Title: Physiotherapy assessment of breathlessness and disordered patterns of breathing: defining a consensus on terminology and assessment.

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Word Count: 3294

**INTRODUCTION**

The diagnosis and management of persistent breathlessness is a clinical challenge. The term “chronic breathlessness syndrome,” introduced in 2017, refers to breathlessness that persists despite adequate treatment and leads to disability (1) although the term adequate is not defined in this context. In 2023 the European Respiratory Journal published a monograph on “complex breathlessness” which was defined as breathlessness without a clear cause or disproportionate to known pathology. These terms acknowledge that there are symptomatic patients with suboptimal treatment.

People with these conditions are often referred to physiotherapy services for breathlessness assessment where physiotherapists complete a detailed assessment of breathing, including its pattern and functionality. The complexities of these presentations are rooted in multifaceted characteristics of breathlessness, including neural, biomechanical, biochemical, cardiorespiratory and psychological interactions (2). Such factors can cause breathing that deviates from allostasis (respiratory or metabolic needs) when conscious or unconscious processes override autonomic control (3). In some cases, this causes decreased arterial partial pressure of carbon dioxide via hyperventilation (4) often influenced by psychological factors like heightened breathing vigilance (5). Individuals have worse physical functioning scores, are more anxious and have poor health-related quality of life (6, 7). Multiple terms are used to describe such presentations including, breathing pattern disorder, dysfunctional breathing and hyperventilation (8).

In a national survey (pre COVID-19), a self-selecting group of 103 UK respiratory physiotherapists indicated their preferred terms for this condition, predominantly breathing pattern disorder (n=43%) or dysfunctional breathing (n=39%) (9). They expressed frustrations with the heterogeneous nomenclature and stated a consensus on terminology was urgently needed. Patients, too, have expressed frustrations with some not understanding what the terminology mean and others feeling discomfort with their ‘label’ The lack of consensus was felt to ‘diminish’ the importance of this condition, leading to diagnostic confusion (9) and hampering clinical and research progress.

*Assessment:* Severalassessment tools and outcome measures exist and unsurprisingly there is substantial heterogeneity in their measurement properties and some elements essential to a comprehensive assessment are missing (10). Objective assessment tools, such as the Manual Assessment of Respiratory Motion (MARM) is complex to use and the breath-hold time lacks sufficient evidence to support its use (4). In clinical research, many studies rely on the Nijmegen Questionnaire (NQ) (11), whereas, in clinical practice, a more comprehensive physiotherapy assessment is completed (9, 12). Cardiopulmonary exercise testing (CPET) and Opto-Electronic Plethysmography (OEP) are two objective assessments. In people with this condition CPET has shown a chaotic response to exercise with erratic ventilation and an increased, fluctuating respiratory rate, with larger tidal volumes (13, 14). In athletes, OEP has shown biphasic changes during inspiration caused by paradoxical movement of the thorax, thought to undermine breathing performance (15). These studies have importantly progressed our understanding of the mechanisms behind this type of breathlessness.

With growing recognition of this condition and a rise in physiotherapy referrals, there is now an urgent need to better characterise it and develop consistent nomenclature and assessment approaches (9, 16). Physiotherapists are well placed to lead on defining consensus of terminology with a patient-centred lens. We aimed to achieve this by using robust consensus-building methodology to provide exploratory evidence for physiotherapists’ preferred nomenclature for this condition and the necessary components for physiotherapy assessments, aiming to provide a springboard to improve definitions in this complicated area.

**METHODS**

This study was conducted in two stages. Stage 1: in focus groups and one-to-one semi-structured interviews we explored thoughts and perspectives on terminology and assessment of this condition with respiratory physiotherapists, clinicians, and patients. These were used to inform the next stage of this research. Stage 2: using the nominal group technique (NGT) we aimed to achieve consensus on nomenclature and assessment. Because we were interested in the terminology, we were sensitive to our choice of language and consistently used the term ‘this condition’ so as not to influence.

**Stage 1 – Focus groups and semi-structured interviews.**

**Participants/recruitment**

Purposive sampling was used to recruit to the focus groups and interviews. The inclusion criteria for Group 1 were UK-based respiratory physiotherapists with two or more years of experience in this area. Group 2 included clinicians (physicians, allied health professionals [excluding physiotherapists] or nurses) with experience working with patients with this condition for over two years. Group 3 included patients assessed and treated for unexplained breathlessness within a physiotherapy service. This included patients with co-existing disease and no pathophysiological reason for breathlessness. Physiotherapists were recruited through the UK professional body for cardiorespiratory physiotherapists, the Association of Chartered Physiotherapists in Respiratory Care (ACPRC), by expression of interest. Using a snowball sampling method, physiotherapy participants were asked to suggest non-physiotherapy clinicians and patients who the study team could approach as potential participants for groups 2 and 3. Due to unforeseen scheduling issues, a pragmatic decision was made to complete groups 2 and 3 as individual semi-structured interviews, which enabled a deeper exploration of concepts. Recruitment aimed for 6-10 participants per group (17).

**Procedures**

Focus groups led by LG, supported by IE and FS, used a semi-structured topic guide (Appendix 1) to discuss terminology and assessment. The development of the guide was informed by published qualitative studies (9) working with our Public and Patient Involvement and Engagement (PPIE) group. It was used to guide both focus groups and interviews to maintain consistency between the interviewers. The aim was to gather a breadth of insight from physiotherapists, clinicians, and patients to ensure representation from all key stakeholders. The information gathered would be shared with the nominal group to inform direct discussions and consensus and to ensure the nominal group were offered a broad range of opinions of these areas.

**Analysis**

The focus group and interviews were conducted and recorded using an NHS Microsoft Teams licensed platform (©Microsoft 2024). Recordings were transcribed verbatim, verified for accuracy by LG, pseudonymized by LG and securely stored on a password-protected computer. LG became immersed in the data by reading and re-reading the scripts. Using the framework method, we took a combined approach to analysis, enabling themes to be developed both inductively from the accounts (experiences and views) of research participants and deductively from existing literature and interview topic guide (18). Having identified a thematic framework, codes were assigned to the themes and subthemes. The research team LG, FS, and IE met and created a matrix of themes/subthemes traceable to the transcripts and participants. A descriptive step was used to explore themes, categories, and typology, linking overarching excerpts of narratives back to the data. Themes and research participants were grouped into higher-level categories/typologies based on similarities and linkages mapped between them.

**Stage 2 – Nominal Group Technique (NGT)**

**Participants/recruitment**

An additional purposive sample of UK-based experienced respiratory physiotherapists were identified for the NGT, with support from ACPRC. The NGT is a consensus-building methodology derived from the aggregation of members’ views. The optimal number of participants in a group is 8–12 for reliability of the group view and manageability of discussions (19). We invited 11 national clinical experts with at least five years of experience treating patients with this condition to work towards a consensus (20, 21).

**Procedures**

The NGT is a structured method for group [thinking](https://asq.org/quality-resources/brainstorming) that encourages contributions from all participants and facilitates quick agreement and consensus (22). The NGT was held within a university setting led by AMR, experienced in this approach, with the support of the research team (LG, IE, HS, and FS). Instructions for the NGT exercise were given to the group via a presentation by LG before the commencement of the exercise. Participants consented to the study and had the opportunity to ask questions (Appendix 2 for NGT process).

***Question for consensus***

***Question 1: What is your preferred term for this condition?***

Each member of the group was given a list of terms used to describe this condition (Appendix 3-list of terms). The first list was informed by a review of search strategies from previous qualitative research and a systematic review (9, 23) (Appendix 4- search strategy). Participants were asked to consider terms independently for 10 minutes without discussion and rank them in order of preference. After this, a discussion was facilitated by the research team about the terms and their choices. The project lead (LG) provided a summary of the results from the focus groups and interviews to provide a broad reflection on the topics for consensus to use alongside the NGT group’s own knowledge and experience. The same list of terms was then given to each participant with additional terms added from the focus groups and discussions. The group was asked to re-rank the terms (Appendix 3-list of terms). These results were shared with the group, and further discussion was facilitated. The revised list was presented, agreed terms were re-ranked, and consensus was defined as having been met when >70% agreement was reached (24).

***Question 2: What are the most important assessment components to be included in all assessments (subjective assessments, objective assessments, outcome measures)?***

Participants were provided with a list of assessment components (Appendix 5), which included approaches described in published qualitative research (9) as well as from the information gathered from focus groups and semi-structured interviews. The group was asked to categorise the approaches as 'core' or 'optional,' and invited to suggest additional components. ‘Core components’ were those deemed necessary for all assessments and ‘optional components’ those that may be used by more experienced clinicians or in specific circumstances. Facilitated discussions ensued, followed by a summary of findings from stage 1 (focus groups and interviews). A revised list was generated (Appendix 5), incorporating new components discussed in the first stage. Further discussions were facilitated until a broad consensus was reached. These discussions informed the development of an assessment guidance document, which was reviewed electronically by the group. Content Validity Index (CVI) (25) was utilised to assess the guide's validity. The CVI was calculated by dividing the number of experts endorsing that section by the number of experts (Appendix 6). Each part of the guide was scored out of four, and a score of more than three indicated endorsement by the experts.

**Analysis**

NGT recordings were transcribed verbatim and reviewed to confirm the accuracy of the consensus discussions and rankings. These data were used alongside the rating and ranking outcomes from both the questions within the NGT. A rigorous interpretative approach to the analysis of the qualitative data was maintained throughout between researchers LG, IE, FS, and AMR. The research team are experienced in qualitative methods (LG/IE/AMR). Ethical approval for this study was received from the Health Research Authority Research Ethics Committee (REC) number 23/WA/0095 IRAS study ID 315897.

**RESULTS**

**Stage 1**

One focus group (n=10) and 14 interviews were completed. See Table 1 for participant characteristics. Code descriptions summarising the focus groups are shown in Table 2 and further detail of the framework matrix is shown in Appendix 7.

**<Insert Table 1: Participant characteristics>**

**<insert Table 1: Description of codes>**

**Stage 2 Nominal Group**

Question 1 Consensus on terminology

Discussions emphasised the need for a label to aid clinical consistency, acknowledging the interchangeable use of terms based on context. ‘Breathing pattern disorder’ and ‘dysfunctional breathing’ were deemed most clinically relevant, with the former favoured by 73%. Both terms were deemed to be accurate but there was a recognition that patients dislike ‘dysfunctional’. Summary of ranking of terms in rounds 1-3 are shown in appendix 8.

Question 2 Consensus on assessment

Discussion included the following areas: the definition of core assessments, minimum expectations of skill levels, and important components of assessment to enable a physiotherapist-led diagnosis of this condition. Participants expressed discomfort in omitting certain components entirely and sought to ensure that specific items were screened as part of the core assessment, though not necessarily fully assessed. This discomfort can be seen within the results of the two NG rounds where individuals found it difficult placing some components as core or optional (please see appendix 9 for full results). Therefore, a guide was developed and informed by these results. The CVI Index on the first review (by the NG) of the document was 0.30 with 3 out of 11 clinicians endorsing the guide and, after edits, it increased to 0.8 with 9 out of 11 clinicians endorsing the guide. The nominal group was encouraged to provide comments at each review (Appendix 10, comments on the assessment guide drafts), comments were detailed including changes to wording, edits to the detail of certain components and consistency of terminology to improve overall clarity. A review of transcribed discussions afforded another level of quality and consistency checking. A summary copy of the guide is shown in figure 1 (the full guide can be accessed online).

**<Insert Figure 1-Summary of the guidance document for the assessment>**

**DISCUSSION**

This is the first study to develop a consensus with physiotherapists’ preferred terminology emerging as breathing pattern disorder. Further discussions determined the acronym BrPD, include a lowercase ‘r’ (not to be spoken), providing differentiation from other similar acronyms, e.g. borderline personality disorder. This consensus was reached by a group of highly specialised expert physiotherapists and reflects terminology that can be adopted by physiotherapy services. This research also adds to the literature on assessment and provides a clear and usable guide for the assessment of BPrD within physiotherapy services. Importantly, we included insights from patients who are often under-represented in BrPD research.

**Significance of findings: Nomenclature**

Previous research has suggested a consensus term would be important to clinicians and necessary to improve recognition of this condition (9, 26). By using BrPD as the consistent term, physiotherapists can provide patients with a clear, dependable term for their symptoms, whilst physiotherapy services can align with the same terminology. This may provide a platform to encourage others to unify terminology. Consistent terminology may confer clinical credibility especially for those who feel their condition is under-recognised or dismissed. It also offers a starting point to enables systematic analysis, leading to a more rigorous synthesis of the literature and strengthening research,

BrPD is not yet classified in the UK, lacking a Health Resource Group (HRG) code to reflect the increasing physiotherapy interventions. HRG codes group patient activities for payment by results through use of procedure and diagnosis codes. The absence of a code may indicate poor recognition and missed clinical care opportunities. This consensus offers information to apply a usable code for BrPD, aiding in developing management pathways and better understanding treatment needs (27). An application (with support from the ACPRC and British Thoracic Society) has been submitted requesting an HRG code for BrPD.

Patient preferences for terminology was an important component to consider and “dysfunctional” was unpopular patients participating in this study. Focus group discussions indicated that patients felt that this term implied blame and diminished the importance of their symptoms and lived experiences. Many physiotherapists and clinicians suggested the term dysfunctional can make individuals feel they are doing something wrong, due in part to the dualism it fosters, (i.e. psychological explanation for symptoms is assumed) causing patient distress due to a lack of validated for the physical symptoms they are experiencing.

**Significance of findings: Assessment**

The assessment guide has utility in supporting high-quality, repeatable clinical assessments. This creates a benchmark of what should be expected from a physiotherapy assessment and provides a credible foundation for further validation including physiotherapy education, clinical skill development and service evaluation. The assessment guide builds upon previous research (9) accounting for the knowledge and experience of the assessor. The guide is underpinned by detailed discussion and consensus between experts, including experienced clinicians with a range of expertise, representation from clinical expert groups and academics with experience in undergraduate and postgraduate training, and importantly informed by patients.

Further work informed by this assessment guide may provide the opportunity to develop the minimum skill level for physiotherapists undertaking BrPD assessments, as well as demonstrating the extensive assessment skills required with more experience.

This study provides valuable insights into the role of breathing pattern disorders (BrPD) and helps to highlight their importance within the broader context of breathlessness pathways. Assessing BrPD may be important in all cases of breathlessness including patients experiencing chronic or complex breathlessness who remain symptomatic despite optimised treatments(28). Identifying patients with BrPD is a clinical priority, as they may benefit from therapeutic interventions aimed at improving breathing patterns and overall function. The findings emphasise the importance of incorporating specialised expertise in breathing pattern assessment within services managing these patient populations. The assessment guide also recognises the importance of a holistic, biopsychosocial approach(29) and includes additional elements essential in assessing breathing patterns i.e. psychological elements, upper airway, and performance. - all these factors are important to consider when developing the right therapeutic pathway for patients (30).

**Methodological considerations**

There are many methodologies suitable for gaining consensus including expert task force groups (31), consensus statements (32) and the Delphi technique (33). This research used the NGT, which represents a robust option for building consensus. It enables individuals to articulate and prioritise preferences independently in response to discussions and ensures the equal participation of all participants (21). Moreover, it provides prompt results for the research team and is more suited to discussion-based decision-making where it is important to generate a solution and evaluate the decision (34). It also capitalises on the expertise of the clinicians and enables them to engage in meaningful research due to its rapid format. Importantly, we included insights from patients with BrPD who are rarely represented in research.

The inclusion of focus groups and interviews before the nominal group was to ensure that the NG members had a balanced background of opinions to consider rather than only depending on their own views. The physiotherapy focus group attempted to widen the scope of inquiry established in the study published in 2023 (9) as well as ensure there had not been a change of opinion since COVID-19, where the interest in breathing pattern assessment as part of post-COVID assessment peaked. Additionally, the semi-structured interviews completed with other clinicians and patients added additional voices of these groups for the first time.

**Limitations**

This study was conducted with clinicians and patients from the UK but may be generalisable given the insights gained. International discussion on nomenclature and assessment has been instigated and this methodology would be worth repeating more broadly in the international community.

We endeavoured to select a wide range of physiotherapists within the focus groups and nominal groups. Those interested in taking part may have had a preferred nomenclature. We acknowledge the lack of gender diversity within our physiotherapy focus groups (all female), however we achieved more balance within the NG with 70% of participants being female, broadly in line with the female predominance of physiotherapists within respiratory services. We also acknowledge that other professional groups (including physiologists) were not included in this study based on the premise that BrPD is, in contemporary practice, mostly a physiotherapy diagnosis.

Whilst this study describes a preference for the term BrPD, robust studies evaluating possible mechanisms contributing to BrPD are lacking. There is a causality dilemma here – should the terminology be defined before or after the mechanistic studies. We hypothesise that mechanistic studies need the terminology to define study populations. We hope that by adopting consistent terminology within physiotherapy services, research will progress.

In conclusion, this paper presents a physiotherapy-specific consensus on the nomenclature and assessment of breathing pattern disorder (BrPD) within the UK, providing a starting point of a consistent framework for physiotherapy clinical practice. Furthermore, it underscores the broader importance of standardised terminology and assessment approaches in the field. A key contribution of this work is its recognition of the value of a clear label, offering patients validation of their symptoms and a better understanding of their condition when they are seen in physiotherapy services. BrPD, as a clinically acceptable and descriptive term, is not only beneficial for patient care but also holds the potential to advance both clinical practice and research in this area.

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**ACKNOWLEDGMENTS**

This study was supported by the National Institute of Health and Social Care (NIHR) research through the funding of a fellowship of the principal investigator (LG) and the Editorial Board of the Association of Chartered Physiotherapists in Respiratory Care (ACPRC) who funded the expenses for the NGT.

With thanks to the focus group, interview, and nominal group participants and the ACPRC Editorial Board for supporting this work. The research group gratefully acknowledges the PPIE group at Royal Brompton Hospitals for their contributions to the design of the study, along with patients with BrPD who contributed to interviews.

**STATEMENT OF CONTRIBUTIONS**

LG, IE, and FS all contributed to the design and development of the project protocol. LG completed recruitment, data collection and analysis with support from IE and FS. AMR led the Nominal group with support from IE, FS and HS. LG wrote the manuscript with support from IE, FS, NH, AL, and CB. AMR and HS helped supervise LG with the project and supported with the final manuscript.