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Non-medical devices for the management of chronic breathlessness: A scoping review of device use, barriers and facilitators for patients, carers and clinicians

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Abstract

Background: Non-medical devices such as the handheld fan (fan), mobility aids (wheeled walkers with seats) and inspiratory muscle training (IMT) devices offer benefits for patient management of chronic breathlessness. We examined the published evidence regarding patient, carer and clinician use of the fan, mobility aids and IMT devices for chronic breathlessness management, and the potential barriers and facilitators to day-to-day use in a range of settings.

Methods: MEDLINE, EMBASE, SCOPUS, EBSCO and the Cochrane Database of Systematic Reviews were searched. Papers were imported into EndNote and Rayyan for review against *a priori* eligibility criteria. Outcome data relevant to use were extracted and categorised as potential barriers and facilitators, and a narrative synthesis exploring reasons for similarities and differences conducted.

Results: Seven studies met the inclusion criteria (n=5 fan, n=2 mobility aids, n=0 IMT devices). All of the studies presented patient use of non-medical devices only. Patients found the fan easy to use at home. Mobility aids were used mainly for outdoor activities. Outdoor use for both devices were associated with embarrassment. Key barriers included: appearance; credibility; self-stigma; technical specifications. Common facilitators were ease of use, clinical benefit and feeling safe with the device.

Conclusion: The efforts of patients, carers and clinicians to adopt and use non-medical devices for the management of chronic breathlessness is impeded by lack of implementation research. Future research should improve knowledge of the barriers and facilitators to use. This would enhance understanding of how decision-making in patient-carer-clinician triads impacts on non-medical devices use for breathlessness management.

Introduction

People with progressive malignancy, cardiorespiratory and neurological conditions frequently experience disabling chronic breathlessness that seriously affects daily life despite optimum treatment of their underlying disease. (1) Limitations extend beyond the physical to social roles, emotional burden and functional impairment (2) This frightening symptom is difficult to manage for patients, carers, and clinicians. (3-5)

Multi-disciplinary ‘breathlessness services’ incorporating non-pharmacological interventions reduce the impact of the symptom, improve quality of life and promote self-efficacy (6-8). Non-pharmacological interventions often support the patients’ self-management of chronic breathlessness (7) and include non-medical devices such as the handheld battery-operated fan (fan), mobility aids and inspiratory muscle training (IMT) devices.

A growing evidence base supports the use of cool facial airflow from a fan, both to reduce the sensation of breathlessness and to help self-efficacy (9-12). Despite fan efficacy studies as early as 1987 (13), the mechanism of action is only partially understood. Stimulation of the lower branches of the trigeminal nerve, the nasal and upper airway flow receptors is thought to modulate central afferent respiratory centres, leading to decreased neural respiratory drive, and thereby also the perceived sensation of breathlessness (13-16). Preliminary work also indicates that the fan can shorten recovery times from exertion-related breathlessness (11, 17) and encourage increased physical activity (17) and less reliance on inhaled beta-agonists (10, 17).

Wheeled mobility aids reduce breathlessness and increase walking distances (18, 19). Only wheeled walking frames are considered suitable for breathless patients, as the repeated upper arm elevation otherwise required incurs extra metabolic and ventilatory effort (20). The forward lean posture and shoulder girdle support are thought to help respiratory muscles increase maximal force generating capacity (19) and thereby improving the efficiency of walking (18). In addition, if the device provides a seat allowing breathlessness recovery, this may increase their self-confidence to manage breathlessness particularly outside of the home (21).

A recent systematic review and meta-analysis of people with chronic obstructive pulmonary disease (COPD) found that using IMT devices decreases breathlessness, improves inspiratory muscle strength, exercise capacity and quality of life (22). Its mechanisms of action are poorly understood, but may involve increased diaphragmatic strength and neural adaptations that facilitate the ability to recruit motor units during maximal voluntary activation of the diaphragm, thus lowering the load-capacity imbalance and perception of breathlessness during activity (23).

Despite review evidence, (8, 24-26) demonstrating the effectiveness of various non-pharmacological interventions such as the fan, (including when delivered as a complex intervention) for the management of breathlessness, there are no reviews that explore implementation. Therefore, little is known about how this evidence-base leads to changes in care (implementation), how those changes become part of everyday practice (embedded), and sustained over time (integrated). Little is also known about the experiences of those who use or recommend the fan, IMT devices and mobility aids for the management of chronic breathlessness.

We aimed to examine the published evidence about patient, carer and clinician use of the fan, mobility aids and IMT devices for the management of chronic breathlessness, and to identify the potential barriers and facilitators to day-to-day use in a range of settings.

Research questions

1. How are non-medical devices (fan, mobility aids, IMT devices) used for the management of chronic breathlessness by patients, carers and clinicians?
2. What are the potential barriers and facilitators for patients, carers and clinicians to the use of these non-medical devices for the management of chronic breathlessness?

Methods

The scoping review is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses – Scoping Reviews checklist extension (PRISMA-ScR) (27). We used an exploratory approach in which data extracted about the day-to-day use of non-medical devices were interpreted, summarized and classified by the authors to identify

the potential barriers and facilitators that may influence patient, carer and clinician use of these devices for chronic breathlessness.

Study Eligibility criteria

The eligibility criteria are reported in Table One.

Table One Study Eligibility criteria

	Inclusion criteria	Exclusion criteria
Design	Any design, both quantitative and qualitative including randomised controlled trials (RCTs), observational, qualitative interviews. Studies of both primary and secondary analyses of data Secondary analyses were included if the study presented unpublished or additional data not included in the primary paper	Guidelines. Reviews. Opinion pieces.
Population	1 Patients; adults with chronic breathlessness due to cardiorespiratory and neurological disease (COPD, lung cancer, interstitial lung disease, chronic heart failure, motor neuron disease). Studies that included a broader range of conditions were included if the majority of participants were living with a cardiorespiratory or neurological disease. 2 Carers or caregivers or informal carers 3 Clinicians of any discipline	Paediatric patients.
Exposure	Non-medical devices 1. Fan (handheld battery operated) 2. Mobility aids (three or four wheeled walker or rollator with or without a seat) 3. Inspiratory Muscle Training (IMT) devices 4. “Complex interventions” – which include any of the non-medical devices above as part of their management strategy if reported separately from the other components. Context of exposure; 1. Patients and carers – use/experience of non-medical device(s) for the management of chronic breathlessness at home and outside in the community e.g. shopping. 2. Clinicians – use/experience of non-medical device(s) for patient management of chronic breathlessness in the community, primary and secondary care; hospitals including Specialist Palliative Care Units (SPCU) e.g. hospice.	Spacers as a non-medical device due to a high prevalence of studies in the paediatric population.
Outcome	Quantitative or qualitative data regarding non-medical device use, and/or potential barriers and facilitators to use for the management of chronic breathlessness.	

Data sources and searches

A protocol was created and is available upon request. ASP searched the following databases: MEDLINE, EMBASE, SCOPUS, EBSCO and the Cochrane Database of Systematic

Reviews (inception to June 2020). The search strategy was developed from a previous Cochrane review protocol (Respiratory interventions for breathlessness in adults with advanced diseases (28)) for MEDLINE and then adapted for the other databases.

The searches were conducted during April to June 2020 and combined keywords and indexing terms where appropriate based on PEO (Population, Exposure, Outcome). Individual searches were performed for each search component in combination

In addition, each individual search for each population (patient, carer and clinicians) and exposure were conducted in combination with keywords relating to breathlessness without the outcome component to improve sensitivity. Terms for patients included each of the diseases of interest.

Different terms were used to describe each of the non-medical devices to ensure the inclusion of all relevant papers. For the IMT device searches, further keywords relating to respiratory therapy were added to the search. The term “complex intervention” was included to capture fan, mobility aid or IMT use, if the results for the non-medical devices were reported separately from the other components of the complex intervention. See supplementary file 1; Search strategy and terms.

The search strategy did not include filters for date or study design. Filters for English language and full-text articles were used.

Study selection

The results of the searches were imported into *EndNote* and *Rayyan* and reviewed against the screening tool checklist, developed for the inclusion of studies, by two independent reviewers (ASP and GIL). Full papers were retrieved and screened where insufficient information was presented in the abstract to enable a decision. Any disagreements or queries for inclusion were resolved by consensus with recourse to FS as a third reviewer.

Data extraction

Data extraction was conducted by ASP with support from FS using a bespoke extraction sheet. Data were extracted on study design, participant characteristics, intervention details, method, data type and outcomes relevant to device use.

Analysis

ASP and FS interpreted and categorised the potential barriers and facilitators to non-medical device use from the outcome data extracted. A narrative approach to synthesis was used wherein ASP and FS compared and contrasted the barriers and facilitators identified in the different studies, systematically exploring any reasons for these discernible from the results (29).

Results

A total of 5837 individual papers were identified from the searches. On title/abstract review, 5739 were excluded due to irrelevant content. After de-duplication, 41 full texts were assessed for eligibility and seven were included in the review. See Figure 1 PRISMA Flow diagram of study selection and retrieval (30).

The non-medical devices used was the fan in five studies (9-12, 17) and mobility aids in two (31, 32). We decided to include two secondary analyses studies (10, 17) in addition to the two primary papers included in the review as it permitted inclusion of fan data not published in the primary papers (11, 12) and report an in-depth exploration of the benefits and factors associated with fan use (10).

None of the included studies investigated IMT; an IMT study that was initially included was later excluded due to too few data on the experience and use of the IMT device (33). Similarly, none of the studies that tested a complex intervention such as the Breathlessness Intervention Service (BIS) studies (7, 34) were included due to the lack of data reported on the individual non-medical devices.

All the studies were regarding patient perceptions with none studying clinicians or carers, if carers were included in the study there were very few data on their experience or use of the devices.

Characteristics of included studies

See Table 2 for characteristics of included studies.

Table 2 Characteristics of included studies

Author and date	Study design (Implementation)	Country of origin	Population	Intervention	Length of intervention and method	Data type, implementation outcome
Bausewein et al (2010) (9)	Longitudinal feasibility Phase II RCT (No implementation framework used)	Germany	n=70 Fan arm= 38 Age 64.5 (9.88) Male n=19 COPD n=24 Cancer n=14	Fan	6-months Researcher demonstrated fan use by showing appropriate areas to direct airflow (central part of face, sides of nose, above upper lip). Leaflet was also given with the same instructions.	Quantitative + qualitative Fan use over 6 months Face to face interview with FU questionnaires for 6 months or death.
Johnson et al (2016) (12)	Feasibility Phase II 3 arm RCT (FAB) (No implementation framework used)	Australia and UK	n=43 Fan arm n= 24 Age 68.5(11.6) Male n=12 COPD n=12, cancer and heart causes n=6, other causes n=6	Fan; high speed fan n=13, low speed fan n=11	28 days Patients received standardised verbal and written advice about the fan and SOB self-management exercises.	Qualitative Semi structured interviews on fan experience and use after day 28.
Swan et al (2019) (11)	Feasibility Phase II 2x2 factorial RCT (CHAFF) (No implementation framework used)	UK	n=40 Age: Fan group (n=10) 70 (7.2) Fan + CH group (n=10) 71 (5.9) Male n=15 COPD n=10, pulmonary fibrosis n=6, other causes n=4 Control group (n=20)	Fan	28 days Patients received standardised verbal and written advice about the fan and SOB self-management exercises.	Quantitative and qualitative Semi structured interviews on fan experience and use after day 28.
Luckett et al (2017) (10)	Secondary analysis of interview data from 3 RCTs (BIS, FAB and CHAFF)	Australia and UK	n=133 (BIS=111, CHAFF=11, FAB=11) Age 71 (10.7) Male n=65 COPD n=68, non-malignant conditions n=23, lung cancer	Fan and table fan	BIS, FAB and CHAFF = 28 days In all 3 studies, patients provided with the same verbal and written instructions on fan use by a healthcare professional. They were told - fan may reduce breathlessness,	Qualitative Semi structured interviews on fan experience and use after day 28.

	(No implementation framework used)		or metastases n=21, other malignancies n=26		to hold the fan 6 inches from their face and direct to their nose or mouth.	
Barnes-Harris et al (2019) (17)	Secondary analysis of survey data from 2 RCTs (FAB and CHAFF) (No implementation framework used)	UK	n=41 Age 73 (IQR 65-76, range 46-88) Male n=24 COPD n=20, HF n=3, cancer n=3, other causes n=15	Fan	28 days Patients instructed to hold fan approximately 15cm from their face to direct airflow at their nose and/or mouth. Use of fan whenever they wished (at rest, before, during or after exertion)	Quantitative Fan survey assessment at day 28 (7 questions on fan use).
Gupta et al (2006) (32)	Phase III 2 arm RCT (No implementation framework used)	Canada	n= 31 Rollator group n=18, Age = 68 (9) Male n=4 Moderate to severe COPD (ATS definition) n=18	Mobility aid	8 weeks Patients asked to integrate rollator (with seat) into their daily life, requested to complete a log of the days the rollators used. All patients were already previous rollator users.	Quantitative Patients requested to complete a log of the days the rollator used. Activities and frequency of rollator use logged over 8 weeks. Standardised questionnaire with specific statements regarding attributes of the device at end of study (8 weeks).
Hill et al (2008) (31)	Cross-sectional observational study (No implementation framework used)	Canada	n=27 Age=69 (9.6) Male n=10 COPD n=27	Mobility aid	7 days All were previous rollator users.	Quantitative Interview done based on the Structured Rollator Utility Questionnaire and the QUEST on rollator use, and general satisfaction of rollator use.

FU = follow up, RCT = randomised control trial, HHHF= hand-held fan, SOB = shortness of breath, COPD = chronic obstructive pulmonary disease, HF = heart failure, BIS = breathlessness intervention service, CHAFF = calming hand and fan feasibility, FAB = fan activity breathlessness, CH = calming hand ATS = American Thoracic Society, fan = handheld fan

Study design

Five studies (n=327) contained data about fan use of (9-12, 17). Two studies were secondary pooled data analyses; survey data from two randomised control trials (RCTs) (n=41) (17) and qualitative interviews from three mixed-methods RCTs (n=133) (10). The remaining three fan studies were feasibility phase II clinical trials; a six month RCT (n=70) (9), three arm RCT (n=43) (12) and a 2x2 factorial RCT (n=40) (11).

Two studies used mobility aids (n=58); one study was a Phase III RCT (n=31) (32), the second, a cross-sectional observational study (n=27) (31).

Patient characteristics

In the intervention arm, the five fan studies recruited a mixed population with chronic breathlessness due to different types of diseases, including COPD (n=155), malignancy (n=75), heart failure (n=3), pulmonary fibrosis (n=6) and other causes (n=54) (9-12, 17). Five patients in one study were described as having more than one cause of chronic breathlessness (17).

Both mobility aid studies recruited patients with COPD (n=58) (31, 32). One study focused on moderate to severe COPD (32).

Intervention characteristics

All of the fan studies provided patients with standardised verbal and written fan use advice. (9-12, 17). Patients were given additional guidance on exercise and techniques for breathlessness management in two studies (11, 12). The length of intervention was 28 days in four studies, (10-12, 17) and 6 months in one study (9).

The length of mobility aid intervention and follow up varied in the two studies; 8 weeks (32) and 7 days (31). The intervention in both studies was the rollator walker (with seat) and the patient population was previous mobility aid users (31, 32). One study requested patients to integrate the mobility aid into their daily life (32).

Outcome data

Four of the fan studies provided qualitative data (9-12); two studies conducted semi structured interviews after day 28 regarding fan experience and use (11, 12) while one study

was a secondary analysis of 133 interviews from three RCTs and included both a quantitative and qualitative analysis of the data (10). The remaining fan study presented qualitative data from an initial patient interview and quantitative results from follow up questionnaires used over 6 months (9). One study presented quantitative data only; a survey of fan use completed after 28 days from two RCTs (17).

None of the included fan studies were designed using implementation science methods to explore implementation as a primary outcome (9-12, 17). All the fan studies presented outcome data on fan use at home from a patient perspective (9-12, 17), with no studies presenting the carer or clinician perspective.

Luckett et al (10) presented data of a secondary analysis of three RCTs and explored factors associated with fan use, its analysis cannot be extracted from the individual studies, such as the data of the Breathlessness Intervention Service study (BIS) (7), thus it was included due to the usefulness of the analysis.

Both mobility aid studies presented various quantitative outcome data (31, 32). Gupta et al (32), requested patients to complete a diary of rollator use over 8 weeks, that included the activities for which the device was used. At the end of the study (8 weeks) a standardised questionnaire was used to tabulate the number and percentage of participants agreeing with specific statements pertaining to the rollator (32).

Hill et al (31) presented data from an interview based on the Structured Rollator Utility Questionnaire, the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) and general satisfaction of rollator use.

None of the mobility aid studies were designed using implementation science with implementation as a primary objective (31, 32). Both of the studies presented data from a patient perspective only with mobility aid use and experience from the context of home use during a 7 day observational study (31) and an 8 week RCT (32).

Use of non-medical devices

See Table 3 Non-medical devices use and potential facilitators and barriers to use
Supplementary file 2

Fan use

There was substantial variability in the way the fan was used in practice by the patients in terms of the timing, frequency, duration and location of fan use. The timing of fan use was between 1-10 minutes (9, 10) with 4-5 minutes being the most common duration (10) and used 4-5 times a day (10, 17). Three-quarters (75-76%) of patients used the fan at least once daily over a 28 day study period (11, 17) and people with COPD were more likely to use the fan every day; 61% (n=19) than other patients 39% (n=12) (OR 5.94 (CI 0.63-56.21) p=0.017) (17). In the one study with longer term follow up, fan use dropped to 40% (n=16/33) after 2 months with only 9 patients still using the fan daily and 7 patients using it occasionally (9).

Fan use over 28 days was tailored to individual preferences and the patients' daily routine (11, 17). It was used early in the morning or during the evening (17) and was incorporated with exercise advice as part of a complex intervention to self-manage breathlessness (12). The fan was used before, during and as part of recovery from exertion, as well as a routine prophylactic measure and for acute episodes of breathlessness (10, 12). The fan was also used as a replacement or adjunct to beta agonist inhalers (10-12) and was considered a first line strategy to reduce breathlessness (10). One study included table top fans in the analysis, which were placed in different locations where most likely needed (10).

Patients perceived the fan as a helpful device (9) that reduced recovery time from exertional breathlessness (10-12) and supported them staying active (17). One study reported that carers had similar perceptions of the fan to patient-participants, but no data were presented (10).

Barriers to fan use

Two of the fan studies identified potential barriers to fan use (9, 10) but three studies reported none (11, 12, 17). Some patients struggled to believe that the fan could be a clinical intervention (9, 10), commenting that it looked like a toy (9). Some patients were less likely to use the fan outside as they were concerned about attracting unwanted attention, especially in the winter months (10). Sensitivity or irritation by the cold airflow (9), particularly in winter, as well as concerns about breathing dust if the fan was not cleaned properly were cited as issues preventing use (10).

Technical barriers revolved around the inability to vary airflow rate to suit individual need (10), reliability (9) and robustness of the fan, the level of noise, the safety of the blades, and operability issues, such as difficulty with battery changes and the need for patients to use their hands to hold and operate the fan (10).

Facilitators to fan use

Facilitators to fan use were identified in all five studies (9-12, 17). In general, fans were acceptable to patients, and the device seen as a helpful management strategy for breathlessness (9-12) which could be readily integrated into and support daily activities (11, 12). The ease of use (10) and the portability allowed patients to tailor to individual needs (10-12) in different contexts (10, 12). Perceived benefits along with a lack of side-effects (10, 12) were strong drivers of fan use such as reduced recovery time from exertional breathlessness (10-12) and increased activity (17). The improved confidence to manage breathlessness (10-12) allowed patients to reclaim control (12) and promoted independence (10). Regular fan use was identified as “making life easier” (9). The possibility of a non-pharmacological alternative replacement for inhalers or oxygen was welcomed by patients. (10-12)

Mobility aid use

The mean duration of rollator use in patients who already used the device over 8 weeks was 26 ± 4 (range 5-60) days (32). Two different types of mobility aid users were identified; frequent users, patients who used the rollator at least 3 times a week and infrequent users, patients who used the mobility aid less than 3 times a week. Frequent users (n=10) reported rollator use range 25-60 days and infrequent users (n=8) range 5-15 days over 8 weeks (32).

Hill et al (31) reported 59% daily rollator use in patients who already used the device over 7 days, with 30% using the device at least once a week and 11% using the rollator less than once a month (31). The activities and reasons for rollator use varied with all patients, 100% (n=27) (31), or most 81% (n=13) (32) reporting rollator use for outdoor walking, or activities outside of the home such as recreation and shopping. Patients reported least rollator use walking inside the home; 30% (n=8) (31) to 31% (n=5) (32), and doing activities inside the home 6% (n=1) (32) to 30% (n=8) (31). Other activities that the rollator was used for included; transition from inside to outside the home; 31% (n=5) (32) to 50% (n=14) (31), getting to and from the car; 38% (n=6) (32) to 60% (n=16) (31), and walking indoors, but not

at home; 81% (n=13) (32) to 90% (n=24) (31), or activities not at home 63% (n=10) (32). Patients also reported that they appreciated the seat (86%) and felt less breathless (71%) with rollator use (32).

Neither study reported any carer data or details of how mobility aid use related specifically to the management of breathlessness.

Barriers to mobility aid use

Although most patients preferred the rollator, nearly half (n=8/18) used it fewer than 3 times a week (32). Indoor rollator use in particular was associated with problems such that 59% (n=16) did not use the device inside the home, although some found it helpful to support other daily activities of living such as washing and dressing, bending and carrying. Patients felt it was too bulky, they had difficulty pushing the device across floor coverings, or they were unable to use it due to the stairs (31). In addition, less than half (41%) of women were able to lift the device in and out of a car compared to 80% of men (31).

Embarrassment also featured as barrier to rollator use outside with 48% (n=13) (31). In addition, while 31% (n=4) of patients felt they were only embarrassed for the first few weeks, 69% (n=9) reported persistent embarrassment (31).

Facilitators to mobility aid use

As with the fan, perceived benefits encouraged use. All of the patients (100%, n= 45) felt improved exercise endurance and reported feeling safe and stable using the rollator (31, 32). In addition, 71% (n= 32) reported decreased breathlessness with rollator use and improvements in quality of life were noted in both frequent (86%, n=9) and infrequent (91%, n=7) rollator users (32).

There was high patient satisfaction with the rollator according to Quest User Evaluation of Satisfaction with assistive Technology (QUEST) (31). This indicates that rollator specifications met the needs of the patient in terms of mobility device dimension, comfort, effectiveness, safety, security and ease of use and adjustment, despite the weight that hindered device use for women (31)

Discussion

This scoping review draws together the available evidence for the use of non-medical devices for the management of chronic breathlessness. Seven papers met the scoping review criteria; five fan (n=327) and two mobility aid (n=58) studies.

We found that patients associate fan and mobility aid use with relief of breathlessness, improved exercise capacity (11, 17, 32) and confidence (9, 11, 12, 31, 32). The fan was readily integrated into patients' breathlessness management and was easily tailored to daily needs around the home and different breathlessness situations (10-12). In contrast, mobility aids were mainly used for breathlessness management with outdoor activities. Barriers around the home, such as bulk and weight reduced the usefulness of the device for breathlessness management indoors, instead patients used the mobility aid to help with other daily activities of living such as washing and dressing (31, 32).

However, both fan and mobility aid use in public places were associated with embarrassment (31) and could attract unwanted attention (10). It is possible that illness perception, that is, the patient's beliefs about the health threats posed by their illness which form the cognitive basis for their adaptive coping responses (35, 36), may influence non-medical device use outside. In people with COPD, high illness perception scores in relation to how they evaluate living with their disease are associated with more breathlessness (35), poorer ability to cope with symptom management, and reduced patients' quality of life. (37, 38) In addition, stigma is already established as a reason to deter patients from using a mobility aid (39, 40). This is important as a high illness perception score coupled with the stigma felt from device use outside may prevent patients using these interventions and limit any breathlessness benefits to activities inside the home.

The current commercial design of the fan may also act as a barrier to device use in public. Patients were sceptical of the intervention (9, 10) and, other problems such as the operability, safety of the blades, noise, robustness, difficulty with battery change and the lack of airflow rate variability were all highlighted as potential issues that could compromise use (10). These concerns may explain the results of a longitudinal study which reported a drop in adherence in fan use after two months (9), and suggest that long term maintenance of fan use for breathlessness management could be compromised by the appearance and technical specifications of the device.

In contrast the appearance of the mobility aid was not identified as a specific barrier to outdoor use. This may relate to public recognition of a non-medical device to support disability. It is possible that the embarrassment experienced by patients from using a mobility aid relates more to the visual signal that the person has an illness, rather than its appearance. Use outside was instead compromised by the lack of portability of the mobility aid in terms of weight and bulk.

This review provides valuable insights into patients' experiences and use of non-medical devices for the management of chronic breathlessness. It also highlights significant gaps in the research evidence about barriers and facilitators for patients, carers and clinicians to routine device use.

Despite broad population inclusion criteria, there were no directly reported data on carers' perspectives on non-medical device use. Carers have an important role in patients' breathlessness management (4) and are acknowledged as driving decisions about the prescription of oxygen. (41), therefore it is essential that future research considers the patient-carer dyad as a unit (4) to understand how carers may influence patient use of non-medical devices for chronic breathlessness.

Chronic breathlessness is recognised as a challenging symptom for clinicians to manage and is often a cause of communication difficulty leading to symptom "invisibility" between clinicians and patients. (3, 42, 43) yet, importantly, the way a clinician delivers an intervention is known to influence outcome (44) However none of the included studies explored clinicians' perspectives and recommendation of non-medical device use for chronic breathlessness management.. This information is crucial to understand as the clinicians' perception and delivery may represent a hidden barrier to patient use of non-medical devices for breathlessness management; a possible problem for the fan in particular given the commercial variability in appearance.

It is likely that the perception and credibility of non-medical devices will vary widely across patients, carers and clinicians. Indeed given the tendency of some clinicians to assume a biomedical focus on disease (45), it is possible that drug and surgical interventions are considered the default management with a higher cultural status (21), while non-pharmacological interventions such as the fan are labelled as "non-clinical activities"

(21); a perception reflected by the review results as patients were sceptical about the credibility of the fan (9, 10).

The review was unable to identify any studies that investigated the use of IMT devices. It is possible that IMT is overlooked as a usual component to include for the management of chronic breathlessness despite the commercial availability and low cost of the device. Given that evidence reports that these devices decrease breathlessness, improve inspiratory muscle strength, exercise capacity and quality of life, (22) the uptake and use of IMT devices should also be considered a priority to explore in future studies.

Finally, none of the included studies used an Implementation Science theory or framework to focus enquiry and enable findings to contribute to emerging interdisciplinary knowledge about implementation (46), Given the MRC Framework for Complex Intervention's (47) emphasis on the need for refinement and ongoing modelling in conjunction with testing in practice, an implementation theory or framework, e.g. process evaluation (48) could provide a valuable structure to identify mediators and measure outcomes that inform optimisation of both intervention and implementation. Also, from the behavioural sciences, the Theoretical Domains Framework could be used to drive research into factors that impact on individuals' uptake of non-medical devices, their adoption into routine behaviour, and the maintenance of their use over time. (49)

To extend research beyond the individual, a social science theory such as Normalisation Process Theory provides significant scope for investigating how the interactions of patient-carer-clinician triads impact on the implementation, embedding, and integration of non-medical devices into complex social systems. (48, 50, 51) By extending the focus further to the level of a unit, organisation or system, a framework from the organisational sciences such as Promoting Action on Research in Health Services (PARIHS) can structure research into the significant broader issues that impact on implementation. (52, 53) If research into pain and symptom management is to learn from and contribute to interdisciplinary scientific understanding about implementation then, in common with research conducted in other fields, it must draw on implementation theory (54)

Strengths and limitations

The scoping review included both quantitative and qualitative data. The inclusion of the qualitative data allows for an in-depth exploration of the participant's perspective and enriches the results. We view our decision to include two secondary analyses as a strength as these studies (10, 17) report unpublished and additional data as well as an in-depth qualitative analysis not included in the primary papers.

Strengths also include the blinding of the two independent reviewers during the full text screening and the data extraction review by a second author which helps to reduce selection and information bias.

Limitations include the lack of quality appraisal of the included studies and the searches were limited to English language and full-text articles.

Conclusions

We found limited data on non-medical device use for the management of chronic breathlessness, all of which focused on the fan and mobility aids rather than IMT devices and the perspective of patients rather than carers or clinicians. None of the studies applied implementation science theory. The fan and mobility aids were identified as useful components of breathlessness management that were tailored to different patient activities. The fan was used around the home, whereas the mobility aid was suited mainly to outside activities. Patient use of the fan and mobility aid in public places was limited. Key barriers were the appearance, credibility of the device, self-stigma and the technical specifications. Common facilitators were ease of use and feeling safe and secure with the device.

Recommendations

Future research should be underpinned by Implementation Science Theory or framework and must not only improve understanding of barriers and facilitators for patients, but also carers and clinicians. This would provide much needed data on how carers and clinicians perceive and use the interventions and help explore the interplay between patients', carers and clinicians' use of non-medical devices and ultimately if this influences the benefits for patient management of chronic breathlessness.

Implications for clinical practice

It is essential that clinicians consider not only the importance of the delivery of non-medical devices for breathlessness management, but the follow up as well. How patients are using (or not using) non-medical devices for the self-management of breathlessness can be assessed easily by demonstrating its use rather than merely recommending it, asking about intervention use at routine appointments and raising awareness of these non-pharmacological interventions amongst the multi-disciplinary team. This may serve to highlight potential problems that will compromise patient adoption and long term use of non-medical devices for the management of chronic breathlessness

Declaration of conflicts of interest: The authors declare that there is no conflict of interest.

Funding statement: This work was supported by the INSPIRE grant generously awarded to Hull York Medical School by the Academy of Medical Sciences through the Wellcome Trust [Ref: IR5\1018].

Authorship contributions: FS and MP created the concept and design of the study. FS and AP created the search strategies. AP and GIL conducted the searches and screened records AP, GIL and FS extracted the data. FS and AP interpreted and analysed the data. FS, AP and MP prepared the manuscript. FS, AP, GIL, MP, MJ and TL edited and reviewed the final manuscript. FS is responsible for the overall content.

References

1. Johnson MJ YJ, Hansen-Flaschen J, Lansing R, Ekstrom M, Similowski T, Currow D. . Towards an expert consensus to delineate a clinical syndrome of chronic breathlessness. . *European Respiratory Journal* 2017.
2. Lovell N, Etkind SN, Bajwah S, Maddocks M, Higginson IJ. Control and Context Are Central for People With Advanced Illness Experiencing Breathlessness: A Systematic Review and Thematic Synthesis. *Journal of Pain and Symptom Management*. 2019;57(1):140-55.e2.
3. Johnston KN, Young M, Kay D, Booth S, Spathis A, Williams MT. Attitude change and increased confidence with management of chronic breathlessness following a health professional training workshop: a survey evaluation. *BMC Medical Education*. 2020;20(1):90.
4. Farquhar M. Carers and breathlessness. *Current Opinion in Supportive and Palliative Care*. 2017;11(3):165-73.
5. Hutchinson A, Barclay-Klinge N, Galvin K, Johnson MJ. Living with breathlessness: a systematic literature review and qualitative synthesis. *The European respiratory journal*. 2018;51(2).
6. Higginson IJ, Bausewein C, Reilly CC, Gao W, Gysels M, Dzingina M, et al. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. *The Lancet Respiratory Medicine*. 2014;2(12):979-87.
7. Farquhar MC, Prevost AT, McCrone P, Brafman-Price B, Bentley A, Higginson IJ, et al. Is a specialist breathlessness service more effective and cost-effective for patients with advanced cancer and their carers than standard care? Findings of a mixed-method randomised controlled trial. *BMC Medicine*. 2014;12(1):194.
8. Brighton LJ, Miller S, Farquhar M, Booth S, Yi D, Gao W, et al. Holistic services for people with advanced disease and chronic breathlessness: a systematic review and meta-analysis. *Thorax*. 2018;thoraxjnl-2018-211589.
9. Bausewein C BS, Gysels M, Kuhnbach R, and Higginson I J,. Effectiveness of a hand-held fan for breathlessness: a randomised phase II trial. *BMC Palliative Care* 2010;9(22).
10. Lockett T, Phillips J, Johnson MJ, Farquhar M, Swan F, Assen T, et al. Contributions of a hand-held fan to self-management of chronic breathlessness. *European Respiratory Journal*. 2017;50(2).
11. Swan F, English A, Allgar V, Hart SP, Johnson M. The hand-held fan and the Calming Hand for people with chronic breathlessness: a feasibility trial. *Journal of Pain and Symptom Management*. 2019.
12. Johnson MJ, Booth S, Currow DC, Lam LT, Phillips JL. A Mixed-Methods, Randomized, Controlled Feasibility Trial to Inform the Design of a Phase III Trial to Test the Effect of the Handheld Fan on Physical Activity and Carer Anxiety in Patients With Refractory Breathlessness. *Journal of Pain and Symptom Management*. 2016;51(5):807-15.
13. Schwartzstein RM, Lahive K, Pope A, Weinberger SE, Weiss JW. Cold Facial Stimulation Reduces Breathlessness Induced in Normal Subjects. *American Journal of Respiratory and Critical Care Medicine*. 1987;136(1):58-61.
14. Liss HP GJ. The effect of nasal flow on breathlessness in patients with chronic obstructive pulmonary disease. *American Review Respiratory disease* 1988;137:1285-8.
15. Johnson MJ, Simpson MIG, Currow DC, Millman RE, Hart SP, Green G. Magnetoencephalography to investigate central perception of exercise-induced breathlessness in people with chronic lung disease: a feasibility pilot. *BMJ Open*. 2015;5(6):e007535.
16. Parshall MB, Schwartzstein RM, Adams L, Banzett RB, Manning HL, Bourbeau J, et al. An Official American Thoracic Society Statement: Update on the Mechanisms, Assessment, and Management of Dyspnea. *American Journal of Respiratory and Critical Care Medicine*. 2012;185(4):435-52.
17. Barnes-Harris M, Allgar V, Booth S, Currow D, Hart S, Phillips J, et al. Battery operated fan and chronic breathlessness: does it help? *BMJ Supportive & Palliative Care*. 2019;9(4):478-81.

18. Honeyman P, Barr P, Stubbing DG. Effect of a walking aid on disability, oxygenation, and breathlessness in patients with chronic airflow limitation. *J Cardiopulm Rehabil.* 1996;16(1):63-7.
19. Probst VS, Troosters T, Coosemans I, Spruit MA, Pitta FdO, Decramer M, et al. Mechanisms of improvement in exercise capacity using a rollator in patients with COPD. *Chest.* 2004;126(4):1102-7.
20. Baarends EM, Schols AM, Slebos DJ, Mostert R, Janssen PP, Wouters EF. Metabolic and ventilatory response pattern to arm elevation in patients with COPD and healthy age-matched subjects. *Eur Respir J.* 1995;8(8):1345-51.
21. Booth S, Moffat C, Burkin J, Galbraith S, Bausewein C. Nonpharmacological interventions for breathlessness. *Current Opinion in Supportive and Palliative Care.* 2011;5(2):77-86.
22. Beaumont M, Forget P, Couturaud F, Reyhler G. Effects of inspiratory muscle training in COPD patients: A systematic review and meta-analysis. *The Clinical Respiratory Journal.* 2018;12(7):2178-88.
23. Langer D, Ciavaglia C, Faisal A, Webb KA, Neder JA, Gosselink R, et al. Inspiratory muscle training reduces diaphragm activation and dyspnea during exercise in COPD. *Journal of Applied Physiology.* 2018;125(2):381-92.
24. Qian Y, Wu Y, Rozman de Moraes A, Yi X, Geng Y, Dibaj S, et al. Fan Therapy for the Treatment of Dyspnea in Adults: A Systematic Review. *Journal of Pain and Symptom Management.* 2019;58(3):481-6.
25. Beaumont M, Forget P, Couturaud F, Reyhler G. Effects of inspiratory muscle training in COPD patients: A systematic review and meta-analysis. *The clinical respiratory journal.* 2018;12(7):2178-88.
26. Booth S, Chin C, Spathis A, Maddocks M, Yorke J, Burkin J, et al. Non-pharmacological interventions for breathlessness in people with cancer. *Expert Review of Quality of Life in Cancer Care.* 2018:1-15.
27. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine.* 2018;169(7):467-73.
28. Bolzani A, Rolser SM, Kalies H, Maddocks M, Rehfues E, Swan F, et al. Respiratory interventions for breathlessness in adults with advanced diseases. *Cochrane Database of Systematic Reviews.* 2017.
29. Popay J, Roberts HM, Sowden A, Petticrew M, Arai L, al. RMe. Guidance on the conduct of narrative synthesis in sytematic reviews. . London: Institute for Health Research; 2006. 92 p.
30. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ.* 2009;339(jul21 1):b2535-b.
31. Hill K, Goldstein R, Gartner EJ, Brooks D. Daily Utility and Satisfaction With Rollators Among Persons With Chronic Obstructive Pulmonary Disease. *Archives of Physical Medicine and Rehabilitation.* 2008;89(6):1108-13.
32. Gupta RB, Brooks D, Lacasse Y, Goldstein RS. Effect of rollator use on health-related quality of life in individuals with COPD. *Chest.* 2006;130(4):1089-95.
33. Hoffman M, Assis MG, Augusto VM, Silveira BMF, Parreira VF. The effects of inspiratory muscle training based on the perceptions of patients with advanced lung disease: a qualitative study. *Braz J Phys Ther.* 2018;22(3):215-21.
34. Farquhar MC, Prevost AT, McCrone P, Brafman-Price B, Bentley A, Higginson IJ, et al. The clinical and cost effectiveness of a Breathlessness Intervention Service for patients with advanced non-malignant disease and their informal carers: mixed findings of a mixed method randomised controlled trial. *Trials.* 2016;17(1):1-16.
35. Borge CR, Moum T, Puline Lein M, Austegard EL, Wahl AK. Illness perception in people with chronic obstructive pulmonary disease. *Scandinavian Journal of Psychology.* 2014;55(5):456-63.
36. Leventhal H, Brissette I, EA. L. The common-sense model of self-regulation of health and illness. Cameron LD LH, editor. London, New York: Routledge; 2003.

37. Braidó F, Baiardini I, Menoni S, Bagnasco AM, Balbi F, Bocchibianchi S, et al. Disability in COPD and its relationship to clinical and patient-reported outcomes. *Current medical research and opinion*. 2011;27(5):981-6.
38. Scharloo M, Kaptein AA, Schlösser M, Pouwels H, Bel EH, Rabe KF, et al. Illness perceptions and quality of life in patients with chronic obstructive pulmonary disease. *The Journal of asthma : official journal of the Association for the Care of Asthma*. 2007;44(7):575-81.
39. Resnik L, Allen S, Isenstadt D, Wasserman M, Iezzoni L. Perspectives on use of mobility aids in a diverse population of seniors: Implications for intervention. *Disability and Health Journal*. 2009;2(2):77-85.
40. MacInnis CC, Ulrich C, Konnert C. Exploring potential prejudice toward older adult mobility device users. *Psychol Aging*. 2019;34(2):208-14.
41. Currow DC, Christou T, Smith J, Carmody S, Lewin G, Aoun S, et al. Do Terminally Ill People who Live Alone Miss Out on Home Oxygen Treatment? An Hypothesis Generating Study. *Journal of Palliative Medicine*. 2008;11(7):1015-22.
42. Lunn S, Dharmagunawardena R, Lander M, Sweeney J. It's hard to talk about breathlessness: a unique insight from respiratory trainees. *Clinical Medicine*. 2019;19(4):344-7.
43. Gysels M, Higginson IJ. Access to Services for Patients with Chronic Obstructive Pulmonary Disease: The Invisibility of Breathlessness. *Journal of Pain and Symptom Management*. 2008;36(5):451-60.
44. Booth S. Science supporting the art of medicine: improving the management of breathlessness. *Palliative Medicine*. 2013;27(6):483-5.
45. Celli B, Blasi F, Gaga M, Singh D, Vogelmeier C, Pegoraro V, et al. Perception of symptoms and quality of life - comparison of patients' and physicians' views in the COPD MIRROR study. *Int J Chron Obstruct Pulmon Dis*. 2017;12:2189-96.
46. Nilsen P. Overview of theories, models and frameworks. Nilsen PB, S.A, , editor. Cheltenham: Edward Elgar Publishing Limited 2020.
47. Medical Research Council. Developing and evaluating complex interventions: new guidance London: MRC; 2008.
48. May C, Finch T. Implementing, Embedding, and Integrating Practices: An Outline of Normalization Process Theory. *Sociology*. 2009;43(3):535-54.
49. Atkins L, Francis J, Islam R, O'Connor D, Patey A, Ivers N, et al. A guide to using the Theoretical Domains Framework of behaviour change to investigate implementation problems. *Implementation Science*. 2017;12(1):77.
50. Murray E, Treweek S, Pope C, MacFarlane A, Ballini L, Dowrick C, et al. Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. *BMC Medicine*. 2010;8(1):63.
51. May CR, Cummings A, Girling M, Bracher M, Mair FS, May CM, et al. Using Normalization Process Theory in feasibility studies and process evaluations of complex healthcare interventions: a systematic review. *Implement Sci [Internet]*. 2018 2018/06//; 13(1):[80 p.].
52. Harvey GK, A. Implementing evidence-based practice in healthcare: a facilitation guide. London: Routledge; 2015.
53. Harvey G, Kitson A. PARIHS revisited: from heuristic to integrated framework for the successful implementation of knowledge into practice. *Implement Sci*. 2016;11:33-.
54. Kislov R, Pope C, Martin GP, Wilson PM. Harnessing the power of theorising in implementation science. *Implementation Science*. 2019;14(1):103.