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Patient perspectives on the Tailored intervention for Anxiety and Depression Management in COPD (TANDEM): a qualitative evaluation

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Abstract

Background Chronic obstructive pulmonary disease (COPD) is commonly associated with anxiety/depression which can affect self-management and quality of life. The TANDEM trial evaluated a cognitive behavioural approach intervention targeting COPD-related symptoms of anxiety and/or depression, comprising up to eight one-to-one sessions delivered by respiratory healthcare professionals prior to pulmonary rehabilitation (PR). The intervention showed no improvement in anxiety/depression or uptake/completion of PR. We present patient perspectives of the intervention to help understand these results.

Method Semi-structured individual interviews, using a semi-structured topic guide informed by Sekhon's Theoretical Framework of Acceptability, were conducted with 19 patients between September 2019 and April 2020. The interviews were audio-recorded, transcribed verbatim and analysed thematically.

Results The following could have limited the impact of the intervention: (1) The lives of patients were complex and commonly affected by competing comorbidities or other external stressors which they managed through previously adopted long-standing coping strategies. (2) Some patients were reluctant to talk about their mood despite the Facilitators' training and person centred-skills which aimed to enable patients to talk freely about mood. (3) The intervention handouts and 'home-practice' were perceived as helpful for some, but not suitable for all. (4) Many patients perceived improvements in their physical and mental health, but this was not sustained due to a mix of personal and external factors, and some did not perceive any benefits. (5) PR non-attendance/non-completion was a result of personal and PR service-related reasons. (6) Discussing COPD and mental health with the Facilitator was a novel experience. Many patients felt that TANDEM could be of benefit if it was offered earlier on/at different time points in the COPD illness journey.

Conclusion We found the delivery of TANDEM prior to PR was not helpful for patients with advanced COPD often experiencing other comorbidities, and/or difficult personal/external events. These patients already utilised long-standing coping strategies to manage their COPD. Holistic interventions, that address the impact of COPD in relation to wider aspects of a patients' life, may be more beneficial.

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Introduction

Patients with long-term conditions, such as chronic obstructive pulmonary disease (COPD), are two to three times more likely to experience mental health problems compared to the general population [1]. Patients with COPD suffer from physically disabling symptoms such as breathlessness, chronic cough and sputum production [2], and typically have one or more comorbidities such as anxiety and depression [1, 3–5]. The mean prevalence of anxiety and depression in patients living with COPD are estimated at 36% (range 6%-74%) and 40% (range 8%-80%), respectively [6]. These comorbidities reduce patients' ability to manage COPD effectively, affecting physical activity and quality of life and increasing their susceptibility to exacerbations, hospital admissions and readmissions [6–8] at major cost to health and care services [9].

There is a clear relationship between breathlessness and anxiety and/or depression, where one can negatively influence the other and a vicious cycle can develop [5, 6, 10–12] resulting in poorer health outcomes. This emphasises the importance of individually-targeted holistic treatments rather than purely focusing on the disease [13].

Unmet physical and psychological well-being needs [14], could be a result of patient and professional barriers [15]. Patients' reluctance to ask for – or accept—support offered by health services may be due to stigma, reluctance to talk about emotional problems, physical symptoms masking mood symptoms [15], or having already adapted to the progressive and fluctuating nature of their COPD and comorbidities; [16–18] conversely, they may want to seek support but lack knowledge of mental health issues, treatment options, where to seek help, or have difficulty in accessing the support they need [14, 15, 19] further increasing the burden of disease/s [1, 2, 20].

The goals of non-pharmacological self-management interventions in COPD include reducing physical symptoms and functional impairments in daily life and improving emotional well-being [21]. Completion of evidence-based supervised exercise and self-management support programmes such as pulmonary rehabilitation (PR) is known to improve both physical and emotional well-being among patients with COPD [22]. However, anxiety or depression being associated with reduced uptake and completion of PR, remain [6]. Evidence of effective strategies to improve referral to, or uptake and completion of, PR treatment is limited [23]. Psychological treatment using cognitive-behavioural therapy (CBT) is an effective treatment for anxiety and depression but there is less evidence of benefit in COPD-related depression [24, 25] and anxiety [25, 26]. A systematic review by Coventry [27] found some improvement in anxiety and depression from interventions combining exercise with psychological and lifestyle interventions in COPD, and there have been calls for more high quality research into this [24, 26].

In response to calls for further research, we developed a tailored, psychological cognitive behavioural approach intervention for patients with moderate to very severe COPD and mild to moderate anxiety and/or depression, to be delivered prior to patient attendance in PR, for evaluation in the TANDEM (Tailored intervention for Anxiety and Depression Management in COPD) randomised controlled trial [28]. We hypothesised that the intervention (referred to as the TANDEM intervention) delivered by trained respiratory health care professionals (referred to as TANDEM 'Facilitators') prior to patient's attendance in PR would improve anxiety and/or depression (intervention aim and primary trial outcome) which in turn would improve patients' uptake and completion of PR which would further improve both their physical and mental health (included in the secondary trial outcomes). The respiratory professionals involved in delivery of the TANDEM sessions were not involved in PR sessions delivery. Table 1 shows the patient inclusion/exclusion criteria in the TANDEM trial.

Table 2 describes the content of the TANDEM intervention. The intervention delivery comprised 6–8 weekly individual, face-to-face sessions with practice of skills between sessions to embed them in everyday life. Weekly or fortnightly telephone support calls to patients prior to patients starting PR and then weekly/fortnightly over the course of PR and for two weeks after completion of PR ensured continuity of support until the end of PR. The TANDEM intervention was designed as a precursor to PR but it was also developed to function as a stand-alone intervention in recognition of the fact that not all participants would want to or be able to take up the opportunity to attend PR. Patients who did not take up previous offers of PR, or who had previously dropped out of PR, were eligible for inclusion in the study. Addressing PR-related barriers was just one of the topic covered in the TANDEM

Table 1 TANDEM trial patient eligibility criteria [29]

Inclusion criteria	Exclusion criteria
• Adults with a confirmed diagnosis of COPD, post bronchodilator FEV1/FVC ratio • Moderate, severe or very severe COPD severity on spirometry, FEV1 < 80% predicted • Probable mild/moderate anxiety and/or depression as determined by the HADS-A and/or HADS-D scores of ≥ 8 to ≤ 15 • Eligible to attend assessment appointment at their local PR service at the time of randomisation, i.e. 12 months have elapsed since last undertook PR or participant has another indication for referral (e.g. recent deterioration; recent hospitalisation with an acute exacerbation of COPD) (Patients who have been offered PR previously but declined the offer or did not complete course will be included)	• Unable to give valid consent • Patients with both HADS-A and HADS-D scores of < 8 (i.e. within normal range) • Severe anxiety/depression suggested by a HADS-A or HADS-D score of > 15 • If a patient has an appointment to commence PR before 4 weeks after the screening visit because there is insufficient time to receive the TANDEM CBA intervention prior to starting the course • Ineligible for PR at their local service at the time of randomisation (e.g. < 12 months since undertaking a course) and no new clinical indications • A comorbidity so severe that it would prevent engagement with the intervention and/or trial processes, including a severe uncontrolled psychological or psychiatric disorder or moderate/severe cognitive impairment • In receipt of a psychological intervention primarily directed at helping to manage anxiety or depression in the last 6 months (note that patients on antidepressants/anxiolytics are not excluded) • Patients currently involved in another clinical trial related to COPD (to avoid overburdening participants) • Insufficiently fluent in English to be able to complete the intervention and/or questionnaires

COPD Chronic obstructive pulmonary disease, *FEV*1 Forced expiratory volume in 1 s, *FVC* Forced vital capacity, *HADS* Hospital anxiety and depression scale, *HADS-A* Anxiety, *HADS-D* Depression, *CBA* Cognitive behavioural approach

Table 2 Description of the TANDEM intervention content

TANDEM intervention [30]	Topics covered	Content	Related Intervention materials
Session 1	Introduction, setting expectations Topic 1—What is COPD? Topic 2—Taking control of COPD Topic 3—The patient experience of breathlessness	Eliciting the patients understanding of COPD, identifying and working with illness and treatment beliefs and acceptance. Teaching basic breathing control	CD topic - Intro to COPD & the lungs, - Managing exacerbations ***Agenda from CD***-To get joint understanding of COPD Handout-Controlling your breathing
Session 2	Feedback from *home practice Topic 4—Introducing mood and COPD	Conducting a formulation and presentation of a cognitive behavioural approach	Handout - Mood and COPD
Sessions 3–7	Feedback from home practice Topic 5—Managing anxiety and COPD Topic 6—Managing depression and COPD Topic 7—Applying the CBA to other problems (optional)	Up to four sessions to conduct cognitive behavioural work on anxiety and/or depression dependent on individual need. One further session available to discuss other problems if needed	Handout – Anxiety and COPD, Depression and COPD Self-help resource CD topic– Living with COPD CD topic – Good days and Bad days ***Agenda from CD*** – Coping with COPD Handout – Problem solving
Sessions 5–7	Feedback from home practice Topic 8—Living with COPD day to day	Self-management approaches to COPD. Learning to problem solve and set goals	
Sessions 6–8	Feedback from home practice Topic 9—Preparing for pulmonary rehabilitation	Expectations of PR, addressing worries and concerns	CD – Staying active/ Pulmonary rehabilitation and exercise booklet

As part of the study participants were provided with the British Lung Foundation (BLF) CD and Booklets http://shop.blf.org.uk/collections/copd

- Living well with COPD

- First steps to living with COPD booklet (code BK31)

- Pulmonary rehabilitation and exercise booklet (code BK27)(N.B this was also provided to the control group)

The intervention participants were provided 11 self-completion leaflets designed specifically for this trial. Seven of this were core leaflets which all participants received and a further four leaflets were provided as requiredIn addition, all handouts from the SPACE (Self-management Programme of Activity, Coping and Education) manual were available to hand out as required and BLF leaflets

- Sex and breathlessness (code FL22)

- Going on Holiday with a lung condition (code BK6)

- Get self-help leaflets for psychosocial difficulties

intervention. In the UK, following patient referral to PR, the timeline of patients attending the PR assessment appointment following referral can take 4–9 weeks and from assessment to first attendance at a PR session can take a further 1–8 weeks. We worked with PR study sites that could accommodate our recruitment and intervention delivery timeline. In addition, to ensure patients had sufficient time to receive the intervention prior to starting PR, we included patients who had at least 4 weeks before starting the PR exercise class.

The TANDEM trial comprised a parallel health economic evaluation and a process evaluation using qualitative and quantitative methods to inform the implementation of the TANDEM intervention if the trial is positive, or assist interpretation of the findings if it was negative [28, 31]. The intervention did not reduce anxiety and/or depression and there was no improvement in uptake/completion of PR [29].

Specific to this qualitative evaluation, the objectives of the study, developed a priori, were to explore from a patient perspective: [31].

- The acceptability of the intervention among patients, considering intervention content (in session, home practice); therapeutic alliance; and practicalities (location, timing).
- Experiences of the intervention, including: its impact on health, quality of care and post-trial implementation.
- Any unintended consequences of the intervention.

Method

The qualitative study was conducted between September 2019 and April 2020.

Sampling and participant recruitment

As part of trial recruitment, consent from patients to be approached for an interview was obtained. Those with scores suggestions severe anxiety/depression were ineligible and were referred to their general practitioner for more intensive mental health support. We planned to conduct 20 interviews with patients in the intervention group to meet sampling requirements to help address the research aim and to meet the trial timelines [31, 32]. We reviewed the sampling during data collection to help decide if saturation was reached and whether there was need to conduct more interviews or stop data collection. Purposive sampling [33], using a sampling frame (Table 3), was used to identify patients who completed/dropped out of the TANDEM intervention and/or PR. The interviews were planned after the 6-month (i.e., after intervention delivery)) or 12-month (i.e., after PR delivery) follow up assessment during the trial. Patients were contacted by telephone to request an interview.

Data collection

Semi-structured interviews were conducted to explore patients' perceptions of the intervention and its potential usefulness for future service development. It was led by a topic guide (Table 4) informed by the conceptual framework for the TANDEM process evaluation [31] and Sekhon's theoretical framework of acceptability [34]. See Supplementary file 1 for the interview topic guide used in the interviews.

The interviews were conducted face-to-face, in the patients' home or by telephone, at a date, location and time that suited the patient or in accordance with COVID regulations (mid-March 2020-April 2020). Interviews were audio-recorded using a digital encrypted recorder. They were conducted by three mixed-method

Table 3 Sampling frame and number of planned interviews

Sampling frame	Type of participant Patient/ Carer	Time point of interview	Number of planned interviews
[a]Completion of face to face TANDEM intervention sessions	Patient	After *6month follow up assessment	5
[b]Dropped out of the TANDEM intervention sessions (but still in study)	Patient	After *6month follow up assessment	5
Completion of TANDEM intervention sessions and ^PR programme	Patient	After *6 *12month follow up assessment	5
Completed TANDEM intervention but dropped out or did not attend PR	Patient	After *12month follow up assessment	5

*6mos follow ups from randomisation start in Jan 2019

*12mos follow ups from randomisation start in July 2019

[a] Completion of TANDEM intervention – i.e. completion of at least 2 face to face sessions ('our definition of minimal dose') and overall more than 4 sessions out of the 6–8 sessions

[b] Dropped out of the TANDEM sessions – i.e. who completed only between 1 and 3 sessions out of their recommended 6–8 sessions. Non-attendance in the intervention sessions were also included within this category

^PR completion – i.e. completer deemed by PR service records of attendance and completion

Table 4 Topic guide

Sekhon's [34] Theoretical framework of acceptability	Topic guide
	Explore COPD, breathlessness these days
Affective attitude: how an individual feels about the intervention	Experience of the TANDEM sessions, the content of the sessions including the home practice, discussions with the TANDEM facilitator Experience of going to PR
Perceived effectiveness: the extent to which the intervention is perceived likely to achieve its purpose	Perceived benefits from the TANDEM sessions (physical, emotional, social, change in behaviours)
Self-efficacy: participant's confidence that they can perform the actions required to participate in the intervention	Application of skills, techniques learnt applied in everyday lives
Burden: the perceive effort to participant in the intervention	Ease of being able to take part in the intervention, preference of location to receive intervention delivery
Intervention coherence: the extent to which the participant understands the intervention and how it works	Understanding, Expectations from the TANDEM sessions
Opportunity costs	Motivation to take part, continue with the TANDEM sessions with other competing demands
	Improvements for the TANDEM sessions
	View on if the TANDEM approach became part of your routine care (outside of the study)?

researchers, KMM (Global Health Development, MSc), AB (Health Psychology, MSc), RS (Health Services Researcher, PhD). The researchers were involved in trial recruitment and data collection and were experienced in conducting qualitative interviews and were part of the patient working group within the wider process evaluation team and were involved in the discussions that informed the methods of the study. The researchers were not known to the interviewees. The interview planning was coordinated between the researchers in line with the trial milestones.

Data analysis

Audio-recordings of interviews were transcribed verbatim. Nvivo (version 12) data management software was used to support data analysis. Thematic analysis was conducted [35, 36]. Researchers (KMM, AB, RS) independently used inductive, semantic, and latent coding to analyse two transcripts and prepare an initial coding framework. The researchers discussed this to reach consensus on the coding framework. The remaining transcripts were individually coded in line with the coding framework and new codes were added to the framework as required, with consensus. Once all transcripts were coded, the researchers jointly reviewed patterns and relationship within the data to generate potential themes and sub-themes. These were discussed with the wider process evaluation team [31] with the correct experience and expertise [37] to finalise the content and themes (Table 5).

Public involvement

Public involvement was incorporated in the design and delivery of the TANDEM trial [31]. Specific to this qualitative enquiry, patient and public involvement (PPI) colleagues (people with COPD, carers of people with COPD) provided comments and feedback to support the clarity, readability, and acceptability of the interview process specified in the participant documents. PPI colleagues reviewed the findings in relation to the main trial results and provided feedback, which supported our interpretations of the results.

Table 5 Emergent themes and subthemes

1. Patient lives are complex	1.1 Impact of COPD and competing comorbidities/ other external stressors 1.2 Stoicism and self-management
2. Relationship with the TANDEM Facilitator and engagement in the intervention sessions	2.1 Knowledge, skills and open communicative partnership 2.2 Engagement with the TANDEM intervention materials and sessions
3. Impact of the TANDEM intervention sessions	3.1 Perceived benefits and the lack of perceived benefits 3.2 Attendance and completion of pulmonary rehabilitation 3.3 Difficulties keeping up the learnt skills or new activity due to personal or external factors
4. Distinguishing TANDEM in COPD care	4.1 TANDEM is different to current care 4.2 Need for psychological support at different time points of the illness journey

Results

Patient characteristics

Of the 29 patients invited for interview, 19 agreed to participate. Data collection occurred between September 2019 to April 2020. Due to the Covid-19 pandemic (19 March 2020—1 April 2020), eight interviews were conducted by telephone. The interview duration was between 30–60 min.

Table 6 presents the patient characteristics. Eleven were male. Two were in the 35–55-year age-group, five in 56–65 year age-group, seven in 66–75 year age-group and two in 76–85 year age group. Three interviewees did not provide their age. Thirteen patients had moderate COPD, six had severe/very severe COPD. Ten had both symptoms of anxiety and depression, five had symptoms of depression only and four had symptoms of anxiety only. Regarding other comorbidities, fifteen patients mentioned other comorbidities namely Heart disease, Stroke, High blood pressure, Parkinson's, Diabetes, Kidney disease, Fatigue, Epilepsy, Diabetes, Pain and Cancer. Interview participants were comparable to main trial participants in terms of age, gender, COPD severity and other comorbidities, although as a group fewer of the interviewees reported comorbidities (79%) than amongst all the trial participants (90%).

Reasons for non-participation were family bereavement ($n=1$), difficulty with hearing on the telephone ($n=1$), uncontactable ($n=4$), not interested ($n=3$) and busy ($n=1$). Those who declined taking part in the interview were mostly from the TANDEM intervention completion group ($n=7$).

Over-arching findings

The findings generated four themes and nine subthemes, three themes related to intervention acceptability in line with Sekhon's [34] theoretical framework of acceptability (TFA). The findings are exemplified with quotes. Theme 1 'Patient lives are complex' encompasses patients living with and managing their COPD alongside other comorbidities and ongoing life/social situations, the challenging interplay of external situations, their own needs, and the adoption-refinement of self-coping strategies over time. Theme 2 'Relationship with the TANDEM Facilitator and engagement in the intervention sessions' highlights the building of rapport and partnership between the patient and Facilitator to deliver the TANDEM intervention sessions and patient engagement with the intervention. This theme links with the Affective attitude TFA construct where patients spoke about how they felt about the intervention and with the Intervention coherence TFA

Table 6 Participant characteristics

ID Patient = PAT	Gender	Age band 35–55 56–65 66–75 76–85 86 +	Symptoms of anxiety/depression	COPD severity
PAT1	Male	59	Anxious (mild) and Depressed (moderate)	Severe
PAT2	Female	51	Anxious (moderate)	Severe
PAT3	Male	72	Anxious (moderate) and Depressed (moderate)	Moderate
PAT4	Male	65	Anxious (moderate)	Moderate
PAT5	Male	75	Depressed (mild)	Moderate
PAT6	Male	Not known	Anxious (mild)	Moderate
PAT7	Male	66	Anxious (moderate) and Depressed (moderate)	Moderate
PAT8	Female	65	Depressed (moderate)	Severe
PAT9	Female	43	Anxious (moderate) and Depressed (moderate)	Moderate
PAT10	Female	68	Anxious (moderate) and Depressed (mild)	Severe
PAT11	Male	Not known	Anxious (mild)	Moderate
PAT12	Female	Not known	Anxious (moderate) and Depressed (moderate)	Moderate
PAT13	Female	66	Anxious (moderate) and Depressed (moderate)	Moderate
PAT14	Female	72	Anxious (moderate) and Depressed (mild)	Moderate
PAT15	Male	76	Anxious (mild) and Depressed (moderate)	Moderate
PAT16	Male	76	Depressed (mild)	Moderate
PAT17	Male	71	Depressed (moderate)	Severe
PAT18	Female	64	Anxious (moderate) and Depressed (mild)	Very severe
PAT19	Male	64	Depressed (moderate)	Moderate

construct where patients understood the purpose of the intervention, what was expected of them to engage in the intervention and spoke about their experience of engagement with the intervention materials [34]. Theme 3 'Impact of the TANDEM intervention sessions' explores the perceived benefits (or lack of sustained benefit), from the intervention in relation to patients' physical, mental, and social health. In this theme, patients, through their understanding of the intervention (Intervention coherence TFA construct); how they felt about the intervention (Affective attitude TFA construct); and whether they were able to apply the learnt skills following receipt of the intervention (Self-efficacy TFA construct) clearly stated whether they benefitted or not from the intervention (Perceived effectiveness TFA construct) [34]. Theme 4 'Distinguishing TANDEM in COPD care' discusses lack of previous provision of psychological support and that TANDEM type of care should be offered to patients earlier in their illness journey. This theme links with the Burden TFA construct where patients spoke about their ease of being able to participate in the intervention. We have not presented the themes under the TFA constructs as these constructs are interlinked and overlapped in how patients spoke about their experience of the intervention.

Core themes and subthemes

Patient lives are complex

Impact of COPD and competing comorbidities/other external stressors

Patients described how the fluctuation of COPD symptoms, suffering from exacerbations, several other health conditions and negative life events could have a cumulative effect on their physical, psychological, and social health. Many patients had previous experience of bad days, *"frightening"* breathlessness, and chest infections. Several mentioned the combination of COPD symptoms, along with symptoms of other comorbidities, resulted in low mood. Getting a new diagnosis (e.g., cancer), experiencing a sudden injury (e.g., a fall), an exacerbation of COPD symptoms, or other long-term comorbidities (e.g., stroke, diabetes, sepsis, dementia) made patients feel they could not fully recover physically and mentally.

> *"The thing that gets me down is I've got Parkinson's as well, which is making walking difficult at the moment. It's got much worse recently. And I get out of breath when I'm… Although I'm walking slowly it takes a lot of effort. So I get out of breath as well." (Male, 66–75, Depressed, Moderate COPD, PAT5)*

They described the adjustments/adaptations (e.g., sitting and resting) they made to manage their condition. Others described having become resigned to what they could or could not do (e.g., avoiding going out of the house).

> *"I used to go out a lot. And now I just don't go out. I even used to do my own shopping with a relative or something. But I don't even do that now. It's just too much even with the help of a trolley. Walking around supermarkets, it's just too much." (Male, 56–65, Anxious and depressed, Severe COPD, PAT1)*

Some patients felt that their COPD or its limitations were not always visible or well understood by others and this caused embarrassment and frustration. A few patients prioritised needs of others over their own health needs.

> *"….Well, I was outside trying to jet wash, and of course it takes it out of you. Always having a job breathing. Of course, I stopped to get my breath back. And it started to rain. Come on, get inside [partner said]. Hang on [I said], let me bloody breathe will you. Just let me try and breathe, and then I might be able to do something. But yeah. Don't you realise I have difficulty breathing? …" (Male, 76–85, Anxious and depressed, Moderate COPD, PAT15)*

Stoicism and self management

Patients described living with COPD and/or other comorbidities or life events as *"I live with it and put up with it"*. Several patients had learnt to adapt and developed coping strategies either alone or with the help of family and friends to overcome their physical limitations and anxiety, panic state or mood.

> *"…it was one of the guys, he lives across the road from me,… He said to me, … the way to look at your breathing is smell the roses and blow out the candles. And that's always stuck. So when I do feel a bit anxious or panicky I think smell the roses and blow out the candles." (Female, Age unknown, Anxious and depressed, Moderate COPD, PAT12)*

Relationship with the TANDEM facilitator and engagement in the intervention sessions

Knowledge, skills and open communicative partnership

The patients developed a good rapport and a positive relationship with their Facilitator over the course of the TANDEM intervention sessions. The positive relationship was nurtured by the Facilitator's knowledge and skills, delivery of weekly sessions and the Facilitator's ability to tailor content to the patient. Their adaptability to modify home practice to suit the patient's level of health literacy and providing practical examples to enhance understanding of a topic was valued.

"Anything to do with writing, I'd just wait until she came and we did it. I didn't do that bit." (Female, 35–55, Anxious, Severe COPD, PAT2)

Patients praised the Facilitator's knowledge of both COPD and mental health and their strong communication and counselling skills. Patients felt that their Facilitator was friendly, empathetic, supportive, and genuinely interested in them. They felt listened to and gently encouraged to speaking openly about their mood which for some was related to their social situations and not COPD.

"Yeah, and maybe asked questions that I would've not fancied talking about possibly. So she did probe. But it wasn't putting me on the spot. Then it made me think, oh yeah, I don't mind talking about that." (Female, 56–65, Anxious and depressed, Very severe COPD, PAT18)

However, some patients did find it difficult to talk about their anxiety or mood with the Facilitator and preferred to discuss other things in the sessions.

"We discussed a little bit of anxiety, because the anxiety, I don't really like to discuss my anxiety, because it just gets to me after a while when I'm talking about it." (Male, 66–75, Anxious and depressed, Moderate COPD, PAT7)

Some patients who lived alone described enjoying the Facilitator's company and the continued opportunity to discuss their illness. A few said that it was like conversing with a friend.

"…And like I say, people are probably the same as me, more benefits with just having that person coming for the company as well as talking about a specific illness." (Male, 56–65, Anxious and depressed, Severe COPD, PAT1)

Engagement with the TANDEM intervention materials and sessions

Most patients understood that the TANDEM study was about education and discussions around their physical and/or emotional health with a focus on improving it. Patients recalled receiving various study-related materials such as leaflet/s, handouts, DVDs, and worksheets for home-practice and setting goals. Some patients had difficulty remembering the home-practice requirements. A few patients chose not to watch the DVD due to lack of interest or lost interest shortly after starting because it felt too repetitive and replicated the handouts/leaflets provided or the exercises shown were not deemed suitable to them.

"The CD was pretty boring. It was very repetitive and I lost interest quite quickly I'm afraid." (Male, 66–75, Depressed, Moderate COPD, PAT5)

Two patients stopped receiving the intervention after two and three sessions because they described not being affected by their mood and were already familiar with the information provided. The third patient chose to discontinue after receiving two sessions because their sessions began to overlap with PR and they wanted to prioritise PR instead.

"Yeah, it was sort of a joint decision. If I had any problems I could give her a ring. But then I more or less carried on with the breathing thing [PR programme], so I did see people over at this breathing session. So any questions and the information you got from that at the beginning was very good Interviewer: And how soon did you join that exercise class after your one-to-one sessions? More or less straightaway." (Male, Age unknown, Anxious, Severe COPD, PAT11)

Two patients did not complete any sessions and had no recollection of the intervention.

Impact of the TANDEM intervention sessions

Perceived benefits and the lack of perceived benefits

The effects of the TANDEM intervention sessions on thoughts, feelings, behaviours and/or symptom management were varied and wide-ranging. Several patients described improvements to their mental health and had adopted positive coping strategies. They described the intervention having helped to shift negative thoughts to positive ones, feel more at ease and able to take control of their anxiety.

"I've got to be honest, when I had this chest infection I thought I was suffocating. My ribs, I thought they were breaking with this cough. And so it [TANDEM sessions] helped me a sense up here [thoughts], keep the anxiety [under control]. Because I was struggling to breathe at one stage." (Female, 56–65, Anxious and depressed, Very severe COPD, PAT18)

Patients felt they made connections between their physical and mental health by acknowledging the presence of depression or anxiety. Patients realised the value of self-reflection. Some adopted a resilient mindset, refusing to let breathlessness, anxiety and/or depression stop them. Instead, they emphasised the importance of not giving up, setting goals, accepting help, and being kind to themselves. This realisation gave them confidence to move forward and see the value of life again.

"I didn't realise I was depressed at the time because I was going to the bed most days in the afternoon, and that was more because I was… I retired last year, so I think it's because I'd recently retired. I

was just bored. So I was going to bed in the afternoons just to kill time. And then I realised through talking to [Facilitator] that that was more me being depressed….I'm going to say it [the TANDEM project] changed my outlook on life. … helped me realise if I get a little bit fitter I'll be a lot happier and I'll probably increase my…not going to say I'm going to live longer, but the years I've got to live I'll be fitter, happier…" (Male, age group unknown, Anxious, Moderate COPD, PAT6)

Many patients described learning skills, techniques and adopting healthy behaviours to enhance their daily management of COPD/COPD-related breathlessness and COPD-related anxiety such as relaxation techniques (e.g., mindfulness, distraction, breathing techniques). These techniques were successfully applied during daily activities, such as walking, climbing stairs, gardening, getting to the car, and shopping. The perceived benefits varied for different individuals and comprised, an increase in knowledge, confidence, acceptance of condition and improvements to social life.

"Well I slow down a bit. I have a lady, [facilitator], from your research team come down last year. And she took me out for little walks, and she discovered that I was taking in too much air. So she did me little techniques of when I go out for a little walk, like doing things in your head, like counting odd numbers or counting from 100 backwards. Little bits like that to get your breathing under control." (Female, 56–65, Depressed, Severe COPD, PAT8)

For a few patients, the sessions did not provide any new material but helped to reaffirm their existing knowledge about their condition and its management or reminded them of techniques/behaviours that could help them to effectively manage their condition. Others did not perceive any benefits from the intervention. One patient did not expect to learn anything new whilst another patient explained they knew most of what was being covered and that they were used to doing things on their own.

"Interviewer: Do you think your confidence levels have changed? "No, I don't think so. No." Interviewer: … Are there any other changes in your social life? No, not really…. I see my friends, at least once a week, sometimes twice. So yeah, I mean I don't want to stay indoors, or watch TV. I do go out and see my friends." (Male, 56–65, Anxious, Moderate COPD, PAT4)

Attendance and completion of pulmonary rehabilitation

Patients recalled discussions with their Facilitator regarding PR, specifically focusing on how PR could potentially benefit them and what they could anticipate from attending the programme. Some patients mentioned they always planned to attend PR despite the TANDEM sessions, whilst others were encouraged to attend PR following receipt of the TANDEM sessions. The reasons given by those who did not attend/complete PR were competing comorbidities which needed prioritisation, and health service-related reasons.

"I've done the pulmonary rehab before and I did go to an appointment but they wanted…because I was waiting for an ECG. They wanted to wait for the results for that, and that kept getting pushed back and pushed back…" (Female, 35–55, Anxious and depressed, Moderate COPD, PAT9)

Difficulties keeping up learnt skills or new activity due to personal or external factors

The application of learnt skills/techniques by patients varied over time with the perceived benefits not viewed as sustainable by some patients. Whereas others stated their learnings from the intervention had become inbuilt and they now knew what to do to manage their condition.

"Emotionally I was quite low, no self-esteem before I saw [facilitator], but afterwards I felt quite a lot better and I've still kept feeling more positive and more confident in those quite a few months since I saw her. I've not slipped back into my old way of thinking and everything." (Female, 66–75, Anxious and depressed, Moderate COPD, PAT13)

For various reasons, some patients were unable to maintain changes they had adopted due to internal or external factors. (e.g., injury, new diagnosis with poor prognosis, new disabling symptoms from COPD, disabling comorbidities affected patient mood negatively; reduced motivation to be physically active, increased gym costs or changes made to the gym made it unsuitable to attend led patients unable to start or keep up with their physical activity; and Covid-19 restrictions affected both mood and physical activity negatively). Some patients attributed their worsening physical and mental health specifically to the Covid-19 lockdown and reduced access to services, whilst others described coping well and trying to continue activities at home, albeit on a much smaller scale to their usual routine.

"I think my breathing's actually got worse …because now we can't go out. So it's…yeah, it's… I'm definitely wheezing a lot more than I was before and get breathless. …if I sit still it's fine. It's when I start moving around. So I think it's probably because

I was going out literally every day. I was going out for a half hour walk, I was doing exercises. And of course now you're stuck in the house and you can't get out. So yeah…" (Female, Age unknown, Anxious and depressed, Moderate COPD, PAT12)

Distinguishing TANDEM in COPD care

TANDEM is different to current care

Patients described the intervention as incomparable to other currently available COPD services. Most interviewees had never previously received any psychological therapy for anxiety/depression. Some had undergone counselling (e.g., for grief, stress) but felt the counselling was not specific to their COPD. One patient who had previously received CBT felt the TANDEM sessions were more helpful.

"I've spoken to my GP just about general depression, not to do with my COPD. And I've had a couple of CBT appointments. But I didn't really find those too helpful. They just seemed to give me one of these assessment sheets every time and I had to write down in the boxes how I felt about each situation. And then they were just adding my score up, oh, this week you've scored a bit higher than last week. They didn't really offer me any advice as to how to improve the situation." Interviewer: And what was different from the one-to-one sessions you had with [Facilitator]? I was able to talk through all sorts of problems that I've had over the last couple of years to do with my COPD and to do with personal stuff as well." (Female, 66–75, Anxious and depressed, Moderate COPD, PAT13)

Having flexibility in the location (e.g., patient's home, GP practice or local hospital) for intervention delivery was highly valued. This flexibility recognised the physical limitations experienced by people living with COPD and was conducive in creating a safe, comfortable, and private environment. Some patients expressed appreciation for not being excluded from receiving the intervention just because they were unable to leave their home. Others preferred the sessions at a GP practice or a public space to avoid distractions at home.

"…Because I said I don't drive, I can't afford the taxi fare. I can't use public transport…So having the opportunity to have her [facilitator] come to the house was a god send, because otherwise I don't think I would've done it. I couldn't have done. I couldn't have got anywhere to do it." (Female, Age unknown, Anxious and depressed, Moderate COPD, PAT12)

Need for psychological support at different time points of the illness journey

Several patients suggested that the sessions would be helpful at diagnosis because some felt they were given insufficient information or support at this time point. Whilst others recommended the sessions at differing stages of their illness because symptoms can evolve over time or be influenced by external life events.

"I think it's the whole package that matters. The cognitive therapy, you might just need that, mightn't you? … So I just embraced it. It's obviously valuable, and I suppose they'll roll it out one day if you have got COPD or have an operation, it'll be offered to you. It's down to the individual." The same participant continued "See generally it's going to be older people doing this thing, I think. I mean younger people there might be more benefit. So a lot of them brought up to keep it…they can't express their emotions. So I wonder…this might be for future generations. But older people are a bit reluctant to talk about themselves. It's like get on with it." (Female, 56–65, Anxious and depressed, Very severe COPD, PAT18)

Despite the overall acceptability for TANDEM, a few patients were considerate of the cost and the time impact upon NHS services. However, it was made very clear that the flexibility of intervention delivery (e.g., at home) should not be compromised.

"I think [home visits] should never be dropped and it should be moved to a place where it's set for you to save money. Because that's when everything starts going down hill then. And people trying to cut corners and then we have a meeting maybe every six months. And they say well, this never used to happen when we used to do one-on-ones at home. And now it is happening. So I think you should carry on exactly the way you are doing." (Male, 56–65, Anxious and depressed, Severe COPD, PAT1)

Discussion

Summary

As part of an integrated process evaluation of the TANDEM intervention, we explored patients', experience of intervention receipt and acceptability to help us understand the trial findings. We found the fluctuation of patients' COPD symptoms combined with comorbidities, and challenging social circumstances meant many patients had already developed coping strategies, including stoicism. Positive experiences of the intervention were attributed to the Facilitator's knowledge in COPD and mental health, their supportive, empathetic, and

person-centred communication skills. This enabled many patients to talk freely about their mental health, acknowledge the connection between their physical and mental health, and disclose interacting social circumstances. Some, but not all, patients found the intervention materials and home practice helpful. Most completers of the intervention perceived improvements in their mood/mental health, physical and social benefits. Sustaining these benefits was challenging for many due to personal, health-related, and external factors (including Covid-19). Patients described the intervention as novel, they valued the flexibility in how it could be delivered. Some patients suggested making the intervention sessions available 'on demand' throughout the illness trajectory so the patient could take them up when needed.

Comparison with other literature

We found only one qualitative study [38] exploring experiences of a home-based psychoeducation intervention within a trial, however, the structure and delivery were different to TANDEM. The intervention targeted symptoms related to breathlessness and anxiety [39] among patients with advanced COPD who reported perceived benefits such as anxiety becoming more manageable and taking control of cognitions [38]. TANDEM intervention completers also perceived improvements such as coping better with anxiety, feeling more content and at ease with oneself, and experiencing a shift from negative thoughts to a more positive outlook. Additionally, patients cited increase in knowledge, confidence, acceptance of condition and improvements to social life/daily activities.

However, the perceived improvements were not sustained and may therefore explain the trial outcomes. In Bove's trial [39], the timing of the outcome assessment was one month and three-month post intervention delivery. Bove explained that this duration was a period for new knowledge and skills to be integrated into everyday life and was the right time for qualitative exploration. In contrast, the outcome assessments for TANDEM were at six- and twelve-months post intervention, [28], recommended for COPD self-management interventions [40]. Our findings show that several personal factors and external events prevented patients from long-term application or adherence of their TANDEM learnings. Non-adherence to learnt self-management skills is known to result in worse health outcomes [41]. Part of our intervention delivery occurred during the Covid-19 pandemic meaning some patients were unable to attend PR or continue their planned physical/social activities and this may have impacted the trial outcomes. The negative impact of Covid-19 on physical activity, social isolation and mental health has been shown in advanced respiratory disease [42]. A recent COPD study [43] reported initial gains made by an intervention were lost without content teaching about how to maintain health behaviours even in times of stress. Although we included problem solving as a topic, for future iterations of TANDEM, it may be useful to include a session involving specific discussions about the likelihood of setbacks/external stressors and practical strategies for dealing with them, possibly as a 'booster' session or 'on demand' during times of stress. It may also have been possible to deliver TANDEM alongside PR rather than as a precursor, however this would have increased patient burden and was not in line with our programme theory that reduction in depression and/or anxiety would be helpful to increased uptake and completion of PR.

Another explanation for the perceived lack of sustained benefits could be the severity of disease and disabling experience of patients from the burden of COPD and interacting comorbidities [44, 45]. Many patients in this study talked about the fluctuating and unpredictable nature of COPD symptoms and the negative impact of ongoing comorbidities. Recognising the comorbidities in COPD, a study [46] discussing future interventions in COPD has suggested inclusion of a 'feedback loop' to assess progress of desired outcomes and treatment expectations related to comorbidities among patients. However, before this, further work is required to understand how comorbidities impact on/interact with COPD [47] and what outcomes are important to this patient group to support intervention development and its assessment in research for better health outcomes. Managing and adapting to the fluctuating nature of ongoing health conditions and its limitations and interactions with the surrounding social environment made achieving 'normality' out of reach for some patients. The perceived lack of understanding about COPD among family members and wider society, was felt to affect mood for some patients. One study, with comparable findings to ours, found difficult living situations, other life events and comorbidities negatively influence COPD-related distress [48]. The Facilitators reported working through problems (social, psychological, physical) with patients that were unrelated to COPD which shifted the focus away from the intervention targeting mood related to COPD symptoms/breathlessness [49]. The latter was perceived as a challenge during intervention delivery [49] and could contribute to explaining the trial outcomes, although overall fidelity to the intervention has been reported to be high [49]. Focusing on the physical/social environment of patients with COPD is important for future interventions in COPD [50], but will require gaining better understanding of the social environment and its impact on individuals [51].

Several patients in our study were stoic, and the stance taken was 'to get on with it'. Stoicism can make patients hold on to strategies they perceive are working for them, they may be reluctant towards the treatment or they may have less realistic expectations of treatment benefits [52] which could have affected the trial outcomes. Some patients found the intervention unsuitable for their needs or failing to meet their expectations. The lack of perceived benefits amongst some is not surprising as, needs, expectations and preferences will vary among individuals. Some patients felt that they had not learnt anything new, whilst for some the intervention helped to reinforce strategies they were already using to manage their condition which will have reduced the potential for improvement in trial outcomes. A person-centred approach, only offering intervention to those with perceived need to reduce anxiety/depression may be more appropriate.

Although not reflected in the trial outcome analysis, a positive experience of the TANDEM intervention was that the patients particularly valued the therapeutic relationship with the Facilitator (a key element of the TANDEM intervention) [30]. The intervention sessions gave patients an opportunity to reflect on what COPD meant to them, recognise their actions were a result of anxiety and/or depression, make connections between their physical and mental health, and adopt home-practice activities which helped to improve their physical activity and symptoms. Despite the trial outcomes, the positive experiences of patients suggest that it might be useful to provide opportunities in practice to enable patients to reflect on the relationship between their physical and mental health [49, 53]. An explanation for the lack of improvement in outcomes, supported by these findings, is that some patients did not do any independent home-practice between intervention sessions because they did not like to write things down or read. Not doing the home-practice may have made it difficult to embed the learning from the TANDEM sessions. The latter could be attributed to comorbidities or poor health literacy previously reported for this population [54]. It has been suggested that not doing CBT-related homework can lead to negative health outcomes [55, 56]. A recent review [57] assessing the efficacy of psychosocial interventions on physical and psychological outcomes in COPD highlighted that older age may yield limited effects as they would be less adept to learn skills and techniques taught in a psychosocial intervention. The median age of patients in the TANDEM trial was 69 years and there were high intervention uptake and completion rates [29], so the offer of psychosocial interventions should continue among this population regardless of their age [57]. However, assessment of health literacy needs should be considered for interventions comprising written materials [43, 46, 50, 54]. Production of intervention materials needs to be more creative than paper-based materials and need to be available in various formats to match patient choice, preferences and literacy levels.

Some patients in our study were reluctant to talk about their mood, which could be due to such discussion being unfamiliar within a healthcare setting. Few had received any psychological support previously for their mental health in relation to their COPD. The new treatment and the lack of familiarity of this psychological approach may have had an impact on trial outcomes. This could be related to the perceived stigmatisation of COPD [24] and mental health [48] or that having a one-off, short-term intervention may not be enough. There are reports of limited screening of mental health issues, and limited review of mental health issues as part of routine COPD review appointments, leading to under-diagnosis and consequently under-treatment [6, 15]. A recent review [57] concluded that more research is needed to identify the ideal duration, or regularity of a psychosocial intervention in COPD, as long duration can have small effects due to waning of the effect or becoming dependent on the therapist. The duration of the TANDEM intervention was not a perceived problem for our interviewees, but they suggested offering TANDEM at diagnosis or at different timepoints in line with the illness journey allowing the opportunity for the patient to take it up when needed. The TANDEM Facilitators felt that offering TANDEM earlier on in the illness trajectory might be more suitable for patients with less complex needs [49]. This highlights the need for more mental health support to be available for patients with COPD.

Strengths and limitations

This study forms one part of the process evaluation work of the TANDEM trial and has provided an insight into why the TANDEM intervention may have not worked. The findings, via Sekhon's acceptability framework [34], highlighted that most patients found the intervention acceptable but the acceptability of the intervention and the positive experiences were not translated into improvement in the trial outcome measures relative to controls. The reported positive and negative experiences of the TANDEM intervention might be useful for researchers and clinicians looking to improve mental health comorbidities in COPD and beyond COPD/COPD-related breathlessness.

We only interviewed patients in the intervention arm and conducted more interviews with those who had completed the intervention. We achieved data saturation among our sample of patients that had completed the TANDEM intervention with and without completion of pulmonary rehabilitation. We would have liked to speak

to more patients who dropped out of the intervention as two patients did not attend any TANDEM intervention sessions and could not recall the reasons for non-attendance. However, we were unable to invite more patients due to administrative delays. Despite this we were able to show a balance of views among the interviewees to help explain the trial findings. A few trial participants had received the intervention by telephone due to the pandemic, but this was not anticipated and hence they were not interviewed.

Implications

More opportunities need to be created in practice to ask about mental health by professionals trained in person-centred skills, psychological skills, knowledge about COPD and common comorbidities associated with/linked to COPD. This is because patients may not be able to ask for treatment or it might not be the right time to seek treatment due to competing demands resulting from the fluctuating and unpredictable nature of COPD, the influence of individual social contexts and interaction with other conditions. Cognitive behavioural approach treatments may be more suited for patients earlier on in their COPD illness journey with built-in sustained follow up, allowing patients to include the learnt skills into their coping mechanisms for improved outcomes.

There is an increased need for co-production work among patients with COPD and comorbidities to develop intervention materials related to cognitive behaviour approach treatments suitable for patients at varying literacy levels, including those who do not like to read any materials or engage in independent home-practice. There is scope to develop interventions that consider an individual's primary symptoms and interacting social environment to improve the physical and mental health outcomes of patients living with moderate to very severe COPD and anxiety and depression. Future research could look into the role of assistive technology interventions (e.g. adaptive and telecare equipment) [58] in COPD [29] that are relevant to improve function, independence, wellbeing and quality of life, particularly technology (e.g. personal digital assistant device) targeted at people with psychosocial disability including anxiety and depression with some evidence of benefit [59].

Conclusion

This study provides an insight into why a person-centred psychological intervention, evaluated in a randomised controlled trial, did not improve symptoms of anxiety/depression brought on by COPD symptoms, particularly breathlessness in patients with moderate to very severe COPD and did not improve uptake/completion of PR. Patients in our study were affected by other comorbidities or difficult social situations that caused anxiety/depression not necessarily related to COPD. Patients had learnt to manage their conditions or situations through long-established coping strategies. Patients who had not received any psychological treatment specific to COPD and mental health previously felt the intervention might be more suited to people earlier on in their illness journey or at different time points to gain benefits. There were patients who did not want to talk about mood, did not perceive any benefits from the intervention and did not want to use the intervention materials or do any home practice work independently. Our study further highlights that the time spent with the skilled Facilitator led some patients to talk freely about their mental health and they perceived improvements in their health including mental health through discussions, use of intervention materials and home practice work but the benefits were not sustainable due to personal/external factors. To improve the mental health of patients with advanced COPD, more opportunities need to be created to discuss mental health in routine assessments for COPD/for multimorbidity with availability of a sustained intervention that considers the holistic and dynamic nature of social and clinical complexities in COPD.

Supplementary Information

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Supplementary Material 1.

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Authors' contributions

R.S., K.M.M., A.B. were involved in data collection, data analysis and interpretation of data. R.S. was the major contributor in writing the manuscript and K.M.M. and A.B. contributed to the revision of the manuscript. S.J.C., H.P. were chief investigators and S.J.C., H.P., M.K., L.S., V.W., V.R., R.S., A.B., K.M.M., C.D.D., A.M. formed the process evaluation team for the TANDEM trial and designed the study. S.J.C., H.P., M.K., L.S., V.W., V.R., C.D.D. K.M.M. and A.M. contributed to the data analysis, data interpretation and the revision of the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was approved by the London-Queen Square Research Ethics Committee, reference 17/LO/0095. All participants provided written informed consent for the interview.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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