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## **Title**

“So, I try not to go...” Acute-on-chronic breathlessness and presentation to the emergency department: in-depth interviews with patients, carers and clinicians

## **Abstract**

**Context:** People with acute-on-chronic breathlessness due to cardiorespiratory conditions frequently present to the emergency department (ED) causing burden for the person concerned, their carers and emergency services.

**Objective:** To understand the reasons for ED presentation for acute-on-chronic breathlessness and how optimal care might avoid presentations.

**Methods:** Qualitative in-depth linked interviews were conducted as part of a mixed methods study. Transcripts of audio-recordings were subjected to thematic analysis. Consenting patients presenting to a single tertiary hospital ED with acute-on-chronic breathlessness able to be interviewed were eligible. Patient-participants (n=18) were purposively sampled for maximum variation. Patient-participant nominated carers (n=9) and clinicians (n=8) were recruited.

**Results:** Theme 1) “The context for the decision to present to the ED” is the experience of acute-on-chronic breathlessness, in which a person faces an existential crisis not knowing where the next breath is coming from, and previous help-seeking experiences. Theme 2) “Reasons for presentation”: some were reluctant to seek help until crisis when family carers were often involved in the decision to present. Others had previous poor experiences of help-seeking for breathlessness in the community and turned to the ED by default. Some had supportive primary clinicians and presented to the ED either on their clinician’s recommendation or because their clinician was unavailable.

**Conclusions:**

The decision to present to the ED is made in the context of serious crisis and previous experiences.

Discussion of the reason for presentation may enable better management of chronic breathlessness and reduce the need for future emergency presentation.

Key message:

This in-depth interview study shows the decision to present to the ED is made in serious crisis informed by previous experience. A primary care review of the reason for presentation and current management may improve care and reduce the need for future presentation.

Key words:

Running title: So, I try not to go...

## **Context and objective**

Chronic breathlessness is a common, disabling and frightening symptom of globally prevalent<sup>1</sup> cardiorespiratory conditions<sup>2-4</sup> persisting despite treatment of the underlying disease<sup>5</sup> and limiting quality of life.<sup>6</sup> Breathlessness crisis is defined as “a sustained and severe resting breathing discomfort...” Although defined in the context of advanced disease breathlessness crises may affect people intermittently over many years.<sup>7 8 9, 10 11</sup> Acute-on-chronic breathlessness: the experience of breathlessness crisis in addition to the burden of chronic breathlessness, is associated with repeated emergency presentation,<sup>12-18 19</sup> and hospital admission.<sup>20,</sup><sup>21</sup> However, a third of patients presenting due to acute-on-chronic breathlessness are discharged home from the ED.<sup>17, 20</sup>

Little is known about why patients with acute-on-chronic breathlessness make emergency presentations. The focus of this paper is on exploring the existential experience of acute-on-chronic breathlessness and how it leads to ED presentation from the perspectives of patients, their family carers and their clinicians.

## **Methods**

In-depth interviews were conducted as part of a mixed-methods study at a single tertiary hospital ED, which included a patient-reported breathlessness prevalence survey of 1,212 patient-participants (findings showed 20% of ED presentations by ambulance were due to breathlessness)<sup>20</sup> and a systematic literature review (in which the Breathing Space concept was developed).<sup>6</sup> Taking a phenomenological oriented approach, linked interviews<sup>22</sup> with patients, their family carer and a nominated clinician were used to gain different perspectives on and a rich understanding of the meaning of the experience of acute-on-chronic breathlessness and the decision to present. Institutional and ethical approvals (NHS National Research Ethics Service Committee South Central-Hampshire B-Ref: 13/SC/0543)

were obtained prior to interview. This study is reported according to COREQ criteria.<sup>23</sup>

A sample of potential interviewees was selected from survey participants presenting with breathlessness willing to be interviewed (n=100).<sup>20</sup> A sampling framework (gender, socioeconomic status, diagnosis, lived alone/not, smoking status, number of previous presentations) was used to purposively select for maximum variation. Each patient-participant could nominate a carer to approach for a joint interview but were interviewed alone if there was no carer. Carers were interviewed *with* patients to gain insight into the dynamic between them<sup>24</sup> and to understand how this may have affected the decision to present. Each patient-participant was asked to nominate a supportive clinician to be approached for interview. Eligible participants gave written informed consent and had sufficient use of English.

Interviews were conducted in patient-participants' homes and clinician-participants' workplaces by AH (independent of clinical team) between December 2013 and September 2014. Patient interviews were conducted within three weeks of presentation and the clinician interviews within sixteen weeks.

A patient/carers topic guide was derived from the literature and team expertise. Questions included sub-themes of the Breathing Space concept including effects of breathlessness, coping and response from clinicians. Additionally, there were questions on their experience of ED presentation and circumstances surrounding their decision to present. The clinicians' topic guide asked for their reflections on the above questions, their views of treating the patient-participant and the patient's healthcare usage and previous discussions about breathlessness management. Interviews were audio-recorded, transcribed verbatim by an independent transcriber and checked for accuracy by the interviewer. The data were managed using NVivo 10 (QSR International, Doncaster, Australia).

Thematic analysis<sup>25, 26</sup> was selected as a flexible method that could be underpinned by a phenomenological perspective and give a rich account of participants' experiences. The analysis involved i) immersion in the data, ii) sensitised by the concept of Breathing Space, a line-by-line production of descriptive labels (codes) that attended to the meaning of the data (two transcripts descriptively labelled by AH

and MJ independently), iii) clustering of descriptions around meanings that arose from the participants to provide themes, iv) the researchers reflected on each of these themes so that they attended to the deeper existential issues experienced by participants in addition to practicalities and contextual details and v) as part of the interpretative process each theme was reflected upon in the light of the whole data and sensitised by the Breathing Space concept. Thus, we used phenomenology as attunement to “an art of radical questioning” to understand the meaning of their experiences leading to ED presentation.<sup>27</sup>

## **Results**

Eighteen patient-participants aged 32 to 84, including eight women, were interviewed. Nine were interviewed with a carer-participant; six women (Table 1). Patient-participants had a range of conditions; six with more than one. The most common was chronic obstructive pulmonary disease (n = 14), followed by heart failure (n = 7) and cancer (n = 3). Eleven patient-participants nominated a clinician; eight participated, three were women. There were four family doctors, two respiratory physiotherapists and two palliative nurses. Interviews lasted 25 minutes to two hours.

### *Theme 1: The context for the decision to present to the ED*

#### *The burden of living with chronic breathlessness*

Living with chronic breathlessness involved burdensome physical, psychological, social and existential effects. These were felt by patients and their family carers who described how physical limitations and dependency brought changes to their social roles and relationships, resulting in anxiety, depression, isolation and fears about the future. Patient-participants described ways in which they coped with and sought help for their breathlessness and the degree to which their clinician saw breathlessness as a target for management or whether the focus was only on the underlying condition. As these findings are described elsewhere with respect to the concepts of ‘Total dyspnea’<sup>28</sup> and ‘Breathing Space’<sup>6</sup>, here we focus on our findings about

experiences of acute-on-chronic breathlessness and of help-seeking in the community, and the reasons for emergency presentation.

### *Experiences of acute-on-chronic breathlessness*

All ED presentations in this study were made for acute-on-chronic breathlessness:

“The pain was intense. The breathlessness was more intense. I was really out-of-breath and feeling weak. I was frightened.” (P19, interviewed alone)

At these times there was a need to feel safe and for something to happen *now*:

“I think you just take it for granted until you’re put into a situation when you realise how much you are struggling, and you need help there and then don’t you?” (Clinician P1209)

“There’s a feeling of security in the hospital. You feel safe.” (P8, interviewed with carer)

However, many patient-participants expressed dissatisfaction at resorting to an ED presentation:

“So, I try not to go, but ultimately I end up going in there.” (P4, interviewed with carer)

“I feel a little defeated whenever I have to go to hospital.” (P8, interviewed with carer)

When people experience acute-on-chronic breathlessness their awareness of their body and its desperate need for its next breath is so overwhelmingly that their need for safety overrides all other concerns and their only resort is to seek help.

### *Experiences of help-seeking for breathlessness in the community*

All the patient-participants had, over time, attempted to seek help for their breathlessness in the community before accessing emergency services. The response they received to their help-seeking influenced future help-seeking. Some patients were offered little in the way of breathlessness management and thought there was nothing that could be done, whilst others happened to access excellent breathlessness management in the community.

Some clinicians were unaware of the existential impact of breathlessness on their patient and so did not offer them breathlessness management. This is clearly illustrated by a clinician who was not concentrating on the patient's breathlessness and a contrasting quote from her patient who described in interview having difficulties due to breathlessness:

"It (breathlessness) wasn't something that I've highlighted as being a problem for her. It probably was a problem to her, but her main thing was the pain...they don't always initiate other things that are concerning them." (Clinician P1209)

"Sometimes when you're breathless it can frighten you. On Sunday I walked and pushed the wheelchair and I nearly got to her house, and in the end I said, "No, I'm gonna have to sit down". I could feel me legs shaking and she wheeled me there, I just couldn't have walked it." (P1209, interviewed alone)

Despite having sought help for their breathlessness in the community some patient-participants gained little understanding: neither of their underlying condition, nor of how to manage breathlessness and thus were denied the opportunity to access breathlessness management services or to make changes to their behaviour to improve their quality of life:

Interviewer: "So you don't feel you've been given very much information that would have been helpful?"

Patient: "No, the doctors don't, do they? They just say, "Well it's COPD", boom." (P258, interviewed with carer)

When a clinician only focussed on the underlying condition rather than on the symptom of breathlessness both patient and clinician then only focussed on treating crises as they arose:

"My recollection of him is that he generally gets on with things and comes to see us when he's got a mini-crisis and then I think he'll come and see me." (Clinician P39)

This clinician's patient described in interview having considerable limitations due to his breathlessness which his clinician was unaware of and yet he was reluctant to seek help for breathlessness.

When patients seek help from clinicians focussed only on treatment of the underlying condition the patient comes to think that is all that can be done and has no expectations that their breathlessness can be managed:

“No, when you’ve got CPO (COPD), I mean you just help yourself really, with yer sprays and take it easy.” (P169, interviewed alone)

“There's nothing they can do for her, they've told us that. The specialist, the hospital, the doctors, they can't do any more for her.” (Carer P84, interviewed with patient)

These patients then felt there was nowhere to turn than the ED when they had a crisis and sometimes were even told that they should go to the ED if they had breathing problems in future.

In contrast, some clinicians understood the effects of breathlessness on the lives of their patient and family carer and offered management for breathlessness in addition to treating the underlying condition, thereby enabling their patients to be less restricted and to manage their breathlessness better:

“One of our questions is looking at social isolation: do they get frustrated, do they get mood swings, and trying to get the reasons why behind it, and it's because, “Well I used to be able to do all of this and now I can't, and that's really frustrating and I have to rely on somebody else”. So, we'll teach them ways to do that; we try and teach the carers as well. We try and get the carers to attend programmes, so that they can see what to do when they get breathless, so they don't panic as well.” (Clinician P508)

Patients of these clinicians valued their support and when they had crises would then turn to them first rather than going directly to the ED.

In summary, the meaning of the experience of seeking help in the community for breathlessness was characterised as either learning nothing could be done or as leading to valuable support.

## *Theme 2: Reasons for presentation to the ED*

The decision to present to the ED is set within the context described above. All patient-participants had previously attempted to seek help for their breathlessness in the community. The response they received shaped their future help-seeking and formed the context for their decision to present to the ED this time. The decision to present was a complex one not taken easily by the patient or the carer. Participants described four reasons for ED presentation (see Figure 1).

### *Reason One: Reluctance to seek further help for breathlessness*

Some participants described reluctance to seek further help either in the community or in the ED for their acute-on-chronic breathlessness, thereby leaving their worsening condition to deteriorate.

Patient-participants found it hard to know *when* they should seek help in the community and this was compounded by not wanting to bother the doctor and gendered help-seeking behaviour:

“I’m always reluctant, because I think is it bad enough?” (P39, interviewed with carer)

“She doesn’t like to feel like she bothers anybody.” (Clinician P5)

“He wouldn’t go to the doctors, because you don’t go to the doctors, do you, if you’re a man. Then it would just get worse and worse wouldn’t it.” (Carer P39, interviewed with patient)

Previous experience of the ED also increased reluctance to present this time, with many preferring to remain in their own home rather than wait in a chaotic environment:

“I don’t like going to hospital, so I’ll hold off as long as I can. I just like me own space.” (P1209, interviewed alone)

“They was very busy, flying all over the place.” (P19, interviewed alone)

“It takes a bloody long time. And waiting, waiting, waiting, it’s terrible.” (P603, interviewed with carer)

This reluctance based on previous experience resulted in leaving presentation until their condition had deteriorated significantly thus necessitating an ED presentation which might have been avoided with earlier treatment:

"I know I have had it really bad, but I still won't ring the nurse and they do go mad at me! They said you know if you ring us we could get this nipped in the bud." (P5, interviewed alone)

When the patient became very breathless carers became vigilant and monitored the patient's breathlessness:

"I say I'm going out and we keep in constant touch on the phone. If she was really bad I'd just say, no I'll stay today." (Carer P258, interviewed with patient)

This vigilance played a key part in a carer taking the decision to present to the ED if the patient was reluctant to make that decision themselves:

"Well I was gasping for breath, and me daughter, she said, "Oh to hell with this, I'm phoning for an ambulance" and they told me I should go straight away to A & E." (P338, interviewed alone)

When others made the decision for them patient-participants were often relieved as their reluctance to seek help was overruled by someone else:

Carer: Well my daughter said "No" she said, "No messing about. I don't care what you say, I'm gonna ring them."

Interviewer: So how did you feel then?

Patient: I was quite pleased really, didn't let on that I was, but kept saying I don't want to go, but it was a relief actually. (P39 and carer, interviewed together)

### *Reason Two: Patients feeling unsupported for their breathlessness by primary clinicians*

Poor communication between patients and clinicians in the community caused difficulties to both patients and carers, leaving them feeling unsupported and unable to access breathlessness management. Time limits on consultations, problems with timely access to clinicians and lack of continuity of care all affected the quality of care they received:

"It was this locum that I saw, he didn't know me records or anything. And he was the only one I could see at the time." (P19, interviewed alone)

Interviewer: Do you have a doctor that you've seen for quite a long time?

Patient: No, don't go very often, do I?

Carer: No, but when you do you never see the same doctor twice anyway...It's just whoever's available. So, you don't build up a rapport with your doctor. (P84 and carer, interviewed together)

Additionally, patient-participants frequently had comorbidities which resulted in attendance at several clinics and sometimes in receiving conflicting medical information:

"Every time I go in there I go into a different department. It's just one thing after another." (P4, interviewed with carer)

"One doctor says "There's nothing wrong with your heart, your heart's OK. We think it might be a chest infection." And another doctor says, "It's heart failure." Then another doctor says "No, it isn't your heart." And I mean, I don't know what's causing it." (P19, interviewed alone)

Difficulties in accessing family doctors, with the lack of continuity of care and no offer of breathlessness management led some to feel there was nowhere else to turn than the ED:

Interviewer: What led you to go to the ED?

Patient: Well you don't really know what's going wrong yerself. If you ring the doctors up, they don't come out, do they? (P84, interviewed with carer)

Additionally, some patient-participants presented to the ED because they had previously been instructed to ring for an ambulance in the future rather than seeking primary care appointment. Thus, they learnt to go directly to the ED:

"He just said "Well if it gets any worse" he said, "Just ring ambulance up." That was it, I was sent on me merry way." (P19, interviewed alone)

The findings indicate a negative cycle that is generated by previous experiences and interactions when seeking help in primary care.

### *Reason Three: Well-supported patients being advised to present to the ED*

Several patient-participants had supportive relationships with their primary clinicians and had received both breathlessness management and treatment of the underlying condition. These patients had sought help from their clinician prior to presenting to

the ED this time and were advised to present to the ED for tests/specialist advice as timely access was difficult for some primary clinicians. Whilst some tests could be arranged in the community, e.g. chest x-rays, the results were inaccessible for immediate clinical decision-making. Clinicians felt that timely access to specialists for people with non-malignant conditions was poorer than cancer services:

“We have the two-week wait system if you suspect cancer, or three months, and there doesn’t seem to be anything in-between. Sometimes you could just do with something, if you could get them seen in the next couple of weeks in the clinic it would be fantastic.” (Clinician P39)

Therefore, in some cases, following assessment, the clinician advised the patient to present to the ED:

“He said to me, “I think you could do with a day or two in hospital. You’ll get x-rayed, you’ll get your blood done and then I’ll know exactly what’s going on.” (P476, interviewed alone)

“We try and control it as much as we can in the community with antibiotics, steroids and one tries to avoid admitting to hospital, but if we really don’t get on top of it then one’s obliged to make sure we’re not missing anything.” (Clinician P476)

#### *Reason Four: Well-supported patients in need of help out-of-hours*

In other cases, well-supported patient-participants needed help out-of-hours and needing support at that moment had presented to the ED. This is illustrated clearly by the following patient:

“She got herself into such a tizz. The first time was just after midnight and then again about 3pm. Well, she knows she won’t get me at that time and so she’d used the paramedics.” (Clinician P508)

Had these crises happened during working hours then the clinician may have avoided the presentation by offering support and advice:

“I’d said, “Well you could have just put your nebuliser on. If you’d sat with that it would have helped.” I think her seeing what the paramedics did and myself going in the following morning and saying “Actually you could have just done this and you would have been OK in bringing this back down yourselves”. And she said, “Oh right, I’ll remember next time, I can do that”. (Clinician P508)

## **Discussion**

## Main findings

This study is the first to explore linked patient, carer and clinician perspectives about the decision to present to the ED with acute-on-chronic breathlessness. The findings explain how these presentations came about, giving insight into how they might be prevented in future. The experience of acute-on-chronic breathlessness and of previous help-seeking formed the context for their decision to present. There were four reasons for presentation.

## Comparison with existing literature

The experience of living with breathlessness described by participants can be understood with reference to the concepts of Total Dyspnea<sup>28, 29</sup> which describes the physical, psychological, social and existential effects of chronic breathlessness. The concept of Breathing Space<sup>6</sup> which describes how a patient's coping and help-seeking interact with the response from clinicians to affect how well they can live with the effects of breathlessness was further illustrated in the findings. Often breathlessness remains invisible and poorly understood or managed by clinicians;<sup>30</sup> less well recognised and treated than pain.<sup>31</sup> Diagnosis and prognosis of the underlying condition can go undiscussed in consultations and patients leave with little understanding.<sup>32</sup> Poor communication with clinicians can be aggravated by their lack of understanding of the experiential gravity of the symptom.<sup>33, 34</sup>

The need to feel safe when experiencing acute-on-chronic breathlessness is consistent with other findings.<sup>12</sup> The uncertain trajectory of the underlying condition and the crises can also be difficult for carers.<sup>35</sup> In 1,212 acute-on-chronic breathlessness presentations<sup>20</sup> most patients had non-malignant disease(s), discussed their breathlessness with their GP, and others were often involved in the decision to present. Carers need support to help breathless family members with informational needs.<sup>36</sup>

Our data support the importance of optimal treatment of the underlying condition combined with breathlessness symptom management. Examples of this approach can be seen in the *aide memoire* Breathing SPACE and "Breathing, Thinking, Functioning" models.<sup>37, 38</sup>

Processes leading to ED presentation were complex and involved tension over whether to present or not. Consistent with other studies sometimes patients and disease-focussed clinicians appeared to agree that all was well apart from exacerbations,<sup>39</sup> and that self-management had been attempted unsuccessfully before calling the ambulance.<sup>40-42</sup> As only the “acute” aspect of the “acute-on-chronic” breathlessness was addressed in the ED, the chronic breathlessness remained invisible.

In common with other findings<sup>43</sup> some patients don’t try to get a doctor’s appointment because of previous difficulties, turning instead to the ED. The role of poor continuity of care in the community, inadequate symptom management and ultimate ED presentation has been described previously,<sup>44</sup> including an association with increased mortality.<sup>45</sup>

The disparity between cancer services and those for non-malignant conditions is noted elsewhere;<sup>46</sup> the needs of patients with non-malignant conditions were not as well met.<sup>47</sup> Multi-disciplinary, cross-setting management of chronic non-malignant conditions in the United Kingdom has been slow to enter policy<sup>48-50</sup> and service delivery.<sup>51</sup> Whilst annual checks are now commonly offered to people with lung conditions the focus is primarily on medication adherence and vaccinations, rather than considering the widespread effects of breathlessness on the patient and their family.

Implications for clinicians and policy makers (see Table 2)

For some, presentation might be avoided with better community management of breathlessness, however, for others, ED presentation is necessary. Some clinicians perceive that these patients should not be in the ED,<sup>52</sup> but provision of emergency palliative care<sup>53</sup> (such as for acute-on-chronic breathlessness) is a necessary function of the ED, for which the staff should be appropriately trained.<sup>54</sup> Greater understanding by ED clinicians of the overwhelming nature of experiencing acute-on-chronic breathlessness may encourage acceptance of their role in caring for this group of patients. Acute-on-chronic breathlessness should be recognised by ED

clinicians and community clinicians alerted to the need for a review of chronic breathlessness management on discharge.

#### Future research

Research is needed to evaluate the clinical and cost-effectiveness of a patient review triggered by an ED presentation.

Research into acute assessment services giving primary clinicians access to rapid diagnostic tests and specialist advice in the community for those with non-malignant conditions is necessary.

#### Strengths and limitations

Patient-participants were drawn from a large sample of survey participants. The phenomenological approach allowed detailed exploration of the participants' experience. Rigour was sought through extensive discussion and interpretation of themes with reflection amongst the researchers sensitised by the concept of Breathing Space. The patient-carer dyad interviews enabled an account of their *joint* experience to emerge but may have limited disclosure of sensitive matters. This sample was not ethnically diverse and included no non-English speakers reflecting local population demographics at the time of data collection, but also due to a lack of translation resources. Therefore, the experience of a significant group is not represented.

#### Conclusions

The decision to present to the ED is made in the context of serious crisis and previous experiences.

Discussion of the reason for presentation to the ED by patients and their primary care clinicians may enable better management of chronic breathlessness and reduce the need for future emergency presentation. As described by the Breathing Space concept the role of the clinician in responding to their patient's breathlessness is vital.

These data support the Breathing space as a theoretical approach to this situation.

## Additional information

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### Ethical approval

Ethics approval, including for the method of consent, was given by the NHS National Research Ethics Service Committee South Central-Hampshire B (Ref: 13/SC/0543) and institutional permission were obtained prior to data collection.

### Competing interests

The authors declare no competing interests.

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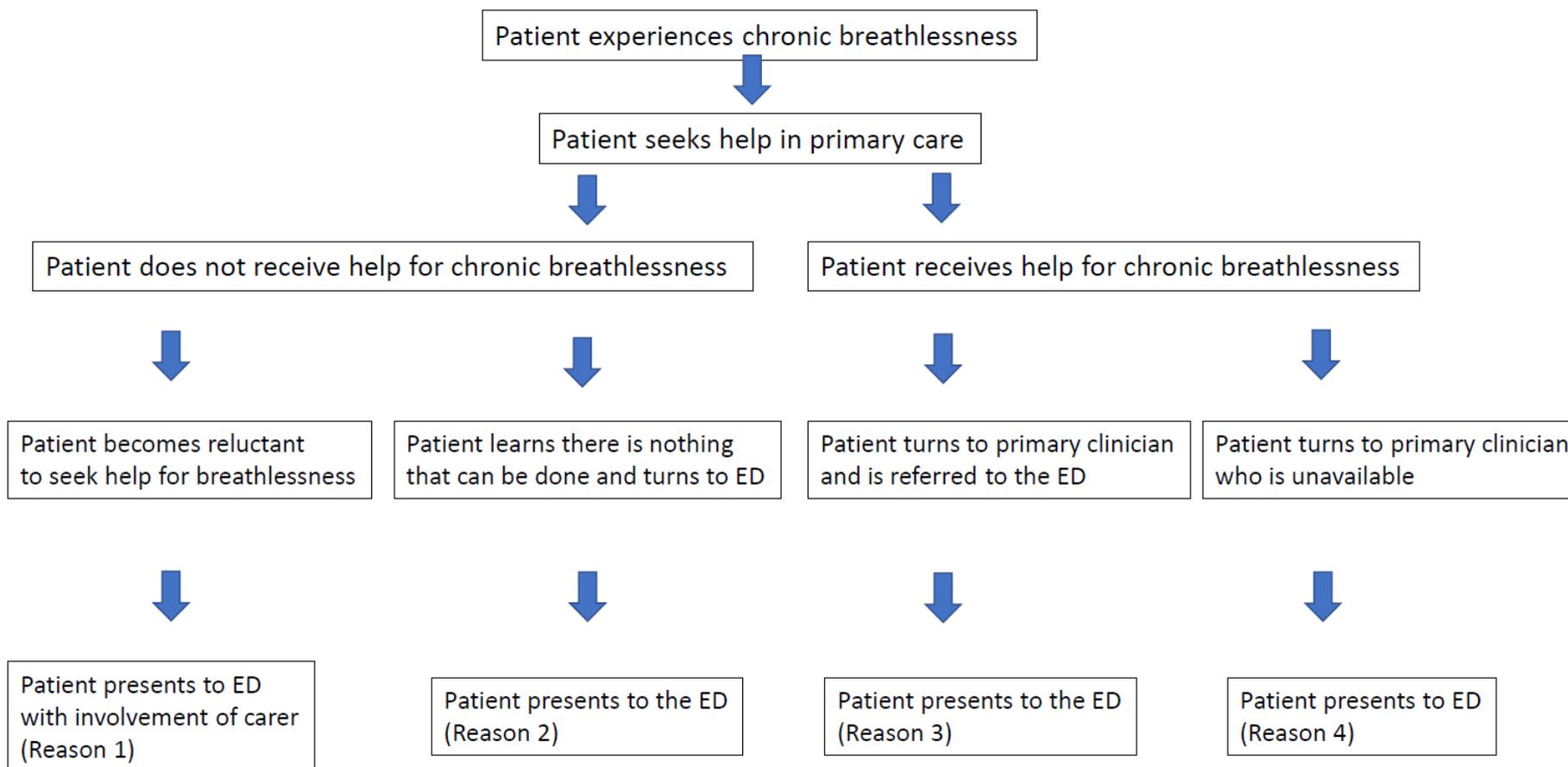
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Figure 1



**Table 1. Participant Characteristics**

<b>Characteristic</b>	<b>Socio-economic status (Defined by IMD, low= most deprived, high=least deprived)</b>	<b>Lives with others or alone</b>	<b>Smoking status (Current/ Ex/Never)</b>	<b>Previous presentations to the ED in last year Few [<math>\leq 2</math>] Many [<math>\geq 3</math>]</b>	<b>Carer-participant (M or F and relation to patient)</b>
<b>Study participants n</b>	Low n= 8 Medium n = 2 High n = 4	Others n = 13 Alone n = 5	Current n=4 Ex n=13 Never n=1	Few n=14 Many n=4	Male spouse n=2 Son n=1 Female spouse n=4 Daughter n=2

**Table 2: Reasons for presentation and how these presentations might be avoided**

	Reason for presentation	How this might be avoided
1	Some patients, not wanting to bother the doctor, were reluctant to seek help in primary care and reached a crisis point where the decision to present was taken by others.	Advice by primary clinicians to patients and their family carers on appropriate help-seeking, demonstrating that their concerns are legitimate, may overcome the reluctance to present to primary care before a crisis makes emergency department care inevitable.
2	Some had found little previous support in the community therefore learning that they should go to the emergency department next time they experienced crisis.	<p>Greater primary clinician awareness of the widespread effects of chronic breathlessness, combined with knowledge of evidence-based breathlessness management strategies is needed, especially for those patients with non-malignant cardiorespiratory conditions.</p> <p>Increased continuity of care in primary care for this group of patients and a review of chronic breathlessness management after an emergency presentation may enable better support in the community.</p>
3	Others had been well supported in the community, by clinicians who understood and managed the impact of breathlessness and directed them to the emergency department for tests and specialist advice.	Timely access to diagnostic tests and to specialist advice for those with non-malignant conditions would support community management.
4	Some who were well supported in the community turned to the emergency department for support when their clinician was unavailable.	<p>Greater investment by commissioners to increase the availability of appropriate primary clinicians out-of-hours may prevent emergency department presentation.</p> <p>Additionally, planning for how to handle future crises may help patients and carers manage better without recourse to a clinician.</p>