronic conditions (Jahnke et al. 2010), although trial design has often been poor (Lee et al. 2011). TC may help alleviate CF symptoms, encourage active self-management and provide a practical way to relieve and manage stress for patients and carers. This in turn may improve QOL and wellbeing. TC is based on the theory and philosophy of Traditional Chinese Medicine (TCM). In TCM 'meridians' or energy channels throughout the body are used to diagnose and treat different aspects of disease. Some meridians are related to organs in the body. The lung meridian influences fluid metabolism and lung function. According to TCM, expansive action of the lungs and diaphragm can also aid digestion and fluid movement in the body. In TCM, the 'stomach' meridian is the source of all fluids; this can be related to pancreatic function in Western physiology. In TCM, all fluids are moved by Qi (vital energy), and fluid stagnation impedes body function. It is these TCM theories which suggest that exercise may be useful in CF to stimulate movement of Qi and fluids. Although aerobic exercise is recommended for CF (Philpott et al. 2010), excessive exercise can in some cases lead to dyspnoea, stress and fatigue. Conversely tai chi allows patients to work within their functional capacity, using gentle movements, to stimulate movement of Qi, mucus, blood, and lymph. TC movements are also likely to improve flexibility and posture, a symptom and aggravator of CF (Tattersall & Walshaw, 2003). Through mindful awareness of the movements tai chi is also a meditative exercise, reducing the body's stress levels, and improving QOL and wellbeing.

Teaching TC can provide a self-management tool for habitual home practice throughout life, improving the health and wellbeing of both patients as well as carers who suffer high levels of stress, anxiety and depression. During the transition phase from child to adult care, the development of skills in self-management is crucial (Tuchman et al. 2010). In addition social support from friends and family is important and should be encouraged in CF management, which teaching TC to participants and a carer and/or friend will facilitate (Barker et al. 2012).

Physical activity in CF is encouraged, in order to develop fitness, social skills, relationships and improve quality of life (Philpott et al., 2010; Wheatley et al. 2011). TC differs from many forms of exercise, as it involves gentle yet demanding movements which are low impact and low stress, practiced with respiratory control and mental awareness. This is based on the mind-body-spirit interconnectivity in TCM; TC is a form of moving meditation, which calms the sympathetic nervous system and engages the parasympathetic systems. This can improve cardiovascular and pulmonary function without release of stress hormones, aiding immune function, reducing inflammation due to chronic illness, preventing infections and improving QOL. TC can also directly relieve and manage stress, which can improve QOL for both patients and carers.

To our knowledge there has been no previous research on TC and CF. Studies have found that TC /qi gong may improve pulmonary function in asthma(Chang et al. 2008)., benefit children with special educational needs (Baron et al. 2005) and is feasible to teach to young people (Witt et al. 2005).

Methods

Study design and aims

This feasibility project piloted and evaluated potential TC interventions to inform a future trial to test the benefits of TC. The aim of this study was to develop a tailored tai chi intervention which takes into account the particular needs of people with CF, and to inform the design of a trial, in particular the choice of innovative outcome measures to provide an indication of sample size that may be required. It is important to develop interventions and outcome measures which are feasible, appropriate, realistic, and to ensure compliance.

There were a number of components to this study:

1. A systematic literature review of the existing evidence for tai chi and cystic fibrosis/respiratory function
2. Designing a tai chi intervention suitable for adolescents with CF, including movements, format (online, face to face), method of delivery, accompanying materials.
3. Quantitative research to collect preliminary data on the effects of tai chi on quality of life, health and healthcare utilisation and costs (at baseline, during the intervention and at follow up)
4. Qualitative research (online focus groups and interviews) to evaluate patient experience of tai chi and of participating in a research study
5. Testing the utility and appropriateness of various outcome measures with this population

Recruitment

The study aimed to recruit ten participants aged 16 or over from CF patients attending the Royal Brompton. We aimed for a purposive sample across age groups. A meeting with members of the adult CF multidisciplinary team was organised to select appropriate patients for the study, approximately 20 patients were suggested. Patients from this group were contacted either by phone or face-to-face, and invited to take part in the study. Dr Su Madge gave interested patients who met the inclusion criteria the invitation letter and the study information and the researcher (AL) met those who were interested at the clinic on their appointment days to discuss the study, and take informed consent.

Inclusion criteria were CF diagnosis, living in Greater London, able to take part in 5 individual sessions of TC and complete questionnaires in English.

Tai chi program

Individual 30minute TC classes were held at participant's homes weekly for 5 weeks. One carer and sibling or friend was invited to attend to participate in the intervention, if acceptable to the participant. Participants were also encouraged to practice at home for around 15minutes a day between sessions and after the delivery of the program. Regularity of practice is more important than duration. Participants were specifically instructed not to replace their physiotherapy with the TC.

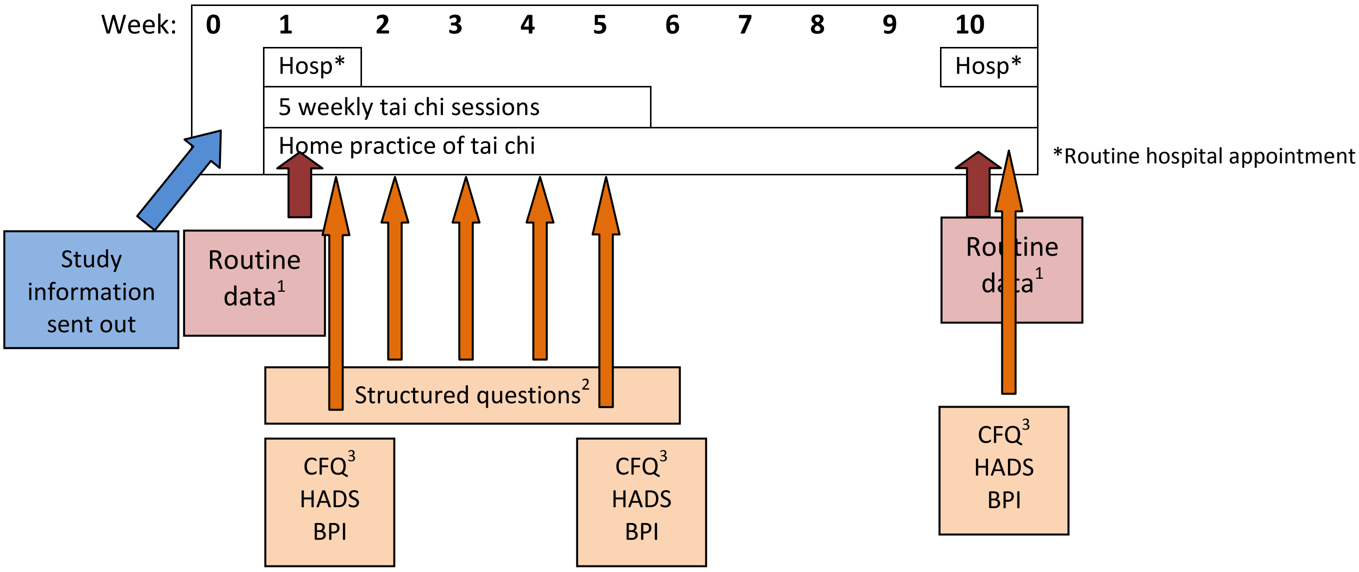
The TC intervention was designed by TC experts (Awais Mian and Michael Acton). Movements were based on the "eternal spring" set, which is achievable, simple, and likely to capture the imagination of participants as it is based on various animal movements. These analogies also act as mnemonics for practice. Movements can be adapted for individual capabilities for example being performed seated. Different movements were discussed in the steering group as to their appropriateness for daily practice and integration into daily life.

The complexity of the movements was kept to a minimum to allow participants to get comfortable with movements in a short period of time. The sequence was kept short for similar reasons. This in turn would help the participants in their compliance with the study and not overwhelm them complex movements, which may take more time to learn and practice. This would make it difficult to both practice TC and do their physiotherapy. Therefore the sequence was designed to complement their physiotherapy, allowing time to do both daily if needed.

Data collection

A number of quantitative outcome measures were piloted and evaluated to assess the impact of TC on quality of life and symptoms. It is important to measure health related quality of life (HRQOL) for patients with cystic fibrosis (Abbott et al. 2003). Therefore, changes in HRQOL were the primary outcome, as measured by the cystic fibrosis questionnaire revised, adult and adolescent version (CFQ-R), a disease-specific instrument (Modi et al. 2003; Quittner et al. 2005). The CFQ-R uses 5 point Likert scales in 9 quality of life domains (physical, role/school, vitality, emotion, social, body image, eating, treatment burden, health perceptions), 3 symptoms (weight, respiratory, and digestion) and health perception. The HADS (hospital anxiety and depression scale) (Zigmond et al. 1983) was also used, a measure designed to evaluate the mental health of chronically ill patients, and the Brief Pain Inventory (BPI). The BPI asks patients to report whether they had any pain, aside from minor daily pains, in the past month, and to rate the severity of the pain on a scale of 0 ("no pain") to 10 ("pain as bad as you can imagine") and has been validated for CF (Flume et al. 2009).

Data was collected before and after (and some during) the 5 week TC program and at 10 week follow up (5 weeks after the programme has finished, during which participants should have been practicing independently at home). Data was not collected during attendance at hospital appointments to reduce the burden on the patient. The following timetable outlines the recruitment and data collection schedule for each patient:



1. Routine data collected as part of hospital appointments was recorded:

- Demographics including age, gender
- Height, weight and BMI
- CF diagnosis history
- Additional antibiotic use (oral and IV)
- Lung function: FEV_1, FVC, oxygen saturation

2. Weekly questions were asked by the TC instructor when he visited to teach the five face to face TC sessions. The following questions were asked about from the previous week:

- Hospital admissions/GP visits/contact with CF centre
- Any changes in medical treatment
- Time off study/work (also for parents)
- Whether the participant had practiced TC
- Whether the participant had taken part in any other exercise
- Sleep: “did you have trouble sleeping?” (always/often/sometimes/never)
- CF symptoms: “Did your stomach hurt?”; “Have you coughed during the day?”; “ Did you wake up at night because you were coughing?”; “Did you have trouble breathing?” (always/often/sometimes/never) (taken from the CFQ-R)
- Visual analogue scale (VAS) for general wellbeing

3. Participants completed the CFQ-R, HADS and BPI, at first TC session, last TC session, and at 10 week follow up.

At the end of the TC programme qualitative research obtained feedback on participants’ experience through focus groups on the feasibility of learning and practicing of TC, engagement with the process, levels of concentration and perceived health impact, as well as feedback on their participation in the study, in particular the appropriateness of outcome measures. This allowed for social interaction and provided further data on experiences. Online synchronous focus groups using Skype were used. Synchronous groups, where participants contribute to discussions in real time are thought to have many similarities to traditional focus groups, including an oral style of writing, emotion is readily expressed, and participants interact(Rezabek, 2000; Stewart et al. 2005). Online focus groups are a relatively recent form of qualitative research, but are ideal for this population where face-to-face meetings cannot be conducted. The patients at the Royal Brompton are familiar with this method as much of their patient education is in this online format. Online focus groups can also equalise individuals and reduce inhibition compared to face-to-face, providing more reliable data (Mercer et al. 2007). They also have practical advantages such as including participants from a wider range of geographical locations.

Data analysis

Data was analysed using a before and after comparison to identify changes in values between the baseline and 1st and 2nd follow up (5 and 10 weeks later), for the CFQ-R, HADS, BPI and clinical data. VAS scores collected weekly at each TC session were also analysed for changes over time. All data was normally distributed so t-tests were used for most variables, with repeated measures of variance ANOVA for the weekly VAS scores and Friedman two-way analysis of variance for the other weekly scores. Subgroup comparisons were not possible due to the low numbers of participants. All analysis was done using PASW Statistics Package (SPSS) version 18.

Qualitative data was transcribed verbatim and analysed using Framework Analysis (Ritchie et al. 2003) and Nvivo software (v10).

After the study was completed we posted copies of questionnaires for potential use in future studies to the participants and asked for their comments on the time taken to complete, appropriateness for CF and ability to capture the benefits of TC.

Steering group

A project steering group met 3 times over the project. In attendance were Dr Su Madge (consultant nurse at the Royal Brompton), Dr Siobhan Carr (consultant paediatrician, Barts and the London), Emma Lake (a Brompton CF patient), Liz Crighton (senior lecturer, previous CF nurse, LSBU) and the project team from LSBU (Prof Nicola Robinson, Dr Ava Lorenc and Awais Mian, TC instructor).

Ethical approval

NHS ethical approval was granted on 10th May 2012 by proportionate review from the NRES Committee East of England – Norfolk, reference 12/EE/0162.

Systematic review (abstract)

Background and aims

Meditative movement (MM; tai chi/yoga/qi gong) may be beneficial for people with CF as a form of gentle exercise incorporating meditation, breathing and relaxation.

This systematic review reviewed the evidence for MM for respiratory symptoms to inform the use of tai chi for CF.

Methods

Both Chinese and English language databases were searched using keywords relating to tai chi/yoga/qi gong, and respiratory symptoms/cough/dyspnoea. Articles were screened and selected by two researchers. Controlled studies or systematic reviews published in English/Chinese after 1980 were included. Data were extracted using a specially designed spreadsheet. Two researchers independently evaluated quality of the research and of the reporting using three standardised checklists. Meta-analysis could not be performed due to heterogeneous methodology.

Results

A total of 1648 papers were identified, 50 included (36 English language, 14 Chinese), 5 systematic reviews, 24 RCTs, 21 non-randomised trials. Twelve studied patients with respiratory disorders, 11 healthy people. Very few were high quality. The main bias with the RCTs identified was randomisation, non-random or poorly reported sampling, for non-randomised studies poor reporting of samples and non-equivalent groups. MM appears to improve FEV_1 compared to no treatment/exercise; intervention groups in four studies showed changes from 0.07 to 0.83. MM may reduce the Borg scale. MM did not appear to affect FEV_1/FVC ratio and does not affect $VO_{2,}$ maximal aerobic capacity or cardio-respiratory fitness index.

The main study limitations were: poor reporting of sampling or methods; small, potentially underpowered samples; non-randomised design; lacking description of randomisation; randomisation by centre; no blinding; lack of reporting of important aspects of MM; short-term follow up.

Conclusions and implications

Limited evidence suggests MM may improve respiratory function. Due to heterogeneity of populations and lack of sampling information, conclusions cannot be generalised to those with CF. More research is needed in this area, in particular powered, randomised studies.

Study Results

Recruitment and Retention

From a list of 20 eligible patients were patients were invited sequentially, once eleven patients had agreed to take part recruitment stopped. Only one patient from the selected list declined to take part in the study saying that her current treatment burden was too overwhelming to take on anything else. From the eleven patients recruited for the study, one dropped out due to illness after the first time point, and did not receive any TC. Two other participants failed to return questionnaires apart from the first. The average duration of participation was 3.41 months.

Baseline Characteristics

Of the 11 participants, five were male, six female and all were White British or White Other. The average age was 38, range from 27 to almost 68 years. Four were married and four were with a partner, one widowed, one separated and one single. Nine had a higher education qualification, 2 GCSEs or lower. At the start of the study, four were working, four not working or studying due to health, two not working for other reasons and one studying at home.

Table 1: Individual participants				
Code	**Gender**	**Age**	**FEV_1 % predicted (baseline)**	**Study completion**
1	Male	27	26%	completed
2	Male	47	29%	completed
3	Female	30	66%	completed
4	Male	67	27%	Did not complete (no TC)
5	Female	28	48%	completed until first follow up
6	Female	39	37%	completed
7	Female	40	59%	completed
8	Male	32	74%	completed
9	Female	27	58%	completed
10	Female	31	23%	completed
11	Male	46	62%	completed until first follow up

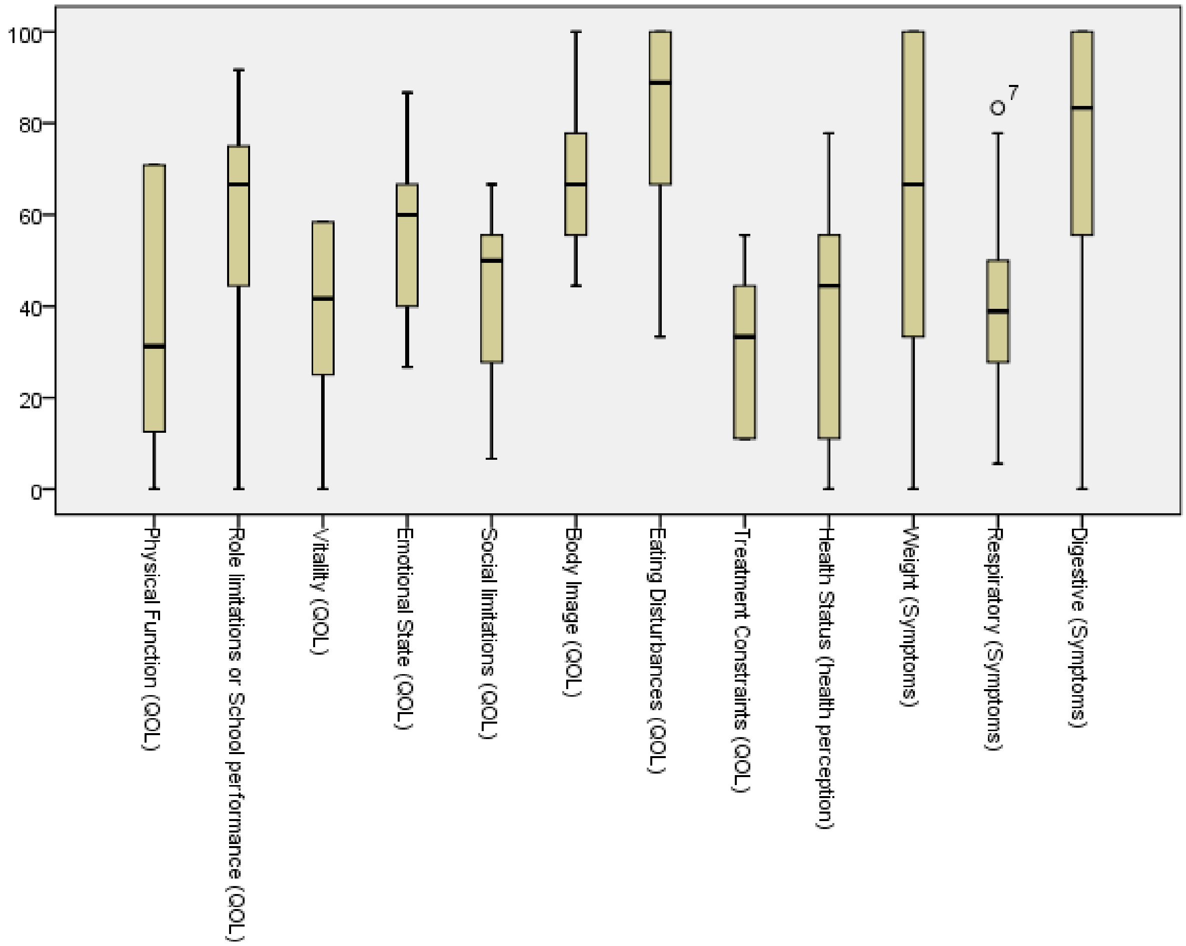
Table 2 shows the baseline data. This data illustrates the wide range in health between participants, including respiratory function, which does not appear to be related to age. Notably some participants scored 0 (lowest possible) on a number of CFQ-R domains, but some scored 100. In addition five had pain according to the BPI at baseline. As seen in figure 1, the highest scoring CFQ-R domains were digestive and eating disturbances; the lowest were physical function, respiratory symptoms and treatment constraints.

Participants were using a wide range of medications, an average of 16 per person at baseline from a total of 70 different medications. On average (median) participants were using 3.5 inhalers, 2 nebulisers and taking 7.5 tablets. All were taking antibiotics (most commonly Azithromycin orally and promixin/tobramycin nebuliser), digestive replacement tablets (most commonly vitamins A&D,

K and E) and a respiratory nebuliser (usually Dnase or Salbutamol). All except one were taking gastrointestinal medication (most commonly Creon, Movicol and Omeprazole) and a respiratory inhaler. In addition five were taking insulin, three were on cardiac medication, three on antidepressants one on painkillers.

Table 2**: baseline data. N=11**	**Mean**	**S.D.**	**Minimum**	**Maximum**
Clinical data				
FEV_1 (litres)	1.52	0.67	0.70	3.11
FVC (litres)	2.96	1.10	1.38	5.19
FEV_1 Predicted %	46.27	18.48	23	74
FVC Predicted %	74.00	20.74	39	103
SAO_2 (%)	96.27	1.49	93.0	98.0
BMI (kg/m^2)	22.08	2.78	18.0	26.96
CFQ-R data				
Physical function (QoL)	38.54	33.74	0	70.83
Role limitations (QoL)	58.33	40.25	0	91.67
Vitality (QoL)	37.50	27.64	0	58.33
Emotional state (QoL)	67.50	20.44	46.67	86.67
Social limitations (QoL)	39.17	22.14	6.67	55.56
Body image (QoL)	66.67	9.07	55.56	77.78
Eating disturbances (QoL)	63.89	22.91	33.33	88.89
Treatment constraints (QoL)	33.33	15.71	11.11	44.44
Health status (perception) (QoL)	47.22	34.40	0	77.78
Weight (symptoms)	41.67	50.00	0	100.00
Respiratory (symptoms)	43.06	28.10	11.11	77.78
Digestive (symptoms)	63.89	47.47	0	100.00
HADS data				
Anxiety score	6.72	4.05	2	14
Depression score	4.63	2.25	1	8

Figure 1: Baseline CFQ-R scores



Tai Chi Practice

As seen in Table 2, in between the taught sessions, most participants practiced TC for between 5 and 15mins around 4 times a week. None practiced or were taught with another person. Nine participants had their taught sessions at home, 1 at LSBU.

Table 3: Tai chi practice during 5 weeks taught		
Participant	**Times per week**	**Duration per session**
1	3	5 to 10 mins
2	4 to 5	10 to 15 mins
3	5 (weekdays)	10mins
5	Variable, between 2 and 5	10 to 15 mins
6	3 to 5 times	10 mins
7	once in whole study	Not specified
8	4	10mins
9	7 (once a day)	5 to 10 mins
10	3 to 4	5 to 10 mins
11	Variable, between 4 and 7	10mins

Changes in Quantitative Variables

Initial questionnaires and clinical data were collected for all 11 participants. Follow up questionnaire data was available for 7, clinical data and weekly data for 10.

A significant improvement (reduction in score) was found for the treatment constraints (baseline to 2nd follow up point) and respiratory symptoms (baseline to first follow up point) domains of the CFQ-R, with scores decreasing on average by 27.78 ($p=0.023$) and 11.90 ($p=0.05$) points respectively (scale is from 0 to 100).

There were no significant differences in:

- VAS scores (measured weekly at 5 time points)(data available n=10)
- Any of the other scores measured weekly (sleep problems, stomach pain, coughing, waking from coughing, breathing trouble) (n=7) – although sleep problems nearly approached significance.
- BMI, FEV_1, FVC, SAO_2, (n=10)
- BPI pain or interference scores (n=4)
- CFQ-R Domains (n=7): body image; digestive; eating disturbances; emotional state; health status; physical function; respiratory; role limitations; social limitations; vitality; weight (neither from baseline to 2nd timepoint or baseline to 3rd timepoint)
- HADS anxiety or depression scores (n=7) (neither from baseline to 2nd timepoint or baseline to 3rd timepoint)

From both the quantitative and qualitative data it emerged that the majority of participants had experienced some period/s of poor health during the study.. Figure 1 gives some examples of the events occurring during the study and their possible influence on VAS scores, illustrating the wide range of events and health issues experienced by participants during the 5 weeks of the taught TC sessions.

Figure 1: Weekly VAS scores over the 5 weeks of TC instruction.

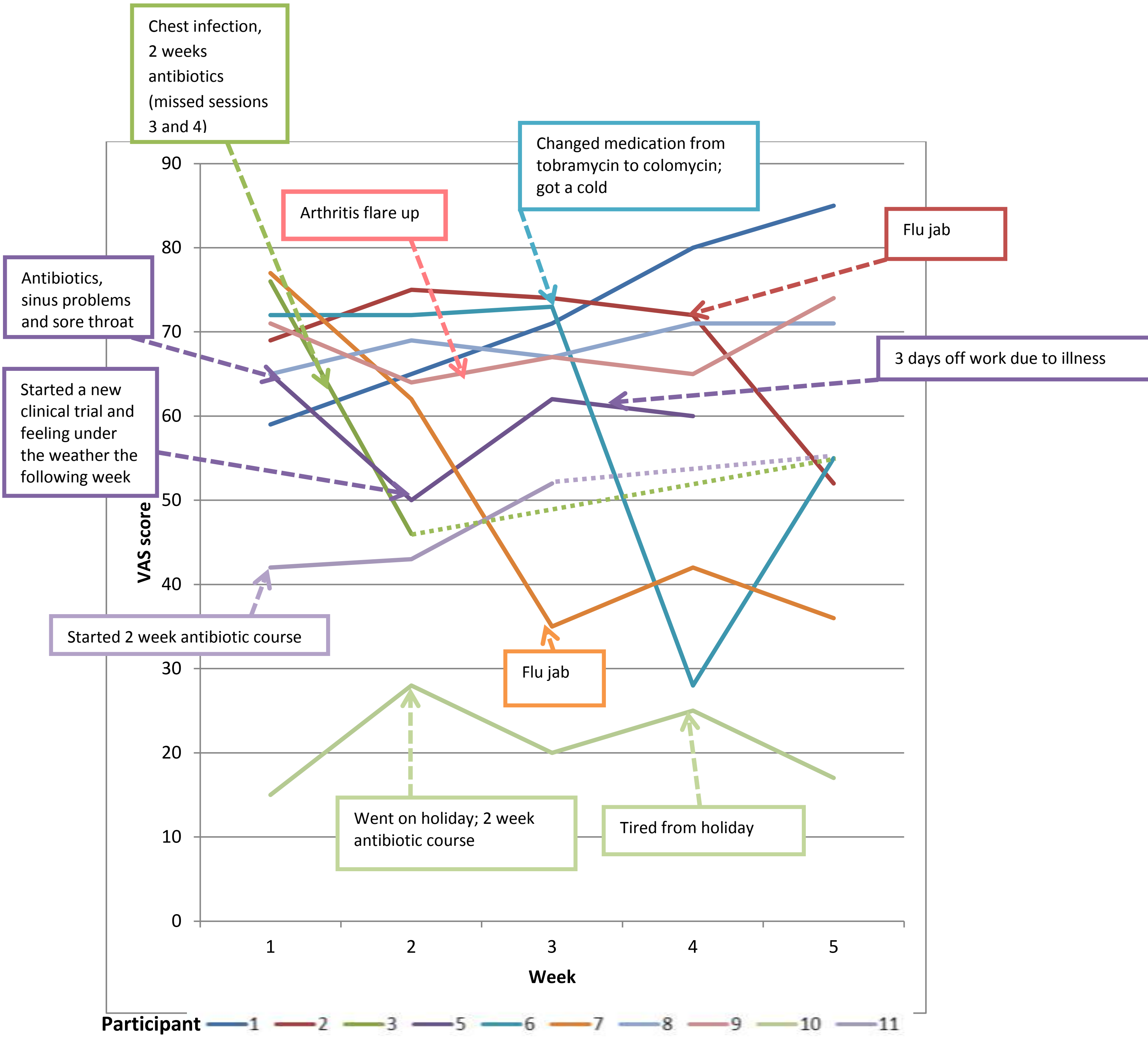
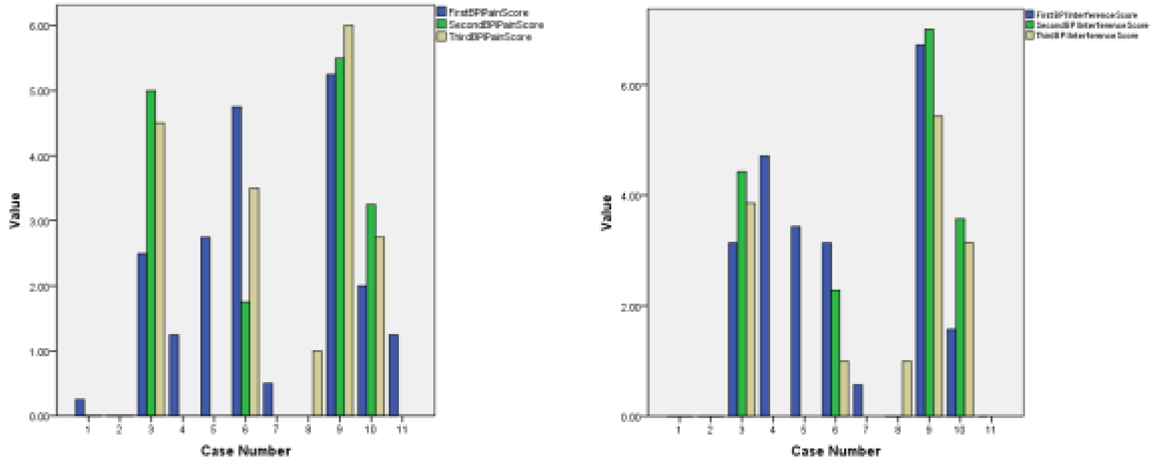


Figure 2: Changes in BPI scores for individual participants



Pain score

Interference score

Qualitative Results

Seven participants took part in two online focus groups (participants 1,2,5,6,8,9,10).

Tai chi principles and practice

- Two participants reported learning seated TC which they found useful.
- One found the mindful breathing techniques very useful and another felt that TC was similar to meditation which they had previously found beneficial.
- One cited practicing TC regularly, in particular the breathing techniques rather than the full movements.
- One cited practising the movements in the night, seated, when they wake to do physiotherapy. Another practised before bed and another mid-morning.
- The 10 minute routine was seen as achievable to practice every day.
- Two cited practicing as much as they could
- One intended to practice with their husband as they felt TC would benefit him as well, and another wanted to practice with a friend who has bronchiectasis, but hadn't so far due as the friend was ill so there was risk of cross-infection. Two cited they would feel too self-conscious to practice in a group/with others.
- Four were planning to continue to practice TC themselves, one was intending to attend a TC class and one hoped to continue once their health had improved. Only one participant did not plan to continue with TC.

> "me and my friend are looking at going to a tai chi class now, if we can find one nearby. It's something I would definitely recommend to people" [6]
>
> "I'll try to do it as much as I can, and I'll see, I'll give it a longer period to see if it has any long-term effects" [5]

Benefits and perceived effects

The most common perceived effect of TC was **relaxing and calming**, cited by 6 participants. This included calming them when they got out of breath and relieving the stress of worsening health.

> "when I've got very out of breath I've actually used that to keep as calm as possible" [10]
>
> "It was very relaxing and enjoyable to do" [5]
>
> "It certainly relaxed me, definitely relaxed me" [8]

Similarly, two participants felt it helped them **sleep**, and another practiced TC when they woke up in the night due to CF.

> "The type of breathing, deep breaths and slowing down my breathing… has helped me try and get to sleep which I've had trouble with before starting tai chi, so I'm less tired during the day because I've slept better" [1]
>
> "It's made my sleeping better…Sleep can be quite a thing with CF, I don't know, you get less exercise sometimes and the natural ways of getting to sleep, sometimes you don't get as much as other people" [10]

Five participants reported **enjoying** the TC. In addition one felt it was easy to do, and one appreciated that it didn't cost anything.

> "I really enjoyed it, it was the first time I've done it and um, yeah I enjoyed it" [1]
>
> "I thought the whole experience was really lovely and a real break from the stresses of everyday life" [10]
>
> "it doesn't cost any money, so. That's really important for people with CF, if you can't work anymore and you're trying to live on one income, it is actually good that it is a free exercise that you can actually do in your lounge" [10]

Perceived impact on **breathing** varied: three participants felt that TC helped them to control their breathing [1,6,10]; one [9] felt it helped with 'tight airways'; one [2] found it difficult to identify any effects on breathing due to having a chest infection (and hospitalisation) during the study and two [5 and 8] cited no improvements in breathing. Those who discussed TC helping with them to control their breathing described TC as a "powerful tool" to slow down breathing and calm worry and stress when breathless.

> "[in TC] you try and think about your breath coming from your diaphragm and you kind of concentrate your thinking there. And when I've got very out of breath I've actually used that to keep as calm as possible…the thought of how to bring your breathing down to a slow pace, I have actually been doing constantly… If you asked me about how worried I was when I was using my breath, and how quickly I was able to control my breath again, like mentally calm myself down, I would have said there's been a better, that's improved since I've been doing the tai chi than before. Even if my breathing was just as bad, my mental control of being able to get myself in a calmer position to bring my breathing down and stop my cough is better" [10]

Three participants cited effects on **mobility, flexibility or musculoskeletal** problems, including relieving tension and pain in the shoulders caused by coughing, which was causing headaches, improved mobility in a frozen shoulder and arthritic joints.

Four found it beneficial in terms of increasing their **exercise levels,** in particular those with poor lung function and low exercise tolerance. This was mainly as a form of exercise itself, but also in improved breathing control which meant they could perform better in other exercises. Specific benefits were being able to do TC seated and in hospital. One felt that they would not continue with TC as they do other forms of exercise.

> "it's brilliant for me now because I can't really do much, so sitting in a chair and doing some exercises is fantastic" [10]
>
> "because I don't have much exercise tolerance, it was something that I found that I was able to um, it sort of pushed me nearly, not quite, to my limit, so it was quite a positive experience" [2]
>
> "I was pleased I did it and I've got it there because when I've got no energy it's at least some form of exercise I can do" [2]
>
> "I could probably do with doing gentle light exercise more frequently, but I'm not really an exercise person. But me and my friend are looking at going to a tai chi class now" [6]

One participant felt that they would like to practice TC as something enjoyable and interesting **rather than as a treatment.** They were hoping to involve their husband in their TC practice as "a 'couple thing' and not a 'health thing'".

> "[TC] began to feel like something else that I had to do, along with everything else medical wise. And I kind of wanted to spend my other time doing other non-CF stuff, you know, not even thinking about my health, completely separate" [10]

Self-management tool

Three participants discussed TC as a "tool" or "skill" to help them manage their own health.

> "psychologically its definitely had, it gave me more kind of tools to work with when I'm not well" [10]
>
> "as a sort of a tool I think it was great…. when I wake up in the night I do a bit of physio and doing a bit of tai chi, gentle exercise has been great" [2]

Challenges

Participants cited a range of challenges to doing TC. These varied widely between individuals, with no single challenge dominating the results.

Three participants cited **hospitalisation and poor health** as affecting their TC practice. One was hospitalised for two weeks during the study, where they "dropped the habit" of doing TC due to other treatments and tests being prioritised, despite an intention to practice TC while in hospital. This participant felt that they needed some protected time to practice TC while in hospital when staff would not come into their room. They also mentioned "heavy discussions" with the doctors as affecting their focus on TC. Another had been on IV antibiotics so missed a TC session, and a third had another health condition which had declined during the study, preventing them from practising.

> "It would be quite good actually if [in hospital] you could get a sign you could put on your door saying 'doing tai chi'. You don't have that personal space to concentrate on what you're doing, because people are constantly, I can't quite exaggerate enough, constantly coming in, you never have any moment where you think 'oh I've got some time to myself', because its constant" [10]

Four participants cited **lack of energy** or stamina as a challenge to TC practice, finding they became tired after the sessions.

> "I haven't had any energy to do anything let alone try and remember moves and everything" [9]

Time/other treatments was an issue for three participants, with other treatments/eating/sleeping/exercise and work taking up their time. One described how they prioritised their other treatments. Another participant who didn't work felt that those who did may find it difficult to fit in.

> "We do so much medication as it is, and trying, because I work as well, trying to fit everything in is difficult" [5]

> "I was struggling to fit it in with other treatments because obviously things like physiotherapy and medicines and inhalers they seem more important" [10]

None felt that TC would be able to become integrated with their other conventional treatments due to lack of time from staff, especially physiotherapists.

> "I think the problem is with the physios, I was trying to learn a new physio technique, and get some exercise and use oxygen, and they're so tight with their time now, to add something else I think, I'm struggling to just see them anyway" [10]

Two participants cited **forgetting the movements**, one after having been in hospital for four weeks and one after missing sessions due to IV antibiotics. The DVD was helpful in reminding them of the movements, and concentration improved during the study and with regular practice.

Two found the **final movement** of the series too tiring, but other than that the movements were fine.

Another issue mentioned by one participant was the risk of **cross-infection** which limited practicing in a group/with friends.

DVD

All participants like the DVD and found it useful for remembering the movements and to motivate them to practice at home.

> "it's a really good DVD, it's at a good pace, it's not too fast which I think is a risk when you're learning new movements. I'm really glad we've got a copy of it" [1]

> "The DVD I think is excellent, I thought it was very well done and it was very helpful…when I was home doing the exercise in front of the DVD kind of kept you going a bit" [2]

> "I think it was brilliant, the DVD was really good" [10]

> "The DVD was really good…because I got to about the fourth or fifth movement and I kind of got a bit muddled up, so I need to be, I need something practical to see" [6]

The research study

Participants were happy to fill in the questionnaires and were used to completing questionnaires for other studies or for annual reviews.

> "I didn't have a problem filling in the questionnaires and I appreciate that it's part of kind of, the relationship where you get to learn something and in exchange we help you guys out" [10]

Two participants felt that the results from this study may have been affected by periods of ill health they experienced during the study, one due to gradual deterioration and one due to a chest infection. Participant 10 described a deterioration in exercise tolerance, breathing, increased infection risk and also difficulties concentrating due to the psychological impact of their declining health.

> "It's difficult to tell [the effects of TC] because I actually got worse because I got a chest infection and was in hospital, I mean obviously it had nothing to do with the tai chi, so I can't say it made any difference to my breathing" [2]

> "my health has deteriorated quite a lot in the last 2 to 3 months, so I think I'm struggling anyway in what I'm capable of doing. And it just happened to coincide with the tai chi trial" [10]

> "my one concern was that the tai chi could have been helping, but because CF can be quite an extreme illness, that any benefits can be masked" [10]

Two felt that a longer study period would be necessary to see any effects and avoid periods of illness biasing the results.

When asked about potential future research studies involving children, participants had mixed views, with concerns that children would not be able to concentrate enough to learn the TC and may not have the same issues with breathing. Participant 10 discussed this at length, explaining that as a child they did not want to think about breathing, which was not yet a problem, and were encouraged to do very aerobic exercise rather than gentle exercise such as TC.

> "for me it seemed quite a mental kind of concentration and the benefits coming from being able to control your breathing more and being able to do some exercises as well. So I don't know if that's an issue that young children with CF have anyway?" [10]

Feedback on potential questionnaires

Following the results of the feasibility study, we identified a range of potential outcome measures to replace/supplement those used in the study, to capture the perceived effects of TC. We then asked sent these to the participants to complete and asked them to provide written feedback on their utility and appropriateness. Four participants responded; the results are given below in table 4.

The outcome measures were:

- Five Facet Mindfulness Questionnaire, Multidimensional Health Locus of Control and Perceived Stress Scale to capture the psychological effects of TC
- Modified Borg Dyspnoea Scale and Dyspnoea-12 scale to capture the effects of TC on controlling breathlessness
- Pittsburgh Sleep Quality Index
- MYMOP (Measure Your own Medical Outcomes Profile) – a patient-generated measure to capture the wide ranging and individually-varying effects of TC

When asked to prioritise which outcomes measures they thought would be most useful for a study of TC for CF, three participants responded; the following were most popular:

- Five Facet Mindfulness Questionnaire (2 people chose)
- Perceived Stress Scale (2 people chose)
- Pittsburgh Sleep Quality Index (2 people chose)
- MYMOP (1 person chose)
- Multidimensional Health Locus of Control (1 person chose)
- Dyspnoea-12 scale (1 person chose)
- Modified Borg Dyspnoea Scale (1 person chose)

Table 4: Participant feedback on potential outcome measures

Outcome measure	Estimated time to complete	Positive comments re effects of TC	Negative comments re effects of TC	Appropriate for CF	Not appropriate for CF	Other comments
Five Facet Mindfulness Questionnaire	1.5 – 6mins	‘deals with the mind’ ‘TC helps relax and be calm’	Would not capture effects of TC	‘yes because feelings and emotions play a strong part in CF’; yes	‘Not enough on the physical’	
Multidimensional Health Locus of Control	2– 5mins	‘deals with the mind’ ‘might help the mind calm’	‘not enough on the mental’; ‘no, relates to my belief system – not sure TC can change my belief system’	‘definitely’ yes		
Perceived Stress Scale	1 – 5mins	‘relates to the mental side for which in my opinion TC is effective’; ‘TC helps to relax and cope’; ‘to see if TC helps calm mind’	‘Too vague’	yes	‘Too vague’	
Modified Borg Dyspnoea Scale	30sec – 5mins	‘TC makes me breathless’	‘TC is more mental than physical’	‘possibly’ yes		‘isn’t much scope for explanation’ ‘very brief’
Dyspnoea-12 scale	1- 5mins	‘yes, breathing’; ‘physical/mental are related e.g. you feel good, more likely to do the treatment e.g. TC =mental’; ‘yes, TC helps to relax’; ‘yes, TC helps relax and cope’		yes		
Pittsburgh Sleep Quality Index	2 - 10mins	‘definitely’; ‘relates to the spiritual/mental aspects’; ‘might help to see if it helps regulate sleep’		yes	‘Only if reasons for poor sleep are investigated (ie chest infection)’	
MYMOP2	1-8mins	Yes, detailed and allows for explanation ‘yes, TC helps to cope with problems’	‘TC is about the mental not the physical’	‘definitely’ yes	Sections on medication not relevant to CF as	

					medication is long term and numerous	

Discussion

The following section discusses the findings from this feasibility study, first as compared to previous research literature and second in terms of their implications for a future trial. Much of the previous research has been conducted with children or young adults which has limited application in this study.

Participants

The participants in this study appear to have slightly poorer health than other CF populations, although it varied widely between participants.

Five out of eleven participants were working or studying, less than national figures for people with CF of 70% (Cystic Fibrosis Trust, 2010).

The baseline data (see table 2) for participants illustrates the wide range in participants' health, which is reinforced by the qualitative data, for example physical function from 0% to 70.83%. Presence of pain and levels of anxiety and depression also varied widely. Overall, participants appeared least affected by digestive and eating disturbances and more so by respiratory symptoms and treatment constraints. Previous studies have also found that digestive symptoms are the least prevalent(Sawicki et al. 2008), with highest CFQ-R scores for the digestion domain (Klijn et al. 2004).

Average FEV_1 predicted was lower than the 2011 national average for people with CF in the UK of 74.7% (SD 54.3-91.1)(Cystic Fibrosis Trust, 2011a). CFQ-R scores were lower for all domains than scores in a longitudinal national American study for adults(Sawicki et al., 2008) and a Dutch study of healthy adolescents (Tibosch et al. 2011). Mean scores in this study were lower than mean scores for the physical functioning domain, treatment constraints domain and weight domain in the Dutch study(Klijn et al., 2004), and consistently lower on most domains than even the 'severe' group in a German study(Wenninger et al. 2003). The average BMI of 22.08 is similar to the 2011 national average for people with CF of $21.9kg/m^2$ (19.9-24.3) (Cystic Fibrosis Trust, 2011a). The average scores for anxiety and depression are very close to the values for the general population (6.14 for anxiety and 3.68 for depression)(Crawford et al. 2001) , which has been previously found(Anderson et al. 2001; Havermans et al. 2008), and is confirmed by data from the CF population at the Brompton (6.42 (SD 4.35) for anxiety, 3.51 (SD 3.24)for depression). Prevalence of pain was similar to that previously found(Sawicki et al., 2008) although pain levels on the BPI were lower than those previously found, with a maximum pain average of 3.6 compared to over 6(Flume et al., 2009).

Results/impact of tai chi

Nearly all participants planned to continue TC practice, with one planning to attend a class. This indicates that participants did find it beneficial.

Quantitative changes

Although the small sample and uncontrolled study design limit conclusions regarding changes in outcomes following TC, the CFQ-R showed significant before and after improvements on two domains, treatment constraints and respiratory symptoms . The improvement in treatment constraints may reflect increased self-efficacy and ability to cope with ill health (see below). The improvement in respiratory symptoms suggests that TC may have improved respiratory function or ability to control breathing (see below). These results may well be due to factors other than the TC.

There were no other significant quantitative results. Based on the qualitative data, we believe this is due to two main factors:

The first is the extreme fluctuation in health of people with CF, as illustrated by Figure 1 and in the qualitative results. A number of participants experienced issues such as declining health, antibiotic courses, chest infections, changes in treatment and flare ups of other diseases. Adult CF patients often also have comorbidities such as diabetes, liver disease, osteoporosis and malignancy (Jones). 2010 CF registry data suggests that adult CF patients spend an average of 29.33 days on IV antibiotics per year (Cystic Fibrosis Trust, 2010). The following quote from one of the participants illustrates the challenges of detecting change when patient's health is so up and down.

> "I was just worried that we could find a lot of benefit from it, but if you're trying to specifically pin down results, you might find it harder to show because, you know, tai chi didn't prevent an infection, and nor would I expect it to, because my lungs are pretty damaged. So, it was having a benefit but I was worried that, from my experience, any benefit it had you may not have noticed from the questionnaire because my health did just take that dip. So for you guys going forward I just worry that it may not look like you can get the outcomes you're looking for, when actually it is helping, I just don't know how you can show that it is"

The second factor is that some of the outcomes measured may not have been the most appropriate. One of the key aims of this feasibility study was to identify appropriate outcomes (see below) and it appears that the main perceived effects of TC were: psychological benefits regarding coping with breathlessness, relaxation and stress relief; improved sleep; increasing exercise levels; and improved flexibility and mobility.

Self-management/coping with breathlessness

Perceived dyspnoea in CF varies widely between individuals, may not be correlated with pulmonary function and may be related to psychological factors(De Jong et al. 1997). When breathless, the most common response of people with CF is to rest to catch their breath(Stenekes et al. 2009), which the breathing techniques of TC can clearly complement. Coping is important in chronic disease, and coping style is thought to be an important influence on quality of life and psychosocial outcomes in CF(Pfeffer et al., 2003b). The use of TC as a self-management tool and its impact on coping indicate an effect on participants' self-efficacy. Self-efficacy (belief in the ability to perform; based on social cognitive theory) is thought to be as important as respiratory function in perceived health status quality of life in CF(Wahl et al. 2005). TC is known to improve self-efficacy (Jimenez et al. 2012; Li et al. 2001).

Exercise is thought to reduce breathlessness in CF, for example 11mins exercise a day significantly reduced breathlessness (as measured on a visual analogue scale), independent of changes in pulmonary function or exercise performance (O'Neill et al. 1987) which may be an additional mechanism

It has been suggested that more research is needed on dyspnoea in CF (De Jong et al., 1997).

Relaxation/stress relief

Research on the psychological issues faced by adults with CF is sparse, compared to that for paediatric patients and their families. A report from a clinic in the UK identified anxiety (including panic attacks and severe worry), depression, problems coping with changes in health and end of life issues(Oxley et al. 2005). One study found that psychological symptoms were common in CF, including worry and irritability, which cause distress and should be addressed in treatment(Sawicki et al., 2008). Psychological issues are included in the clinical guidelines for CF (Cystic Fibrosis Trust, 2011b). TC may provide an adjunctive treatment to address the stress and worry associated with CF.

Sleep

Sleep problems are common in CF (Jankelowitz et al. 2005), primarily due to respiratory symptoms(Sawicki et al., 2008) such as cough(Stenekes et al., 2009). These sleep disturbances are bothersome to patients(Goss et al., 2009). We could not identify any previous research on interventions to improve the sleep of CF patients, suggesting a potential role for TC in improving sleep.

Flexibility and mobility

The perceived impact of TC on flexibility may be related to a build-up of muscle tension in the chest due deteriorating respiratory function and chronic coughing, which causes adhesion of the muscles involved in the respiratory process. Tightness in the chest may then lead to restricted thoracic movement during breathing and poor movement of the intercostal muscles, which would further restrict the diaphragm, and inhibit breathing. TC can open or unbind the chest, loosen the shoulders, and promote relaxation which allows the tense muscles to more flexible.

Challenges

The effect of hospitalisation and poor health on TC practice is similar to previous findings for compliance with exercise, where acute exacerbations and decreasing exercise capacity and CF severity affected exercise adherence(Myers, 2009; Prasad et al. 2002a)

The barriers of time due to competing treatments, complex treatment regimes, and lack of energy are known to be barriers to exercise in CF (Prasad & Cerny, 2002a; White et al. 2007), and are not surprising given that participants were taking an average of 3.5 nebulisers, 2 inhalers and 7.5 tablets, similar to previous reports of 7 daily treatments, taking 108mins daily (Sawicki et al. 2009). It is also thought that those with higher severity will prioritise physiotherapy over exercise(Myers, 2009). One of the main barriers to self-management of CF previously identified is the high treatment complexity(George et al. 2010) – TC was generally not seen as part of this, but rather as something enjoyable and fun, perhaps a form of exercise (although time was a barrier). CF patients are thought to see exercise as separate from other therapies (Prasad et al. 2002b). Keeping TC as separate to the complex conventional treatment regimen may be beneficial in ensuring patients adhere to TC practice. According to our results TC may even help to reduce treatment burden.

Feasibility results

This study was designed as a feasibility study to inform the design of future research. This section therefore focuses on the key issues and makes suggestions for future study design.

Outcome measures

The most important result from this feasibility study was regarding the outcome measures, as apart from the CFQ-R, those used did not demonstrate improvements.

- Individual variations in health and symptoms may mean that either a patient-generated outcome is useful, or that different outcomes are used depending on symptoms (e.g. only 4 participants had pain to complete the BPI).
- Adapted/different outcome measures would be required for children who may not experience the same symptoms or priorities as adults. In particular the CFQ-Child and Parent versions would replace the CFQ-R. Further patient feedback would be needed to inform the choice of other child/parent outcome measures.
- Recommended outcome measures:
    - **CFQ-R** – very useful and appropriate. We would however advise collecting data more frequently in order to detect fluctuations in health and CF status
    - **Perceived stress scale (PSS)** as participants found this relevant for capturing the calming and relaxing effects of TC. One participant felt it was 'too vague'
    - **Pittsburgh Sleep Quality Inventory (PSQI)** which participants found relevant and appropriate. One participant suggested extra data on reasons for sleep problems is collected. Jankelowitz et al (Jankelowitz et al., 2005) recommend PSQI for detecting sleep problems
    - **Five Facets Mindfulness Questionnaire (FFMQ)** which participants found relevant and appropriate to capture the calming effects of TC.
    - **Dyspnoea-12 scale** to capture the effects of TC on breathing and relaxation
    - **Exercise diary** - date, type of activity, duration in minutes, and level of intensity from 1 to 5 (for example from 1 for "easy", 3 for "easy conversation while exercising", to 5 for "too difficult to talk", as used by (Schneiderman-Walker et al. 2000))
    - **Generalised self-efficacy scale (GSES)** to measure effect on ability to self-manage and cope with CF, as used by (Wahl et al., 2005).
    - **BPI** – although this was only relevant for some participants pain is an important outcome measure in CF and TC
- Possible other outcome measures which may or may not be useful:
    - **Measure Your Own Medical Outcomes Profile (MYMOP)–** may not be able to be self-completed without face to face guidance (in this study participants did not always fully understand how to complete it), although participants appreciated its ability to obtain detailed explanation. Also took up to 8mins to complete, and the section on medication may not be relevant

  - **Multidimensional Health Locus of Control** – one participant felt this was useful for the calming effects of TC, however these may be better captured by the PSS/PSQI/FFMQ. Two participants felt it would not capture the effects of TC
  - **Modified Borg Dyspnoea Scale** – participants were not overly positive about this one (they preferred the Dyspnoea-12 scale)
  - **VAS** –did not appear to show an improvement although it may be useful as a quick and easy overall measure of health
  - **HADS –** participants did not appear to be affected by anxiety or depression and did not show any change
- Although the clinical data did not show any changes, although it is useful to have objective data and to monitor changes over the study which may affect study outcomes.
- Qualitative feedback is essential
- Online focus groups worked well using Skype.
- Re CFQ-R – note that respiratory symptoms domain only improved at 2nd follow up not first so may support a longer follow up period.

Study timing and duration

This study highlighted that the fluctuations in health experienced by those with CF are a major potential confounding factor. We have a number of suggestions for dealing with this:

- Longer study and follow up periods are needed in order to minimise the impact of fluctuating changes in health during the study. Given that periods of ill health appear to last approximately 2 weeks, a total study period of at least 12 months is needed
- Frequent assessment of health and medical treatments, as in the weekly short questions used in this study, is essential to capture fluctuations in health which may affect the outcomes. We would recommend using the CFQ-R fortnightly. Alternatively a diary could be used such as the CF Respiratory Symptom Diary (CFRSD) (Goss et al., 2009)
- Dividing the population in cohorts according to severity may help (well, moderate and severe disease with lung function)

Missing data.

Using post for the return of questionnaires caused some problems and likely contributed to incomplete data collection. In future we would advise collecting data face to face at TC sessions or hospital appointments and/or using online methods where available. Participants were happy communicating by email so online versions would likely be successful.

Recruitment/attrition

Collaboration with the Royal Brompton was essential for this study. Dr Su Madge recruited the participants following discussion with CF MDT (multi-disciplinary team) to select appropriate patients (based on distance from the hospital, ability to participate and participation in other studies (research burden)). Dr Su Madge has a good relationship with patients which is important as -- potential participants must trust the person and the setting where participation is requested(Lowton, 2005).

Participants were keen to take part and were happy to complete questionnaires and ‘attend’ the online focus group. People living with CF are often keen to participate in research, even to the extent of actively volunteering, perhaps due to being an active participant in their own treatment and management (18).

The intervention

- The participants were happy with set of movements and a number expressed finding the focus on mindfulness and breathing techniques very useful. Being able to adapt the movements for a seated position was useful for at least 2 participants. All participants reported practising TC at home, with the majority planning to continue to practice.
- The DVD was very helpful and appears to be sufficient in terms of support materials. No one requested additional skype/phone contact with the TC instructor to help with home practice.
- Duration and frequency of practice was as recommended. Flexibility in the scheduling of taught sessions and home practice was essential to cope with lack of time due to treatments, individual’s preferences, abilities and fluctuations in health.
- A number emphasised the usefulness of TC as a self-management tool. This is a key component of the teaching of TC which always starts with self-awareness, for example becoming aware of the quality of the breath and then in turn adjusting the breath with the TC to be more comfortable.
- None of the participants practised with a family member/friend, but a few felt this would have been useful. This should be encouraged if appropriate.
- Nearly all TC sessions took place in the patient’s home. This was beneficial for them; however it did cause some delay in the study due to the extensive travelling and scheduling required by the TC instructor. With a larger number of participants this would be unfeasible. Suggestions for future studies are to have a central teaching location which participants attend one-by-one, as well as increasing the number of instructors. Teaching TC in the hospital when participants were inpatients was originally planned, however, there was insufficient space available or patients were too ill or receiving too many other treatments.
- One participant was planning to attend a TC class following the study. This has implications for a study with a longer follow-up period as participants may wish to attend a class during the study. We would recommend encouraging attendance at TC classes with an instructor experienced in working with chronic illness (details of local classes can be provided by the instructor), and monitoring such attendance as it is likely to affect study results.
- Although participants described a lack of time and competing priorities with other treatments, nearly all found time for regular practice during the study. This may be attributable to the emphasis in instruction on TC not replacing physiotherapy and doing TC when they could, not strictly every day. However, a longer term study is needed to assess the continued practice after the taught sessions.
- The qualitative data from this study emphasised that if children were included in the study we would need to develop a TC sequence specific to their issues, in particular not to focus on breathing, and perhaps using more engaging movements to hold their attention.

Conclusion

Researching TC as a potentially useful intervention for people with CF is feasible, given successful study recruitment, retention and good compliance with TC practice. TC may influence respiratory symptoms, reduce treatment burden, relieve stress, help cope with breathlessness, provide opportunities for enhanced self-management and act to increase exercise levels.

Studies of TC for people with CF need to take into account the numerous factors affecting participants' health and wellbeing, including hospitalisation, daily fluctuations in health (which can be severe at times), lack of time (due to routine CF management) and competing treatment priorities. A range of outcome measures and a longitudinal design are recommended for future studies.

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