How Physicians in South India Recognize, Assess, and Manage People with Chronic Breathlessness Syndrome: A Thematic Analysis

Matilda MM Barnes-Harris, Sunitha Daniel[1,2], Chitra Venkateswaran[3], Ann Hutchinson[2], Miriam J Johnson[2]

Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, [2]Wolfson Palliative Care Research Centre, University of Hull, Hull, HU6 7RX, UK, [1]Department of Palliative Medicine, General Hospital Ernakulam, Kochi, [3]Department of Psychiatry, Believers Church Medical College, Thiruvalla, Kerala, India

Abstract

Objectives: Chronic breathlessness syndrome has been defined to help clinicians actively seek, and patients legitimately present with, persistent breathlessness, and to drive services and research. However, views from low- to middle-income countries were not included. We aimed to explore the views of hospital physicians regarding chronic breathlessness syndrome, its recognition and management. **Methods:** This was a secondary analysis of qualitative data collected during a service development project. Three focus groups of physicians caring for patients with chronic breathlessness in a single tertiary hospital in South India were conducted in English, audio-recorded, transcribed, and subjected to thematic analysis. **Results:** Fifteen physicians from oncology, palliative care, cardiology, and respiratory specialties participated. Three major themes (impact, invisibility, and purpose) were generated. Findings mirrored those in high-income countries. Chronic breathlessness, as defined, was seen as prevalent, with a major impact on patients, families, and physicians. Nonpalliative care physicians described therapeutic helplessness with poor awareness and/or ability to manage breathlessness accompanied by active avoidance. This helplessness, a perceived lack of assessment tools and lack of access to palliative care contributed to the "invisibility" of chronic breathlessness. Most participants agreed with the name of chronic breathlessness syndrome. All agreed that systematic identification would foster education regarding assessment and management and support service development and research. **Conclusions:** Chronic breathlessness syndrome is recognized in South India but, as in higher-income countries, risks being invisible due to the lack of awareness of therapeutic interventions. A named and defined syndrome was seen as a way to improve identification and management.

Keywords: Chronic breathlessness, dyspnea, India, qualitative, syndrome

INTRODUCTION

Chronic breathlessness is defined as disabling breathlessness that persists despite the optimum treatment of the underlying condition.[1] It is prevalent in common chronic cardio-respiratory conditions, especially in advanced disease.[2] The severity of breathlessness is recognized as a predictor of prognosis, contributes to the staging of disease, and helps guide management in chronic obstructive pulmonary disease (COPD),[3] but is rarely considered in other conditions, other than signposting for diagnosis.[4]

Despite its association with the increased use of health services[5,6] and serious burden for patients and their families,[7] chronic breathlessness is not routinely addressed by physicians[4,8] and is often accepted as inevitable.[7] Patients may not be asked about their breathlessness nor volunteer information about it until in crisis, delaying medical help.[9,10] Patients commonly appear comfortable at rest, adding to the "invisibility" of breathlessness. When they do present, some receive help, but others are frustrated by disease-focused approaches that neglect symptom management.[7,9,10]

Access this article online

Quick Response Code:

Website:
www.jpalliativecare.com

DOI:
10.4103/IJPC.IJPC_139_20

Address for correspondence: Dr. Matilda MM Barnes-Harris,
Wolfson Palliative Care Research Centre, Hull York Medical School,
University of Hull, Hull, HU6 7RX, UK.
E-mail: matilda.barnes-harris@nhs.net

Submitted: 18-May-20 **Accepted:** 01-Jul-20
Published: 17-Feb-21

How to cite this article: Barnes-Harris MM, Daniel S, Venkateswaran C, Hutchinson A, Johnson MJ. How physicians in South India recognize, assess, and manage people with chronic breathlessness syndrome: A thematic analysis. Indian J Palliat Care 2021;27:54-61.

There are evidence-based interventions to manage breathlessness, including pulmonary rehabilitation, breathlessness services, and self-management programs.[11,12] These complex approaches can be structured using the "breathing, thinking and functioning" model; sensory perception, affective domain, and the functional impact of breathlessness.[13] The clinician's role appears crucial; those responding to the symptom in their disease management help to maximize the patient's "Breathing Space" (living well with chronic breathlessness).[7] Despite this evidence base, many patients and physicians remain unaware of these options and services are patchy.

The aims of defining chronic breathlessness syndrome were to: (i) give physicians an entity to seek, (ii) give patients legitimacy in bringing their symptoms to clinical attention, and (iii) drive service development and research.[1] However, the consensus process – albeit international-included resource-rich nations only.[1] Chronic breathlessness is particularly pertinent to resource-poor countries where urban air pollution, high smoking rates, and practices such as open fire cooking[14] contribute to a high prevalence of lung disease.[15] Respiratory disease occurs in approximately 7% of India's adult population,[14,16] and cardiovascular disease occurs in 54.5 million;[17] this translates into large absolute numbers given that 18% of the world's population lives in India,[18] and breathlessness is, therefore, likely to be a serious concern. Many breathlessness interventions are inexpensive, such as the hand-held fan[16] or breathing techniques training,[19] and thus potentially widely available.[20]

Our aim was to explore the views of physicians caring for people with conditions causing chronic breathlessness in South India on chronic breathlessness syndrome as part of a service development project to improve the management of these patients.

METHODS

This is a secondary analysis of anonymized focus group data collected as part of a service improvement project for which institutional approval was given at the hospital where the project was conducted. Participants gave written informed consent for audio-recording, anonymized transcription, use of quotes, and use of data in future research. Further approval was not required.

Participants were physicians (respiratory, cardiology, oncology, and palliative care) caring for people with conditions causing chronic breathlessness from a single tertiary care institution in South India. Although sampling was mainly by convenience, a range of clinical specialties was purposively sought. All the physicians working in the chosen specialty were approached in person by the researcher (SD), who is trained in qualitative methods, and were told about the purpose of the service development project, this was then followed up by E-mail communication about the time and date. Interested participants responded, and the groups were organized according to their availability. There were no drop-outs after the study commenced. A topic guide regarding recognition of chronic breathlessness as a clinical entity, its impact and possible management and views regarding the name and definition and its relevance to practice in their clinical setting was developed informed by published literature and in discussion with MJ.

Data collection

Three semi-structured focus groups of approximately 45 min were held at the institution for participants' convenience. Groups were facilitated by SD using the topic guide. The groups were conducted in English, recorded, transcribed and each focus group had an independent observer taking field notes as necessary. Transcripts were checked for accuracy by SD Transcripts were not reviewed by participants, but the facilitator summarized the group discussion at the end of each for the purposes of the service development.

Methodological approach and data analysis

A mixed inductive-deductive approach from a pragmatic perspective was used given the project's purpose in guiding service development and thus the need to be relevant to daily clinical practice.[21] Focus groups were used as a way to explore the degree of consensus.[22] Thematic analysis was chosen due to the focused nature of the enquiry. We used a combination of reflexive and code-book approach;[23] (i) familiarization with the data by reading/re-reading the transcripts, (ii) MJ and MBH independently line-by-line coded the transcripts to agree a codebook, (iii) MBH then coded the whole dataset, (iv) MBH and MJ grouped codes into initial themes taking the whole dataset into account, and (v) MBH, MJ and SD agreed final major themes with specific names and definitions. As the data were originally collected as part of a service development project, no theoretical framework was used to inform the study design; however, the findings are discussed using the lenses of the "Breathing Space" concept[7] and theory of "diagnostic overshadowing."[24] Similarly, in this secondary data analysis, the sample size was not informed by data saturation.

Research ethics approval

This is a secondary analysis of anonymized focus group data collected as part of a service improvement project for which institutional approval was given at the hospital where the project was conducted. Participants gave written informed consent for audio-recording, anonymized transcription, use of quotes, and use of data in future research. Further approval was not required.

RESULTS

Participants

Fifteen physicians participated (median age 42, range 32–55 years; 4 women; median experience 12 years, range 5–22 years) representing cardiology, respiratory medicine, general medicine, critical care, palliative medicine, and oncology (medical, clinical, and hemato-oncology) [Table 1]. As some specialties were represented by one clinician only, the further breakdown is not given to preserve anonymity.

Findings

Three major themes and 12 subthemes were generated from the data [Table 2]. The major themes were: impact, invisibility, and purpose. These are reported below.

Theme 1: Impact

The impact and suffering caused by breathlessness came across strongly in all of the focus groups: the severity and widespread distress caused to patients, their families and to the physicians themselves. One poignant comment summarized the overall feeling, "everybody is in despair" (Physician 2; Group 2).

All physicians agreed that they often see patients suffering for many months to years with "permanent" (Physician 2 Group 1) chronic breathlessness caused by a range of medical problems.

"It involves sometimes some underlying pulmonary issues, maybe some upper respiratory infective symptoms, things like that, increased secretions and lower respiratory issues as well, just due to the mechanical difficulties of breathing with large tumors in your lungs" (Physician 1; Group 2).

They acknowledged that it affected physical, practical, and psychological domains of life:

"They can't even go to the loo, that's when is becomes a distress, because there's the absolute basic need that you need to do and this is something that your patient is not able to do" (Physician 3; Group 1).

"There is a vicious cycle between breathlessness and anxiety" (Physician 5; Group 3).

Not only is it a debilitating symptom for patients, but it also affects family and friends.

"Its very difficult for the bystanders also who are along with them to cope with the stress" (Physician 4; Group 1).

Chronic breathlessness was challenging to physicians themselves. One clinician even described these patients suffering from chronic breathlessness as a "pain in our neck" (Doctor 3, Group 1). The impact of chronic breathlessness on patients and families led to difficult consultations aggravated by a disease-directed belief that there was nothing that could be done to help.

"Seeing the patients' discomfort, it is difficult for us" (Physician 1; Group 1).

"We often find it difficult to convince the patient and as well as convince the family that the symptoms are going to persist and we may have to live with that" (Physician 3; Group 2).

However, some physicians felt less pressure to "cure always" reporting that:

"Many patients do think that this illness is not going to be cured and they want, relief rather than cure" (Physician 2; Group 2).

Theme 2: Invisibility

Underestimation and therapeutic nihilism

Initially, the predominantly expressed view in the groups was that chronic breathlessness was an issue only at the end of life, seen only during the last days and weeks.

Table 1: Clinician characteristics

	Number of physicians, n=15
Median clinician age (years), range	43 (32-55)
Number female, *n*	4
Specialty, *n*	
Cardiology, pulmonology and critical care	4
Palliative medicine	2
Oncology	6
General medicine	3
Median years of experience (range)	12 (4-22)

Table 2: Major and sub-themes with their definitions

Theme	Sub-theme	Definition
Impact	Impact on daily life	Effect of breathlessness on the lives of patients', their families and the physicians caring for them Examples of effects on patients' lives
	Common	Breathlessness is perceived as a common issue
	Trajectory	Progression of disease prognosis
	Family	Effects on family, carers and those close to patient
	Physicians find it difficult	Effect of patients with breathlessness on physicians personally
Invisibility	Presentation	The unseen suffering of those with breathlessness Multifactorial causes and how patients present to healthcare
	Assessment	How breathlessness is identified, measured and assessed by physicians
	Management	Treatment for chronic breathlessness, covers advice given to patients and hopelessness/ "nothing can be done" attitude and barriers towards accessing palliative care
	Difference in patient's and physician's wishes	Patients' and physicians' aims of care may differ
Purpose	Definition	If, why and how chronic breathlessness syndrome should be defined Of chronic breathlessness; disabling breathlessness despite optimal treatment of underlying condition.
	Consequences	Includes prevention of chronic breathlessness, improving management, services and research purposes
	Pain	Comparison to chronic pain syndrome or pain as a symptom

"If they're feeling this breathlessness and it may be a sign of they're going to die within weeks or something like that" (Physician 1; Group 1).

Although this view changed during discussion, it illustrated a pattern of under-recognition in daily practice that their patients are experiencing chronic breathlessness for many months or years.

"We all tend to underestimate the presence of breathlessness and the fact that breathlessness is a symptom, like pain, which is dependent on the individual" (Physician 2; Group 3).

This was felt to be partly due to the difficulties in measuring a subjective experience. They agreed that their assessment of breathlessness was inconsistent and inadequate and also understood that objective measures, such as blood oxygen saturation, were poor markers of an individual's experience of breathlessness. There was the recognition that the wider impacts of breathlessness might be measured, such as with distress scales, and that a patient-centered, subjective approach was necessary.

However, some physicians recognized their own discomfort and lack of symptom-related focus, and felt this was made more difficult by the complex nature of the breathlessness:

"We don't really focus on managing the symptoms, do we?" (Physician 2; Group 3).

"It is very difficult because it is really multifactorial" (Physician 1; Group 2).

All groups agreed that patients rarely presented with breathlessness itself and were remarkably uncomplaining even if distress was visible. Difficulties were often managed by the patient by avoiding exertion:

"You can see the patient is in distress, but (patient will say …) I'm OK, so if you ask the patient (…what is the distress score, they say) fine because I am OK, I'm, I'm able to do my normal duty, normal work, and I'm not doing any exertional work" (Physician 6; Group 1).

If patients volunteered a symptom, it was usually pain and only mentioned breathlessness if it had become significantly more severe. This delay was compounded by physicians' poor confidence in identifying and managing breathlessness.

"If they come and see you in the (outpatient department), if... they might not for, come up and say that it's breathlessness, they may come and say they're in pain" (Physician 2; Group 3).

"We are very sensitive to a person's pain, but we don't understand dyspnoea" (Physician 2; Group 3).

Many physicians felt that managing breathlessness itself was not their responsibility. The physicians' role was to treat the disease only with the expectation that patients self-manage breathlessness as an inevitable feature of their disease and they (physicians) had no further responsibility.

"If they're able to live with their disease that's how people will live, and they're adapted to it that's perfectly sufficient" (Physician 3; Group 1).

However, others recognized that, "most patients will find it difficult to cope" (Physician 3; Group 2) and there may be different expectations between the physicians and the patients.

"For them (the patients) it is a major concern, and for them to come to the hospital more for breathlessness part than for the cancer part, but at the end of 5 years we tell them you're cured, go away, don't come back to us" (Physician 3; Group 1).

Even if they did want to help, and even if the patients did present with breathlessness, many physicians felt that there was nothing they could do.

"There are serious concerns about how we deal with patients with breathlessness, but it is not always related to something that is solvable" (Physician 3; Group 1).

This feeling of nihilism was further aggravated by a sense of guilt – particularly amongst the oncologists who saw breathlessness sometimes as a consequence of their cancer treatments.

"Where you've probably cured the patient of the breast cancer or of the lung cancer, but you've ended up having a problem like this (chronic breathlessness)" (Physician 3; Group 1).

Barriers to breathlessness management

Some participants were aware that a multidisciplinary holistic approach, including nonpharmacological methods, may be helpful. However, this was only mentioned by palliative physicians and one general physician, who also emphasized this, was best practice, though rarely accessed, and then only when other options had been exhausted.

"And where we don't have too much of medicine, medical management … maybe by some kind of therapy and some kind of psycho, psychological assessment; and that actually can help to reduce the symptoms where we don't have too much of options left" (Physician 6; Group 1).

Most had a poor understanding of breathlessness interventions, especially nonpharmacological approaches, other than noninvasive ventilation or surgery, although there were mixed views on morphine as having a benefit for breathlessness as well as pain.

"We feel that these patients will definitely improve with morphine, and I have a list of patients whom actually morphine was better" (Physician 6; Group 3).

Palliative care was viewed as a way to help, but there were barriers to timely access. Consistent with the initial response that chronic breathlessness was only a feature of very end-stage disease, referral to palliative care services was late in the disease trajectory. Poor integration between palliative care and other specialties – particularly noncancer - was seen to restrict earlier access to breathlessness management.

"A harmonious interaction between the palliative group and (other medical specialties)… it doesn't happen" (Physician 1; Group 3).

One clinician mentioned "keep the palliative patient comfortable" is often forgotten and should be remembered as part of the management plan for chronic breathlessness.

"There should be an integrated approach to management of dyspnoea, like I'm not just saying palliative care but there should be an integrated approach, like just not seeing that as just a physical symptom and giving medication"(Physician 5; Group 3).

The net result of physicians' helplessness in the face of such a symptom, in combination with not "seeing it," or at least not seeing it as their responsibility, appeared to be an attempt to protect themselves against their patients' distress, albeit only partially successfully.

"These patients are already breathless patients, so we actually we will try to ignore them whether the breathlessness is increasing or decreasing" (Physician 2; Group 1).

"They're going to die in say 6 weeks I'm probably not concerned because if I am able to give them some TLC ('tender loving care') else then probably we are able to keep them quiet and calm or probably sedated, or give some terminal treatment so that he passes off" (Physician 3; Group 1).

Theme 3: Purpose of the syndrome

Definition and name

The definition of chronic breathlessness was immediately recognized by the participants, agreeing that "this is a very common problem" and "it's something we deal with quite often" (Physician 1; Group 2).

"Many of them (patients) tell you that they are still breathless in spite of your medications, in spite of your measures, they are still breathless" (Doctor 3; Group 3).

"This is a very common problem we see in end of life care patients specifically. And despite oftentimes maximal pharmacologic therapy and trying to, trying to adjust any other underlying causes of breathlessness, we see a lot of air hunger in our patients" (Physician 1; Group 2).

As mentioned above, during the course of the discussion, the initial feeling that chronic breathlessness only occurred in the last stages of life modified to a recognition that patients could suffer for many months to years with "permanent" chronic breathlessness, worsening over time with accumulated insults.

"This (chronic breathlessness) is a very common problem we see in the end of care patients specifically, but you do see it in other patients as well" (Physician 1; Group 2).

Most participants agreed with the name "chronic breathlessness syndrome," although some suggested "distressing breathlessness syndrome." All groups agreed that the length of time suffering from symptoms did not require defining. They felt it was more important to identify the presence of breathlessness, thereby increasing patient and family access to breathlessness management interventions systematically.

Consequences

All agreed that delineating chronic breathlessness as a distinct syndrome would encourage physicians to learn skills in breathlessness management so they could offer support both earlier in advanced disease and as part of the end of life care. Most physicians, apart from the palliative care physicians and an oncologist, while they all described dealing with patients with chronic breathlessness, recognized that they did not know how to manage such patients:

"… we will find it difficult to treat with any particular drug alone, at that point of time, I think we are to go with more of a palliative" (Physician 5; Group 1).

"A multi-factorial, multi-system approach is required" (Physician 2; Group 2).

An additional benefit of naming and defining chronic breathlessness syndrome to those published previously was the idea that if chronic breathlessness was clearly recognized, then more effort would be taken to prevent it, particularly during cancer treatment. It would also stimulate more research into the causes and management:

"Why not try to do something like that; categorize the group, find out those people who are expected to have a higher chance of having this kind of symptom and upfront treat them properly, up, upfront plan them properly, explain them that this is going to happen and mentally also and medically also, prepare them so that they don't end up in this kind of situation. That will be the ideal thing" (Physician 6; Group 1).

"We are talking about that group of patients where we cannot do anything more, so that [defining the group] will open up future research" (Physician 2; Group 1).

Comparison with pain

All three groups related the discussion to chronic pain syndrome and felt this was an illustration of what could happen if chronic breathlessness syndrome was recognized with respect to increasing physicians' symptom management skills, service development, and further research.

DISCUSSION

The widespread impact of chronic breathlessness on patients and their families, consistent with other research,[7] was described by physicians but accepted as part of the disease process. There was a pervading feeling of helplessness, aggravated by a perceived lack of assessment tools and poor awareness of therapeutic interventions. The combination of therapeutic nihilism and clinician distress at witnessing suffering led to active avoidance of the symptom contributing to its "invisibility," focussing on the underlying disease only. However, a multidisciplinary, holistic approach was recognized by some as best practice and the use of morphine was advocated.

The definition and syndromic nature of breathlessness under these circumstances were unanimously agreed. Most were happy with the name of chronic breathlessness syndrome. All agreed that the definition of this group of patients would help identification, improve education, focus monitoring, and drive services and research in line with the aims of the original consensus paper.[1] Breathing signals life; our first and last breaths the world over. Therefore, unsurprisingly, our findings largely mirrored those from high-income countries.

Consistent with the concept of breathing space,[7] physicians in this study described adaptation by some patients. However, most physicians could not see their role in helping patients gain maximum breathing space; instead tending to use disease-directed treatment and viewing breathlessness as inevitable. Thus, the underlying diagnosis appears to "over-shadow" the symptom of breathlessness. Disregarding a symptom by assuming it can be explained by a previously diagnosed condition has been described in the field of mental health: "diagnostic overshadowing."[24] This "ignoring" of chronic breathlessness is also seen in high-income countries.[8,4]

The evidence-base behind non-pharmacological and pharmacological interventions for breathlessness itself-many of which are possible in low or middle-income countries[16,19] - is still not well-known in clinical practice. This, coupled with poor access to services that could help provide such interventions, understandably pulls the physicians to the disease rather than the symptom. A novel finding from this dataset is the explicit expression that physicians find it personally distressing to the extent that some actively avoid, ignore or even resent the patient's symptom. In our study, holistic and multidisciplinary approaches were mentioned as breathlessness interventions by only one nonpalliative care clinician.

Breathlessness may also be "invisible" due to the insidious onset and stigma of smoking-related diseases.[25] The impact of breathlessness on one's mobility and ability to socialize often "hides" patients from view. Embarrassment has been reported in many suffering with breathlessness, leading to a cycle of avoiding social situations further decreasing mobility and function.[25] Cultural variations about symptom presentation have also been described for pain management in advanced disease,[26] although inter-individual differences still result in different distresses in advanced disease.[27] The health-care system in India may also impact on the acceptability of breathlessness treatments; palliative care is free but is still only systematically available (as judged by numbers of physicians qualified to prescribe morphine completing the basic palliative care course required) to approximately 1%–2% of the population.[28] There may be a poor uptake to nonpharmacological management as the costs of breathlessness management and other rehabilitative services will be expensive with regard to staff time. In addition, there may be a perception that nondrug measures are less effective, as seen in higher-income countries.[29] Finally, a fatalistic attitude to disease, as seen in South Asians with diabetes, may prevent engagement with self-management.[30]

Our participants felt that pain was seen by patients as a more legitimate symptom to present with than breathlessness,-an example of testimonial injustice,[7,31] as physicians often do not recognize chronic breathlessness as a trigger for additional management.[4] A further novel finding in our study was the guilt experienced by some oncologists who saw the patient's chronic breathlessness as a potentially avoidable consequence of cancer treatment. This added to the previously expressed purposes of defining a chronic breathlessness syndrome[1] – that it could stimulate research into prevention as well as management.

Inconsistent and inadequate assessment of chronic breathlessness[32] was reported by this group of physicians, along with a perception that there were few useful clinical measures of breathlessness despite a plethora of breathlessness measurement tools with some usable in clinical practice even in advanced disease.[33] This is consistent with a recent systematic review exploring clinical use of breathlessness measures.[34] Included papers were those showing clinical use of measures to identify and assess breathlessness in primary care, secondary care and palliative care settings from around the world, including nine studies from Asia. Few studies were from primary care, and in the secondary care setting, most studies came from respiratory, for example, pulmonary rehabilitation services, with very few from oncology.

Chronic pain syndrome[35] is an example of how defining a syndrome can lead to better recognition, services, and research. A randomized trial of a clinical scenario of an optimally managed patient with COPD with either severe pain or severe chronic breathlessness showed that pain was more likely to be recognized and managed than breathlessness.[4] Since the definition of chronic breathlessness syndrome was published, Carette *et al*. published the findings of their COPD cohort study showing a chronic breathlessness syndrome (disabling [modified Medical Research Council scale 3 or 4 breathlessness] on optimal inhaled therapy) prevalence of 50%.[36] Few of these patients had evidence that their chronic breathlessness was being managed, consistent with our findings. The impact of changed clinical attitudes when a syndrome gains an evidenced-based standard of care, along with sufficient resources, can be seen from the field of stroke medicine. For example, strokes used to be regarded with, not only nihilism in terms of what *could* be done, but also nihilism in terms of what *should* be done ("a stroke of God's hands").[37,38]

Strengths and limitations

This focus group provided a dynamic interaction and allowed individuals' views to modify and consensus to emerge in each group. The semi-structured guide allowed discussion of all topics by all groups and also allowed flexibility. Despite all participants being physicians (and therefore on a similar "hierarchical rung," there is still a risk that focus groups can be dominated by particular voices. However, our data showed contributions from all participants, with varied views, and evidence that members were able to successfully challenge others within the group. MJ's involvement with defining chronic breathlessness syndrome is recognized as a bias; however, the study was conceived by SD and CV (independent from the original definition process), and data collection was facilitated by SD only. We also recognize that patients and their families were not included in this study, and it is important that the views of those with personal experience of chronic breathlessness are sought worldwide.

This study represents a small sample of physicians from one hospital in one state, in one resource-poor country; therefore, it cannot be representative of all resource-poor countries. However, the similarities with previous work in a range of countries are striking.

Implications for clinical practice and research

Physicians need to be educated and skilled in the management of chronic breathlessness to facilitate identification in routine practice. Simple clinical measurement tools may help, but the knowledge and provision of breathlessness services would help reverse the vicious cycle of therapeutic nihilism in feeding the invisibility of chronic breathlessness and diagnostic overshadowing by the underlying disease.

Systematic enquiry by physicians may also encourage patients to volunteer this legitimate symptom at the clinic; a key component of the "Breathing Space" concept. Emergency presentation for breathlessness should not only result in the management of the acute presentation but also result in the identification of acute-on-chronic breathlessness and therefore trigger a review of the management of chronic breathlessness.[39] Future work must seek views in other resource-poor countries and the opinion of those with personal experience; patients and their families.

CONCLUSIONS

Chronic breathlessness syndrome is recognized as a significant issue in clinical practice in South India with widespread effects for patients, families, and their physicians. Helplessness and therapeutic nihilism contribute to diagnostic overshadowing by the underlying disease, with few physicians recognizing their role in helping patients manage this disabling symptom. Defining chronic breathlessness syndrome was seen as a good way to stimulate education, training, and research in breathlessness management and better integration with palliative care services, thereby leading to systematic identification and improved care for patients. This is likely to improve patient's "Breathing Space" through clinician acknowledgment of chronic breathlessness and increased understanding of its management, encouraging patients to present the debilitating symptom for assessment and appropriate management.

Acknowledgments

We would like to thank the participants for their honest and insightful contributions.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

REFERENCES

1. Johnson MJ, Yorke J, Hansen-Flaschen J, Lansing R, Ekström M, Similowski T, *et al*. Towards an expert consensus to delineate a clinical syndrome of chronic breathlessness. Eur Respir J 2017;49:1602277.
2. Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. J Pain Symptom Manage 2006;31:58-69.
3. Singh D, Agusti A, Anzueto A, Barnes PJ, Bourbeau J, Celli BR, *et al*. Global strategy for the diagnosis, management, and prevention of chronic obstructive lung disease: The GOLD science committee report 2019. Eur Respir J 2019;53:1900164.
4. Ahmadi Z, Sandberg J, Shannon-Honson A, Vandersman Z, Currow DC, Ekström M. Is chronic breathlessness less recognised and treated compared with chronic pain? A case-based randomised controlled trial. Eur Respir J 2018;52:1800887.
5. Currow DC, Clark K, Mitchell GK, Johnson MJ, Abernethy AP. Prospectively collected characteristics of adult patients, their consultations and outcomes as they report breathlessness when presenting to general practice in Australia. PLoS One 2013;8:e74814.
6. Hutchinson A, Pickering A, Williams P, Bland JM, Johnson MJ. Breathlessness and presentation to the emergency department: A survey and clinical record review. BMC Pulm Med 2017;17:53.
7. Hutchinson A, Barclay-Klingle N, Galvin K, Johnson MJ. Living with breathlessness: A systematic literature review and qualitative synthesis. Eur Respir J 2018;51:1701477.
8. Currow DC, Abernethy AP. Therapeutic nihilism: The next hurdle in improving the treatment of breathlessness. Curr Opin Support Palliat Care 2011;5:69-70.
9. Elbehairy AF, Quint JK, Rogers J, Laffan M, Polkey MI, Hopkinson NS. Patterns of breathlessness and associated consulting behaviour: Results of an online survey. Thorax 2019;74:814-7.
10. Gysels M, Higginson IJ. The experience of breathlessness: The social course of chronic obstructive pulmonary disease. J Pain Symptom Manage 2010;39:555-63.
11. McCarthy B, Casey D, Devane D, Murphy K, Murphy E, Lacasse Y. Pulmonary rehabilitation for chronic obstructive pulmonary disease. Cochrane Database Syst Rev 2015;2:CD003793.
12. 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 2019;74:270-81.
13. Spathis A, Booth S, Moffat C, Hurst R, Ryan R, Chin C, *et al*. The breathing, thinking, functioning clinical model: A proposal to facilitate evidence-based breathlessness management in chronic respiratory disease. NPJ Prim Care Respir Med 2017;27:27.
14. Siegel KR, Patel SA, Ali MK. Non-communicable diseases in South Asia: Contemporary perspectives. Br Med Bull 2014;111:31-44.
15. Salvi S, Kumar GA, Dhaliwal RS, Paulson K, Agrawal A, Koul PA, *et al*. The burden of chronic respiratory diseases and their heterogeneity across the states of India: The Global Burden of Disease Study 1990–2016. Lancet Glob Health 2018;27:27.
16. Swan F, Booth S. The role of airflow for the relief of chronic refractory breathlessness. Curr Opin Support Palliat Care 2015;9:206-11.
17. Abdul-Aziz AA, Desikan P, Prabhakaran D, Schroeder LF. Tackling the burden of cardiovascular diseases in India. Circ Cardiovasc Qual Outcomes 2019;12:e005195.
18. Dandona L, Dandona R, Kumar GA, Shukla DK, Paul VK, Balakrishnan K, *et al*. Nations within a nation: Variations in

epidemiological transition across the states of India, 1990–2016 in the Global Burden of Disease Study. Lancet 2017;390:2437-60.
19. Ekström M, Bajwah S, Bland JM, Currow DC, Hussain J, Johnson MJ. One evidence base; three stories: Do opioids relieve chronic breathlessness? Thorax 2018;73:88-90.
20. Leng ME, Daniel S, Munday D. Respiratory problems in low-resource settings. Curr Opin Support Palliat Care 2017;11:174-8.
21. Morgan DL. Paradigms lost and pragmatism regained: Methodological implications of combining qualitative and quantitative methods. J Mix Methods Res 2007;1:48-76.
22. Morgan DL, Krueger RA. When to use focus groups and why. In: Successful Focus Groups: Advancing the State of the Art. Thousand Oaks, CA: SAGE Publications, Inc.; 1993.
23. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:77-101.
24. Reiss S, Levitan GW, Szyszko J. Emotional disturbance and mental retardation: Diagnostic overshadowing. Am J Ment Defic 1982;86:567-74.
25. Gysels M, Higginson IJ. Access to services for patients with chronic obstructive pulmonary disease: The invisibility of breathlessness. J Pain Symptom Manage 2008;36:451-60.
26. Siriwardena AN, Clark DH. End-of-life care for ethnic minority groups. Clin Cornerstone 2004;6:43-8.
27. Lunn JS. Spiritual care in a multi-religious context. J Pain Palliat Care Pharmacother 2003;17:153-66.
28. Rajagopal MR. The current status of palliative care in India. Cancer Control 2015.
29. Becker WC, Dorflinger L, Edmond SN, Islam L, Heapy AA, Fraenkel L. Barriers and facilitators to use of non-pharmacological treatments in chronic pain. BMC Fam Pract 2017;18:41.
30. Patel NR, Chew-Graham C, Bundy C, Kennedy A, Blickem C, Reeves D. Illness beliefs and the sociocultural context of diabetes self-management in British South Asians: A mixed methods study. BMC Fam Pract 2015;16:58.
31. Fricker M. Epistemic Injustice: Power and the Ethics of Knowing. Oxford, England: Oxford University Press; 2007.
32. Johnson MJ, Currow DC, Booth S. Prevalence and assessment of breathlessness in the clinical setting. Expert Rev Respir Med 2014;8:151-61.
33. Bausewein C, Booth S, Higginson IJ. Measurement of dyspnoea in the clinical rather than the research setting. Curr Opin Support Palliat Care 2008;2:95-9.
34. Elliott-Button HL, Johnson MJ, Nwulu U, Clark J. Identification and assessment of breathlessness in clinical practice: A systematic review and narrative synthesis. J Pain Symptom Manage 2020;59:724-33.e19.
35. Treede RD, Rief W, Barke A, Aziz Q, Bennett MI, Benoliel R, *et al*. A classification of chronic pain for ICD-11. Pain 2015;156:1003-7.
36. Carette H, Zysman M, Morelot-Panzini C, Perrin J, Gomez E, Guillaumot A, *et al*. Prevalence and management of chronic breathlessness in COPD in a tertiary care center. BMC Pulm Med 2019;19:95.
37. Biller J, Love BB. Nihilism and stroke therapy. Stroke 1991;22:1105-7.
38. Schiller F. Concepts of stroke before and after Virchow. Med Hist 1970;14:115-31.
39. Hutchinson A, Johnson MJ, Currow D. Acute-on-chronic breathlessness: Recognition and response. J Pain Symptom Manage 2019;57:e4-5.