

What influences the presentation of patients with chronic breathlessness to the Emergency Department? A mixed methods study

Short title: Breathlessness and the emergency department

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Abstract

Background: Chronic breathlessness is a common and distressing symptom of many long-term cardiorespiratory conditions and cancers which are highly prevalent in both the UK and worldwide. It is associated with presentation to the emergency department (ED) and admission to hospital.

Aim: The aim of this research is to improve our understanding of the role of chronic breathlessness in ED presentations by people with advanced cardiorespiratory disease and to identify potential targets for interventions to prevent or avoid emergency presentations.

Methods: Mixed methods study with integration of findings at analysis. A systematic review and qualitative synthesis were performed to examine the literature on the experience of breathlessness. A prospective survey and case note review were conducted to establish the prevalence of presentations due to acute-on-chronic breathlessness at the ED and to identify the demographic and clinical characteristics of those patients. The perceptions of patients with chronic breathlessness, their carer and healthcare professionals regarding presentation to the ED due to acute-on-chronic breathlessness were explored by semi-structured interview.

Findings: Living with chronic breathlessness involves widespread effects on the lives of both the patient and those caring for them, yet this impact may remain largely invisible to others. Quality of life with chronic breathlessness is maximised by a patient's engaged coping style and a clinician's responsiveness to breathlessness as well as to the underlying disease. This is described by the Breathing Space concept. Presentation to the ED sits within this context and occurs as a result of a breathlessness crisis. There are a proportion of patients who may have avoidable attendances and could be more optimally managed in the community.

Conclusions: Greater public and professional understanding of the widespread effects of breathlessness, combined with appropriate assessment and management of the symptom, including planning for crisis may reduce the need to present to the ED.

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Author's Declaration

'I confirm that this work is original and that if any passage(s) or diagram(s) have been copied from academic papers, books, the internet or any other sources these are clearly identified by the use of quotation marks and the reference(s) is fully cited. I certify that, other than where indicated, this is my own work and does not breach the regulations of HYMS, the University of Hull or the University of York regarding plagiarism or academic conduct in examinations. I have read the HYMS Code of Practice on Academic Misconduct, and state that this piece of work is my own and does not contain any unacknowledged work from any other sources. I confirm that any patient information obtained to produce this piece of work has been appropriately anonymised'.

Publications, presentations and prizes

Publications

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Chapter One: Breathlessness in context

1.1 Introduction

Chronic breathlessness is a common and distressing symptom of many long-term cardiorespiratory conditions and cancers which are highly prevalent in both the UK and worldwide. This thesis will explore the experience of people with chronic breathlessness to examine the factors which influence their decision to present with breathlessness to the emergency department (ED), with a view to identifying those which could be targets for interventions to reduce presentations which do not benefit the patient.

This chapter will start with a definition of breathlessness. A summary of the relevant literature will be reviewed on both the prevalence of breathlessness and of the main long-term conditions causing breathlessness will be presented to set this thesis in context. The chapter concludes with an exploration of breathlessness as part of patient presentation to the ED, since reducing the pressure on EDs throughout the country, enabling people to die in their preferred place of death and providing adequately for the healthcare needs of the ageing population are all important areas of research in line with current government priorities.

1.2 Definitions

The American Thoracic Society (ATS) defines dyspnoea or breathlessness as “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity” and goes on to explain that the experience of dyspnoea is shaped by psychological, social and environmental factors in addition to physiological factors (1). This definition encompasses all types of experience of breathlessness from whatever underlying cause and recognises its subjective nature. It is worth noting that there are several terms used in the literature for breathlessness, including dyspnoea and shortness of breath. In this thesis the focus is on chronic breathlessness, defined as experiencing breathlessness most days in the last month. Chronic breathlessness is caused by many different underlying conditions and treatment

is most often aimed only at these underlying conditions. When optimal treatment for the underlying condition has been provided many patients continue to experience chronic breathlessness which is generally not seen to be a target for treatment in itself. This may be for a number of reasons including clinicians' perception that chronic breathlessness is difficult to palliate and also that the most recent research recommendations are not being quickly taken up into clinical practice (2). The concept of 'total dyspnea' (3) is useful as it recognises the importance of breathlessness as a target for treatment in its own right and also the importance of managing the impact that breathlessness has on the quality of life of the patient and those caring for them (4).

1.3 Epidemiology of breathlessness

Breathlessness is common in the general population and is a distressing symptom for people with chronic cardiorespiratory conditions and cancer. Estimates of breathlessness in the general population vary from 9% to 59%, reflecting differences in both definition (i.e. what score on which scale was used and whether or not the study aimed to measure chronic breathlessness, acute breathlessness or acute-on-chronic breathlessness [an acute episode of more severe breathlessness on a background of chronic breathlessness]) and also differences in the mean age of those surveyed, as breathlessness is more prevalent in the elderly. An average of 15% of men and 23% of women reported breathlessness (grades 2-5 on the medical research council (MRC) breathlessness scale) in the Health Survey for England (5), however the duration of breathlessness was not reported. Population-based studies in Norway, Australia, Korea and Wales show different degrees of prevalence of mild to moderate dyspnoea in the adult population, varying between 9% in an Australian study (6) to 13% in a Norwegian study (7). Studies show that breathlessness increases in prevalence with age. A Korean study reported that 23-59% of adults aged between 40 and 69 years were breathless, with a trend of increasing breathlessness with age and breathlessness being reported more amongst smokers than non-smokers (8). Also a survey study in Wales reported that 32% adults aged over 70 experience breathlessness (defined as MRC grades 3-5) (9).

The only study to explicitly measure the prevalence of chronic breathlessness was the community population survey in South Australia (6). A 9% prevalence of chronic breathlessness in the general population was found (modified MRC dyspnoea scale: chronic breathlessness being defined in this study as grades 1-4 occurring most days for more than 3 of the last 6 months), with 2.6% suffering a more marked impairment (modified MRC dyspnoea scale: grades 2-4). It is clear from these studies that breathlessness is reasonably common in the general population and that it is more common in women (5) and in older people (9).

The medical research council (MRC) dyspnoea scale rates the functional impact of breathlessness and is scored from 1-5 as shown in Table 1 below. The scoring of the scale has been altered to 0-4 in the modified MRC (mMRC) as opposed to 1-5 (MRC), which is a more intuitive way of grading breathlessness as zero, rather than one, on the scale represents not being troubled by breathlessness.

Table 1 Medical Research Council dyspnea scales

Medical Research Council dyspnoea scale	Modified Medical Research Council dyspnoea scale
<p>Grade Degree of breathlessness related to activities</p> <p>1 Not troubled by breathlessness except on strenuous exercise</p> <p>2 Short of breath when hurrying or walking up a slight hill</p> <p>3 Walks slower than contemporaries on level ground because of breathlessness, or has to stop for breath when walking at own pace</p> <p>4 Stops for breath after walking about 100m or after a few minutes on level ground</p> <p>5 Too breathless to leave the house, or breathless when dressing or undressing</p>	<p>Grade Degree of breathlessness related to activities</p> <p>0 Not troubled by breathlessness except on strenuous exercise</p> <p>1 Short of breath when hurrying or walking up a slight hill</p> <p>2 Walks slower than contemporaries on level ground because of breathlessness, or has to stop for breath when walking at own pace</p> <p>3 Stops for breath after walking about 100m or after a few minutes on level ground</p> <p>4 Too breathless to leave the house, or breathless when dressing or undressing</p>

Chronic breathlessness is common in advanced cardiorespiratory diseases such as lung cancer, heart failure and COPD affecting millions of people globally (10). In their final year of life 78% of patients with lung cancer and 94% of patients with chronic lung disease suffer breathlessness (11). Another study found that 65% of lung cancer patients experience breathlessness in their last 12 months of life, with 95% experiencing breathlessness as they approach the end of life (12). In a systematic review on the prevalence of symptoms in cancer, AIDS, heart disease, COPD and renal disease (13) it was observed that breathlessness was a common symptom in all these conditions near the end of life. The highest rates of prevalence of breathlessness were in heart disease (88% (14)) and in COPD (94% (11)). A prospective study of contemporaneous

clinical assessments of breathlessness of patients with different conditions attending a regional community palliative care programme showed the prevalence and severity of breathlessness to increase markedly in the last months of life (15). Thus, not only is breathlessness a common symptom in patients with long-term conditions, but it becomes worse as the disease progresses.

1.4 Epidemiology of the main diseases causing breathlessness

Chronic breathlessness is common in cardiorespiratory diseases such as lung cancer, heart failure and COPD which affect millions of people worldwide (10). Globally, non-communicable diseases such as respiratory diseases, cardiovascular diseases and cancers accounted for 50% of deaths in 2010 (16) and breathlessness is a common symptom of all. COPD caused 4 million deaths (5% of all deaths) worldwide in 2010 (16). According to World Health Organisation (WHO) predictions COPD is set to rise from the 13th to the 5th leading cause of burden of disease globally by 2030 (17).

Cardiovascular diseases are the leading cause of death in the world causing 16 million deaths (30% of all deaths) in 2010 (16). The WHO predicts that globally deaths per year due to cardiovascular diseases will rise from 17 million in 2004 to 23 million by 2030 (17).

Lung cancer is the most common cancer worldwide and it accounted for 1.5 million deaths in 2010 (16). The total number of deaths due to cancer was 8 million (15% of all deaths) in 2010 (16) and the number of deaths due to cancer is predicted to rise to 12 million by 2030 (17). Breathlessness is a common feature of intra-thoracic malignancy, however breathlessness may also be experienced by patients with cancers in other body areas because of the associated respiratory muscle wasting and fatigue that often accompanies advanced disease (18).

In England and Wales the three leading causes of death are cardiovascular (circulatory) disease (29%), cancers (30%) and respiratory diseases (14%) (19). In total these deaths accounted for 73% of all deaths in England and Wales in

2011. As these diseases are all long-term conditions which feature breathlessness, the prevalence of breathlessness in England and Wales must be a cause for concern.

In Hull the percentage of deaths caused by respiratory disease is 17% which is statistically significantly higher (using the Wilson Score Method) than the average for England (14%), whilst the percentage of deaths caused by cancer are in line with the national average (29%) and the percentage of deaths caused by CVD is 27% which is statistically significantly lower than the national average (30%) (20). (The figures given in brackets here are for the national average are for the year 2010, however national data for the year 2011 is very similar, with the combined total percentage of deaths due to cancer, cardiovascular disease and respiratory disease being 73% in both years (19).) All together respiratory disease, cancer and CVD accounted for 73% of the deaths in Hull in 2010 which is in line with national rates.

The changing population structure in the UK is an important factor leading to the increasing prevalence of breathlessness. The number of people aged over 65 is predicted to increase by two-thirds to approximately 16 million by 2031 (21). This means that by 2031 people aged over 65 will make up 22% of the UK population and therefore it is likely that breathlessness will increase in prevalence as respiratory disease, cardiovascular disease and cancer are largely found in older people. Recently the government predicted that the percentage of the population of Hull who are over 65 will increase by 38% by 2030 and those over 85 will increase by 62% (22). The figures above show that there is a high prevalence, both nationally and globally, of chronic conditions involving breathlessness and that the national and global burden of disease caused by these conditions is set to increase, so it is clear that management of breathlessness is an issue which needs to be addressed urgently by healthcare providers.

1.5 Breathlessness and presentation to the Emergency Department

Not only do patients with breathlessness require health service support from both primary and secondary care, breathlessness may lead to presentation to

the ED. An increase in a patient's background level of breathlessness or episodes that are worse, or more frequent, or which do not settle as expected may be a factor precipitating emergency presentations. In an analysis of a national database it was found that breathlessness was the primary reason given by 2.7 million adults for attending the ED in 2007 in the USA (3.2% of all visits per year for that age group) (23). Other estimates of prevalence of breathlessness as a primary reason for presentation range between 2.7% and 9% depending on the method used (24) (25). Unscheduled emergency presentations due to acute-on-chronic breathlessness can lead to distress for the patient and carer and are a burden on the already stretched ED.

Another reason why breathless patients with long-term conditions may present to the ED is that they are dying and may be without the necessary support at home and therefore they are in need of palliative care. However the treatment offered in the ED is aimed at acute episodes as opposed to chronic management and the ED is not an appropriate place of death as it is a busy environment geared towards acute care, rather than a setting appropriate for end of life care. An international survey found that the majority of cancer patients would prefer to die in their own homes rather than in hospital (26) and yet a retrospective analysis of data from the Office of National Statistics (27) found that hospital is still the most common place of death for cancer patients in England with 48% dying in hospital, although the trend for rising hospital deaths now seems to be reversing.

When considering all causes of death 55% of deaths in England occur in hospital (rather than at home, in a care home or in a hospice) and in Hull there is a significantly higher number of deaths in hospital (62%) than occurs nationally (20). As discussed previously the prevalence in Hull of the main diseases which cause chronic breathlessness reflect the national average (apart from respiratory disease which is more common), however, death in hospital (rather than at home) from these diseases is greater in Hull than in the rest of the country. The reasons for this observation are not fully explained and research to identify why the rate of death in hospital is comparatively high is needed in order to see how this phenomenon could be addressed.

Not only is breathlessness a common cause of presentation to the ED, patients thus presenting have a high rate of being admitted to the hospital, rather than being discharged home. One clinical record review showed that a quarter of people admitted to hospital from the ED were those presenting with breathlessness (28). In a study of 57 consecutive patients with heart failure presenting with breathlessness to the ED, 88% were admitted to hospital (29). Similarly in a study with 114 patients suffering COPD presenting to the ED, a high proportion (60%) were admitted to hospital (30). It is important to consider the appropriateness of admission to hospital of patients with breathlessness as it can be a disruptive event and if no change in management of their condition arises from the visit, the experience may not have been worthwhile for the patient.

In Hull the rate of admission to hospital via the ED by patients with COPD, a condition with a high prevalence of breathlessness, is approximately 340 admissions per 100,000 patients with COPD presenting at the ED, which is twice as high as the national average of approximately 160 admissions per 100,000 patients with COPD presenting at the ED (31). The rate of readmission to hospital for COPD is also very high in Hull (16% readmissions within 30 days of discharge, compared with a national average of approximately 13%) with mortality due to COPD in Hull also being very high (46 per 100,000 population compared to a national average of approximately 26 per 100,000). Hull is an area in the highest quintile of number of emergency admissions per 100,000 population for conditions judged to be rich in avoidable admissions including COPD (between 2,739 and 4,359 admissions per 100,000) (32).

This combination of high admission to hospital via emergency presentation and high mortality from COPD is challenging for the healthcare providers in Hull and consideration needs to be given as to how best to configure breathlessness services in both primary, secondary and tertiary healthcare in order to provide better care for COPD patients and to reduce mortality.

Another factor which needs consideration is the pattern of use of the ED by breathless patients, as it may be linked to the high admission rates and high mortality rates found in Hull. Since there is such large variation amongst Primary Care Trusts (PCT, now known as Clinical Commissioning groups

(CCGs)) in England in the rate of admission to hospital via the ED and readmission to hospital due to COPD, it is imperative that research into which factors are amenable to amelioration by intervention is carried out and then applied to how breathlessness is treated in England and in particular all the PCTs with high rates, including Hull. This may reduce the number of admissions to hospital via the ED thus improving quality of life and also potentially saving valuable resources.

1.6 Management of breathlessness in the ED

The primary purpose of the ED is to make urgent assessment and triage with regard to the cause and immediate risk to the patient and to institute necessary acute measures to stabilise the patient, if possible reversing the current pathology. By necessity the ED operates on a primarily biomedical model aiming to save life and therefore breathlessness is seen in terms of a clinical sign – e.g. raised respiratory rate, oxygen saturation levels and visible signs of laboured breathing, rather than being seen as a subjective symptom affecting a patient's life experience.

The American College of Radiography recommends that it is important to assess whether the breathlessness is acute or chronic which can be done by asking the patient and to attempt to diagnose the cause of the breathlessness using protocols to guide imaging investigations (33) particularly targeting potentially treatable conditions such as acute decompensated heart failure (ADHF), acute bronchospasm, or an infective exacerbation of COPD. In their guidelines for the assessment of dyspnoea in patients with heart failure in the ED, Pang and Zaman (34) emphasise the importance of seeking patient reported assessment of breathlessness severity and effect on daily activities including a comparison of how they feel now to their usual level of discomfort, to enable the doctor to make a more accurate assessment of their dyspnoea than can be done by inspection alone. A verbal dyspnea score was found to be predictive of admission to hospital in breathless patients (35). Baker et al. (36) have demonstrated that a tool for routine assessment of breathlessness in hospital wards is feasible and acceptable to nurses and that its use lead to a high level of assessment of this important symptom. However, this more

biopsychosocial approach is not systematically applied in everyday clinical practice where the focus of care is on clinical procedures and interventions.

As increased severity of breathlessness may indeed be a sign of a serious acute condition, presentation to the ED, with its emphasis on immediate management of reversible pathology, may be absolutely appropriate for the patient with breathlessness due to a long-term condition. However presentation to the ED may not be appropriate for other breathless patients who do not need the acute medical treatment available in the ED and whose needs could be met in the community, or through other non-emergency services. If the presentation is due to social or psychological factors (e.g. care at home may have failed because of carer fatigue and/or distress) there may be no reversible physical components to address, although the reassuring arrival of paramedics and presence of health care workers may well settle anxiety. In these circumstances, a full holistic assessment (including social, spiritual and financial assessments) and interventions put in place to deal with these aspects of their experience of breathlessness is the required management plan, however the ED is not presently equipped to deal with this.

1.7 Unnecessary emergency presentations and admissions

It is important to differentiate between emergency presentations and emergency admissions. Emergency presentations involve attending the ED; this is to be differentiated from an emergency admission which is defined as an admission to hospital which resulted from an emergency presentation.

Two forms of unnecessary emergency admission can be distinguished: avoidable and preventable. Avoidable admissions are when acute health problems are dealt with differently by the urgent care system (including emergency GP appointments, visits from a community nurse or paramedics attending a patient) in a way such as to avoid admission. Preventable admissions are when primary care professionals work with the patient to prevent the acute health problem from arising (32).

Research on unnecessary emergency admissions has shown that socioeconomic deprivation is associated with emergency admissions in health

conditions judged to be rich in avoidable admissions such as COPD, as are factors related to the urgent care system including ED attendance rate, conversion rate of ED attendances to admissions and the proportion of ambulance calls which are transported to hospital (32). The authors recommend that further consideration of interventions to either prevent or avoid emergency admissions is necessary particularly in areas of high deprivation such as Hull.

1.8 Aim

The overall aim of this research is to improve our understanding of the role of chronic breathlessness in emergency presentations to hospital by people with advanced cardiorespiratory disease and to identify potential targets for interventions to prevent or avoid emergency presentations.

1.9 Research questions arising from Chapter One:

- 1 What is the prevalence of presentations to the ED at Hull Royal Infirmary (HRI) that are due to acute-on-chronic breathlessness?
- 2 What clinical pathways are followed by patients who present to the ED due to acute-on-chronic breathlessness?
- 3 What predicts hospital admission (ED departure status) in people presenting to the ED with acute-on-chronic breathlessness?

1.10 Objectives

- 1 To measure the prevalence of presentations to the ED at Hull Royal Infirmary (HRI) due to acute-on-chronic breathlessness. The primary outcome was self-reported breathlessness as a reason for presentation by people with chronic breathlessness. Chronic breathlessness was defined as having shortness of breath most days in the last month.

- 2 Information on the patient pathway upon presentation to the ED will be assessed from the survey and by case note review.
- 3 Predictors of admission will be assessed from both survey and case note data.

1.11 Summary

This chapter defines chronic breathlessness and describes the epidemiology of both breathlessness and of the underlying clinical conditions. The impact on the ED due to presentation by breathless patients and the present management of breathlessness in the ED are described to set the context for this thesis. The aim and objectives are stated. Chapter Two will outline the patient and carer experience of chronic breathlessness.

Chapter Two: Experience of Chronic Breathlessness

2.1 Introduction

Chapter One outlined the extent to which chronic breathlessness is a problem for both the individuals who experience it and also for the healthcare system that deals with its effects. A patient with acute-on-chronic breathlessness may not receive the best management for their breathlessness in a busy ED which is designed to investigate, diagnose and treat acute reversible illness. In this chapter, a summary discussion of the literature relating to patient and carer experience of living with breathlessness is given.

2.2 Experience of breathlessness in daily living

Chronic breathlessness has wide-ranging effects on the lives of patients and of those who care for them. The experience of chronic breathlessness entails considerable variability. Systematic reviews of qualitative research on breathlessness, irrespective of underlying cause, have demonstrated that it not only imposes considerable physical limitations on patients, but also results in psychological distress, changes to social relationships and existential concerns (37) (38).

2.3 Variability of breathlessness

Unless very severe, most patients have stable, manageable or no breathlessness at rest, but experience breathlessness induced by exertion and/or other triggers such as emotion or a change in the environment. Breathlessness usually returns to baseline levels on rest or removal/cessation of other triggers. Consequently a common coping strategy is to avoid exertion (39). If the symptom intensity does not return to baseline levels or patients experience increased breathlessness of unknown cause, which occurs “out of the blue”, they can find this very distressing.

Breathlessness can be experienced as both a constant condition and also as short bursts known as episodic breathlessness (40). Episodic breathlessness as experienced by patients with a variety of chronic conditions is characterised by having several bouts a day. These bouts are of a high severity (self-report of 7/10), usually for up to 10 minutes and can have a range of physical, emotional and environmental triggers or no apparent trigger at all (40). Patients describe a wide variety of environmental triggers for breathlessness including physical exertion, anxiety, hot or cold air, humidity, smoke, air pollution and time of day (41).

The variability of breathlessness leads to uncertainty for both patients and their carer, leading to difficulty in planning as they may not be well enough on the day to carry out the planned activity. As breathlessness can change even within a day, they become vigilant; monitoring levels of breathlessness. Alongside this variability in the daily experience of breathlessness, patients may have exacerbations of their underlying condition often accompanied by worse breathlessness which may then trigger an emergency presentation to their GP or the ED (42). In a meta-synthesis of the qualitative literature on the experience of exacerbations COPD patients describe both acute and long-term effects of these exacerbations on their lives (43). Acute effects include experiencing intense emotions, increased vigilance of their bodies and an urgent need for rescue. In the long-term, exacerbations interrupt the daily pattern of their lives and are a serious cause of uncertainty. Thus the trajectory of functional decline for people with COPD is one with many ups and downs with accompanying uncertainty (see figure 1). (42) A similar trajectory also being observed in heart failure (44).

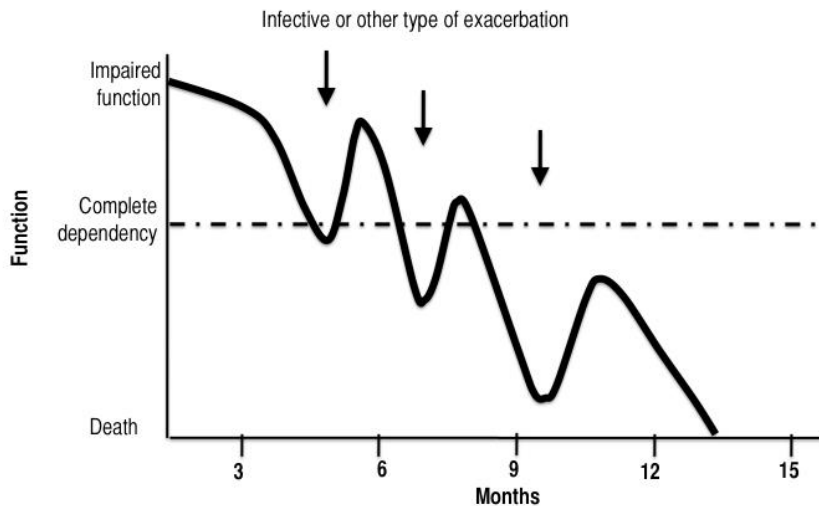


Figure 1 COPD disease trajectory: Updated clinical view

Reprinted from Br J Gen Pract, Vol 54; Lehman R. How Long Can I Go On Like This? Dying from Cardiorespiratory Disease, p 892-893, with permission from the Royal College of General Practitioners.

2.4 Physical effects of breathlessness

Chronic breathlessness irrespective of whether it is caused by cancer, COPD (45) or heart failure (46) results in difficulties engaging in physical activity such as walking, lifting and climbing and thus impedes patients' daily activities and reduces their quality of life. Physical activity is involved in many activities of daily living e.g. walking to the shops, preparing meals, bathing, cleaning, gardening, working, performing hobbies and socialising, therefore reduced ability to be physically active has wide implications for the breathless patient and their carer. Patients' describe how their daily activities become increasingly restricted by breathlessness; not only do patients become less active, but they become increasingly disabled and dependent on others to help and support them.

This is supported by ethnographic research with Canadian COPD patients (47) where many examples of disability due to breathlessness were found, including not being able to mow the lawn, carry heavy bags, do the shopping, vacuum the house or walk across a car park. All of these examples of disability were found

to have a considerable limiting effect on the patients, thus reducing their ability to live their lives independently.

The effect of breathlessness on physical activity has been explored from a phenomenological perspective; Carel describes how breathlessness makes many things impossible for her and that it appeared to her that her lifeworld was shrinking (48). She also argues that the physical world becomes altered for breathless people, as the effort required to manage physical activities means that they are forced to attend to the environment around them in a different way to those who are not impeded by illness. She eloquently describes how breathlessness affects perception of the environment:

“The trail that seemed so inviting and beautiful is now harsh and endless.”

2.5 Psychological aspects of the experience of breathlessness

2.5.1 Anxiety, fear and panic

For both the patient and carer, breathlessness is a very distressing and frightening symptom. Patients may experience episodes of breathlessness during which the distress may be so severe that the patient fears they will suffocate. The manner of death of breathless patients is clearly a concern for them; many feeling they will die unable to catch their breath and fear they will be alone and no one will know.

The distressing nature of breathlessness is illustrated by the highly emotive descriptors of breathlessness commonly used by patients, e.g. “choking”, “smothering”, “couldn’t get air”, “deathly sick” and “fighting for breath” (29). Patients find their breathlessness terrifying, unpredictable and causing them to worry how long they have to live (45).

Psychological distress and breathlessness are clearly linked. In a literature review it was found that the prevalence of anxiety in COPD patients varied between 10 and 100% in different studies, depending on disease severity (49). For example a French study using structured interviews in their research with COPD patients found that 49% suffered psychiatric disorders (according to

DSM-IV criteria) such as anxiety, panic and depression, significantly higher than the population average of 31% (50). They also found that women were significantly more likely to suffer anxiety and panic than men and that they reported more physical limitations due to breathlessness than men did, even when adjusting for disease severity. An Italian questionnaire study found the prevalence of anxiety (28%) and depression (19%) in COPD patients to be approximately 4 times those in the control group (51).

The link between anxiety and breathlessness is illustrated in figure 2, which represents a model developed for use in cognitive behavioural therapy by Padesky and Mooney (52). This model shows there to be a complex interaction between thoughts, mood, bodily sensations and behaviour which can result in a vicious cycle of increasing breathlessness. For example when bodily sensations such as increased breathlessness and heart rate are sensed this may lead to thoughts such as “I’m going to suffocate” which may lead to anxiety, which in turn leads to increased breathlessness and heart rate. Thus misinterpretation of bodily sensations can lead to increased anxiety and suffering due to breathlessness.

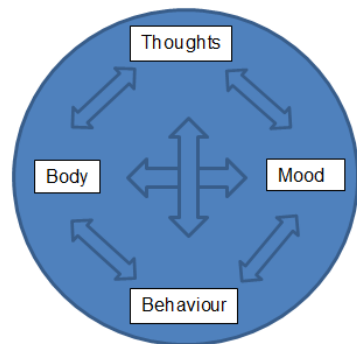


Figure 2 Hot cross bun model adapted from Padesky and Mooney (1990)

Anxiety and panic are frequently described in the qualitative literature on the experience of breathlessness in terms of a vicious circle (53) and the link between breathlessness and anxiety is clearly described. The uncertainty of the experience of chronic breathlessness engenders anxiety which in turn leads to a loss of control and leads people to feel they are no longer in charge of their lives.

2.5.2 Depression

Depression is also commonly experienced by breathless patients (50) and may result from the long-term disability and loss associated with the physical limitations imposed by breathlessness. The depression which can be associated with chronic breathlessness may lead to feelings of hopelessness where they may feel they no longer have anything to live for. Furthermore, carers may also suffer from depression, helplessness and exhaustion when faced with the relentless task of caring for someone who is chronically breathless, due to the unremitting nature of the care needed (45).

In summary psychological distress, such as anxiety, panic and depression related to the experience of breathlessness is frequently felt by both patients and carers, affecting their lives detrimentally. This distress also influences how breathlessness is perceived and reacted to and thereby may lead to emergency presentation. Therefore an effective intervention to reduce presentation to the ED would need to tackle these psychological correlates of breathlessness, thereby enabling patients and their carers to cope better with the breathlessness without recourse to the ED.

2.6 Social aspects of the experience of breathlessness

Accompanying the physical and psychological aspects of the experience of breathlessness there are social aspects such as social isolation, embarrassment in social situations and changes to relationships, identity and roles.

2.6.1 Social isolation

Both patients and their carers tend to become socially isolated and experience considerable disruption to their lives due to breathlessness. The physical limitations that breathlessness imposes on the patient (e.g. difficulties with walking, speaking and lifting) result in great difficulties in taking part in activities

such as shopping, going out for a meal, dancing, fishing and working. Not being able to take part in these activities results in considerable limitations to social life and leads to social isolation. For example not being able to walk very far, nor lift heavy loads means that a breathless patient cannot easily go shopping. Not only are they unable to buy things for themselves but neither do they have the everyday social interactions that go along with shopping like walking along the street and having a chat with people they know.

Leisure activities such as walking, dancing and fishing which all involve considerable physical activity become impossible for breathless patients and often by association for their partner/carer. Not being able to take part in these activities any more limits the social lives of both patient and carer and results in a sense of loss and isolation (54).

2.6.2 Social embarrassment and stigma

Another reason why breathless patients may suffer isolation is that many feel a degree of embarrassment in social situations as a result of their severe breathlessness and also coughing/phlegm production and this leads many patients to hide their condition by isolating themselves to avoid potential embarrassment. This intentional hiding of symptoms is one aspect of “the invisibility of breathlessness” (55).

2.6.3 Changes to relationships

As previously described breathlessness leads to physical restrictions for the patient which in turn can have psychological effects on the patient and their carer and also result in numerous social limitations and increased isolation. As a result of all of these changes it is unsurprising to find that breathlessness results in changes to the relationships of the patient and carer. Often the carer of a breathless patient is a wife or husband and breathlessness has its toll on intimate relationships. For one wife life has become “just being with each other, putting up with each other” and she reports that she feels she “would give anything to just get out of the house” (56).

The changes that can happen to breathless patients affect the way they relate to others and this can strain patient/carer relationships. Not only are husband/wife relationships affected by living with breathlessness but so are relationships with the wider family, for example limitations in playing with children and grandchildren (57).

2.6.4 Changes to social identity and roles

All humans have a personal identity which is formed partly by their genetic makeup and partly by the social and cultural conditions they live in. A person's identity is made up therefore partly by their own individual traits and partly by the social groups with which they identify. Social groupings may be on the basis of such categories as gender, ethnicity, socioeconomic status, religious affiliation and occupational group.

When someone identifies with a particular social group they take on a role which they act out in compliance with how they perceive people in that group should act. There are many roles people may adopt and so a person may act in multiple roles at any one time, for example as an elderly, white, British, Christian, working class woman. A person's ability to fulfil their roles affects how they see themselves (their identity) and when they are not able to fulfil a particular role the resultant change to their identity may cause them psychological distress.

When living with chronic breathlessness there are many limitations on the physical activities that a person can carry out and this can lead to no longer being able to fulfil certain roles and a consequent change in their identity. The roles which are commonly affected by living with breathlessness include gender, carer and worker. The role of worker is also frequently challenged by breathlessness as it can lead to patients having to stop working. Carers may also have to stop working due to the pressures of caring for a breathless person (41).

Finally both patients and carers may become restricted in their roles related to social activities and hobbies such as dancing, gardening and long distance walking. Not only are carers often not able to continue their previous roles e.g.

as dancers or walkers, since these are social activities that they had previously enjoyed with their now ill partner, they also feel they have to take on many other roles such as nurse, doctor, house-wife and gardener too. (58)

2.7 Existential aspects of the experience of breathlessness

Existential or spiritual concerns are an intrinsic part of being human and may be expressed through an organised religion or in other ways that are meaningful to the individual (59). Existential concerns such as being at peace, having a sense of purpose and connection to others and holding beliefs about the meaning of life lead to a sense of wellbeing. However, when suffering from breathlessness and nearing the end of life existential distress can arise due to a sense of suffering and loss, with distress about relationships, loss of control, being a burden on others and death (60).

It is important to recognise the existential distress that arises from living and dying with chronic breathlessness which may include: challenges to their faith; difficulty finding meaning and purpose; relationship difficulties; uncertainty; problems in maintaining a sense of identity; isolation and hopelessness. Some of these issues have been described previously and in this section the existential distress that arises from limitations to a patient's ability to carry out their desired religious observance and the hopelessness/ lack of meaning felt with respect to their future will be described.

Some patients find solace in their religious convictions and practices which enable them to live with their breathlessness and cope with their suffering (61) (41). However, due to the physical limitations exacted on breathless patients it can become very difficult for them to continue with any form of religious observance they may wish to perform and this may affect them adversely, due to not being able to gain support from their religious community at the time when they may very well need it e.g. church attendance could become difficult due to restrictions in walking (62).

Living with an underlying condition which causes breathlessness and limits life entails a considerable degree of uncertainty, due not only to the variability of breathlessness and the unpredictability of exacerbations, but also to the

uncertainty about progression, decline and death. This uncertainty can lead to feelings of hopelessness and some patients begin to wonder if it is worth continuing to live at all, even if such thoughts would be out of previous character (41). Alternatively other patients learn to face their suffering and existential distress and cope with their changed lives (63).

2.8 “Total dyspnea”

It is clear that chronic breathlessness not only affects people’s physical abilities, but also can cause psychological and existential distress and thereby dramatically alter the quality of life of both patients and their carer.

Breathlessness can be better understood when considered as “total dyspnea”, a term used by Abernethy and Wheeler (3) who argue that breathlessness is better understood as a subjective experience with physical, psychological, social and existential dimensions, than by focusing only on physical signs of breathlessness. This approach to breathlessness is modelled on the concept of “total pain” pioneered by Dame Cicely Saunders (64) and is an example of the biopsychosocial approach pioneered by Engel (65). Adopting the concept of “total dyspnea” allows us to see the wide-ranging effects that breathlessness can have on a person and their carer, from limitations to physical activity, disability and dependency to changes in their social relations and the consequent psychological and existential distress caused by these losses and restrictions.

2.9 Quality of life

The limitations to physical activity caused by breathlessness often lead to psychological distress as a result of increased dependency on others, restrictions that are placed on social activities and the lack of ability to perform usual roles. All of these aspects affect the quality of life of both the patient and their carer. Quality of life has been defined as "The degree to which a person enjoys the important possibilities of his or her life" by Raphael et al. (1997) (66) who have developed a model of quality of life which encompasses the three

domains of Being, Belonging and Becoming, each domain having physical, psychological, social and spiritual dimensions (66).

This model does not concentrate on health merely being the absence of illness, but instead focuses on the existential possibilities that people value e.g. being able to manage daily activities and cope mentally, belonging to family and community groups and becoming what is important to them by being able to pursue their own goals. The model is derived from the work of philosophers in the phenomenological tradition such as Heidegger (67) and Merleau-Ponty (68) who argue that as our body is the basis of our interaction with the world “being able to” carry out our activities and projects in the world is central to our view of ourselves, without which we can feel lost and useless. Thus living with breathlessness can affect whether we see ourselves as “being able to” or “not being able to” and therefore affects the quality of our existence as a whole. The quality of life of both patients and their carer can be severely affected by breathlessness (56). Being disabled by breathlessness and not being able to continue with activities that make life meaningful, can result in feelings of worthlessness and loss of self-respect (41).

2.10 Research questions arising from Chapter Two:

From Chapter One, we know that acute-on-chronic breathlessness is a reason to attend the ED. However, less is known about patient experience and how that influences presentation to the ED.

From Chapter Two we learnt that chronic breathlessness is experienced in all domains of the person’s life.

Therefore the research questions arising from Chapter Two with regard to patient experience are:

- 4 What is the experience of people living with daily breathlessness due to chronic medical conditions and those caring for or treating them with regard to their coping with and help-seeking for their breathlessness, particularly with regard to their interaction with healthcare services?

- 5 How do coping with and experience of help-seeking in the community influence their decisions to present to the ED?
- 6 What is the experience of patients and their carers when presenting with acute-on-chronic breathlessness to the ED?

2.11 Objectives

- 4 To explore research question 4 a systematic literature review and qualitative synthesis will be performed; further information to answer this research question will be gained from primary qualitative interviews.
- 5/6 Research questions 5 and 6 will be explored by primary qualitative interviews.

2.12 Summary

Chapter Two described the experience of living with chronic breathlessness for both patients and their carer. Physical, psychological, social and existential aspects of the experience of breathlessness were described. Finally, research questions that arise from Chapter Two are stated. Chapter Three will describe and provide the rationale for the methodology used to address the research questions from Chapters One and Two.

Chapter Three: Methodology

3.1 Introduction

Chapter Three outlines and justifies the choice of methodology to answer the research questions arising from Chapters One and Two:

- 1 What is the prevalence of presentations to the ED at Hull Royal Infirmary (HRI) that are due to acute-on-chronic breathlessness?
- 2 What clinical pathways are followed by patients who present to the ED due to acute-on-chronic breathlessness?
- 3 What predicts hospital admission (ED departure status) in people presenting to the ED with acute-on-chronic breathlessness?
- 4 What is the experience of people living with daily breathlessness due to chronic medical conditions and those caring for or treating them with regard to their coping with and help-seeking for their breathlessness, particularly with regard to their interaction with healthcare services?
- 5 How do coping with and experience of help-seeking in the community influence their decisions to present to the ED?
- 6 What is the experience of patients and their carers when presenting with acute-on-chronic breathlessness to the ED?

In this chapter an overview of the methods used will be described (see Chapters Four, Five and Six for more detail) in order to frame a subsequent discussion about the methodological approach used for this thesis.

3.2 Overview of methods used

In order to address this variety of research questions (both epidemiological study and exploration of the experience of patients, carers and healthcare

professionals) a variety of methods were used. A systematic review and a qualitative synthesis were performed in order to examine what is in the literature about the experience of breathlessness and how it affects interaction with healthcare provision. The research aimed to establish the prevalence of presentations due to acute-on-chronic breathlessness at the ED and to identify the demographic and clinical characteristics of those patients by use of a prospective survey and case note review. Furthermore the experience of patients and their carer in the ED, and the decision to present, was examined in the survey and by interview. The research also aimed to explore the perceptions of patients with chronic breathlessness, their carer and healthcare professionals regarding presentation to the ED due to acute-on-chronic breathlessness by semi-structured interview. An overview of the methods used is given below (also see figure 3).

3.2.1 Systematic Literature Review and Qualitative Synthesis

A systematic review of the literature on the experience of breathlessness from the perspective of patients, carers and healthcare professionals was performed and a thematic synthesis was produced.

3.2.2 Patient Survey

The survey measured the prevalence of acute-on-chronic breathlessness as a cause for presentation to the ED at the HRI and included questions to identify patient and clinical characteristics (e.g. sex, age, living alone/not, diagnosis, co-morbidities, severity and distress due to breathlessness, smoking status) and also clinical and informal support for their breathlessness and who had been involved in the decision to present to the ED.

3.2.3 Case Note Review

Data to identify demographic and clinical characteristics relating to the presentation and the investigations/ treatments of the episode of breathlessness

causing presentation to the ED (e.g. their diagnosis, any co-morbidities, assessments done and whether or not they were admitted) was extracted from the clinical records.

3.2.4 Semi-Structured Interviews

Qualitative semi-structured interviews of patients who completed the survey, their nominated carers and healthcare professionals were used to explore the experience of breathlessness in the context of presentation to the ED.

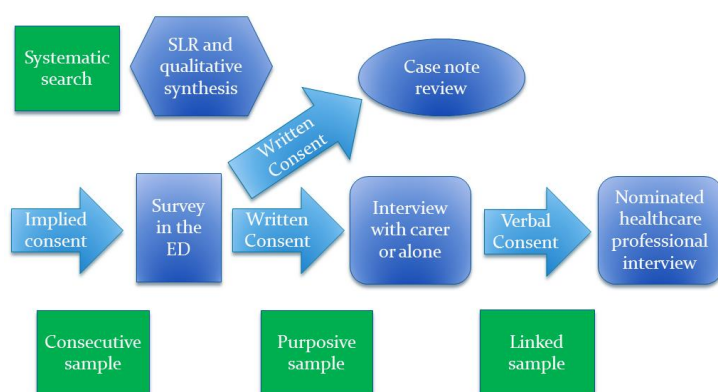


Figure 3 Overview of methods used in this thesis

3.3 Methodological approach for this thesis

3.3.1 Mixed-Methods Design

The mixed-methods approach of using a combination of a prospective survey, case note review, semi-structured interview and the qualitative synthesis was adopted to gain a fuller understanding of how chronic breathlessness contributes to emergency presentations by integrating the findings from each method. A justification of the methodology of each component of the research will now be discussed.

3.3.2 Systematic Literature Review and Qualitative Synthesis

Methodology

There are many papers about the experience of breathlessness, however research is usually centred on the experience of specific conditions that have breathlessness as one feature of the condition, for example COPD or heart failure, rather than describing the experience of breathlessness *per se*.

Therefore the focus of this review is to bring together what is known in the literature about the experience of chronic breathlessness (irrespective of underlying causes) from a wide range of sources to describe the experience of breathlessness and in particular how patients with chronic breathlessness interact with the healthcare system.

In performing a literature review it is important to draw on as wide a range of sources as possible to avoid selection bias and so a systematic search was performed as recommended by the Centre for Reviews and Dissemination (69). Systematic reviews are an effective way of summarising the findings of many individual studies and making these findings more available to healthcare professionals to inform their understanding and practice. Systematic reviews use pre-specified and reproducible methods and thus the findings have high validity (69).

The search identified qualitative papers only and a qualitative synthesis of the findings was performed. One way of presenting data would have been to describe the findings in narrative fashion, but that would risk losing the opportunity to provide a synthesis which goes beyond the individual findings of the papers and enables a more generalisable and powerful conclusion to be drawn (70). Whilst methods for synthesising quantitative data are well established, this is not the case for qualitative research, although qualitative syntheses are becoming a more recognised method in the health sciences. The Cochrane Library now includes qualitative syntheses which was hailed as a milestone for the Cochrane Library by Gulmezoglu et al. (71) who argue that such syntheses provide an important contribution of knowledge to bodies such as the WHO enabling better recommendations on healthcare practices to be made.

There are several methods for performing qualitative syntheses including meta-ethnography, critical interpretive synthesis, thematic synthesis, realist review and meta-aggregation (70). The method chosen for this qualitative synthesis was thematic synthesis as outlined by Thomas and Harden (72). Thematic synthesis is a well-developed method of systematically searching for relevant qualitative research and then synthesising their findings based on the principles of thematic analysis (73). Thematic synthesis is recommended for use as a realist method of synthesis which can develop a final product capable of informing health policy and practice (70). Thomas and Harden (72) argue that producing a synthesis of qualitative research allows the unique perspective that individual pieces of qualitative research can provide to be synthesised into one paper. This can then reach a wider audience to inform practice.

In her overview of the methods of qualitative syntheses available Paterson (70) argues that the method chosen should reflect the philosophical stance of the researcher and also the type of research studies available. The dimensions she suggests the researcher pay attention to are aggregative/interpretive, epistemology and degree of iteration. Thematic synthesis was chosen because it involves a realist approach that research can adequately represent an external reality, in line with the epistemological position held by the researcher, in which data is aggregated and then themes are developed with a certain degree of interpretation. Thematic synthesis aims to take some account of the context of each study, whilst aiming to produce a synthetic product which is to some extent generalisable and represents a shared reality (74). The range of primary qualitative research studies available in the area of breathlessness was found to be heterogeneous in terms of their research aims and populations studied and therefore it would not be suitable to perform a meta-ethnography, which typically is performed on a small number of homogeneous studies where it is possible to compare the themes developed in each piece of research (75). Thus having considered the research studies available, the researcher's epistemological position and resource requirements necessary as Paterson suggests (70) thematic synthesis was chosen as the most suitable method for a qualitative synthesis of the studies available.

3.3.3 Survey Methodology

In order to establish the prevalence of chronic breathlessness causing presentation to the ED a prospective survey was devised. This is a quantitative research method where the aim is to reduce bias and to produce both generalisable and replicable findings. A cross-sectional or survey design is the most appropriate method of obtaining descriptive information from a large number of people at a single point in time and is commonly used in applied health research to collect quantitative data (76). One limitation of the survey method is that it obtains descriptive information of what people do, however cannot easily explore the reasons behind their behaviour (77). Therefore this descriptive information collected will then be integrated with findings from the other methods used, to give both the basic facts and an appreciation of why people present to the ED. This method was chosen (rather than a randomised controlled trial or a case control study) as descriptive information was needed and no intervention was being evaluated nor was aetiology of a condition being investigated.

This is an appropriate research method as a prospective survey was also used in a similar (but much larger scale) study in the USA which found a prevalence of 3.2% of adult presentations to the ED were due to breathlessness (23). Their survey was however filled in by staff rather than patients and didn't distinguish between chronic breathlessness and acute breathlessness. This survey at the HRI added to the findings of this study as it asked specifically about chronic breathlessness and also had items about patient decision making and care accessed.

A prospective survey was chosen as it was not possible to use a retrospective method of extracting data from hospital records to obtain much of the data needed by this study. This is because the required information was from the patient's perspective and also information on chronic breathlessness is not routinely collected in the ED, as it is primarily an acute setting. Prospective data also gives more complete information than retrospective data collection (78). To reduce participant burden any information that was easily accessible from patient records was extracted from the notes (with consent) rather than having more items in the survey and thus increasing its length. A paper survey was

used, rather than a postal or internet survey, as the participants were all people who were in the ED and were waiting there with time to fill in a survey if they chose.

This survey was designed as a self-completed survey rather than a researcher administered survey and this is an appropriate method as both the explanation given for the study and the types of questions used were straightforward (76). Closed questions were used, with an easy to follow design consisting of only four pages to reduce respondent fatigue. Another reason for choosing a self-completed survey design was that the research was carried out by only one researcher who would not have been able to administer the necessary number of surveys to reach the sample size needed for accurate calculation of prevalence in the time available. One drawback of using a self-completed survey is that low literacy may be a barrier to completion and thus result in a lower response rate, however to overcome this issue the questions were written in plain language and also carers were allowed to help the participant fill in the form if necessary. Unfortunately resources for translating the survey into other languages were not available and so non-English speakers would not have been able to fill in the survey, thus possibly reducing response rate.

Sampling is another important aspect of carrying out a survey, as the sampling method chosen can reduce or increase bias (77). By using a prospective method, with a consecutive sample, selection bias was reduced and external validity was increased, as all patients presenting to the ED (with capacity to complete a survey) at any time and on any day were offered the survey to complete, rather than only selecting a convenience sample of patients. The survey was given consecutively out for 18 days until the predetermined sample size had been reached in order to be able to estimate the prevalence of presentation to the ED due to chronic breathlessness with an acceptable level of precision. Probability sampling, such as randomly choosing certain patients to give the survey to, or purposive sampling whereby patients with specific characteristics are targeted, could have led to unnecessary confusion in an already busy working environment and possibly resulted in a lower number of people being offered the survey.

One limitation of this method is that the sample was those people attending the ED at the HRI in the month of May only, rather than at several time points throughout the year, thus the prevalence measured does not take into account any seasonal variation and the likelihood is that the prevalence measured is an underestimate compared with one measured throughout an entire year. However every care has been taken when designing the survey to ensure that the findings are as generalisable as possible.

The survey was designed to be straightforward to read and fill in, with much attention paid to reducing participant burden and to minimise missing data. To this end the majority of participants only needed to fill in the first page of the survey, with the minority of participants (those with chronic breathlessness) filling out the whole survey. Participant burden was also reduced for those participants who continued filling out the survey as the questions asked were limited to information only they could supply, with any information already recorded (e.g. time and date of presentation, number of previous attendances in last 12 months...) being extracted from case notes.

In summary, the choice of a prospective, self-completed paper survey design with a consecutive sample is justified to answer certain aspects of the research questions of this study. This choice of design also allowed the researcher to obtain consent from the participants to view their clinical notes and to ask for permission to contact some participants to request an interview.

3.3.4 Case Note Review Methodology

A case note review is a retrospective, quantitative research method. The use of existing data and its secondary analysis is a useful study design used across a variety of research disciplines (79), for example this design was used in health science research by Sari et al. (80) when assessing the sensitivity of patient safety reporting in a UK hospital. In this thesis case notes were used to access routinely collected information to enable an analysis of how patients were assessed, treated and referred on when presenting to the ED with chronic breathlessness. One advantage of collecting treatment data retrospectively is that the clinicians making the notes are not aware that the documents are being

used in research and therefore it is unlikely that there will be any bias due to their knowing they are being observed (78). Thus if the aim is to investigate usual care, then this method will not risk influencing care given because the clinicians are not aware of the subject being studied. However, the primary limitation in using existing data is the information may be incomplete and/or documented inconsistently (78), especially where the topic of investigation is one which is not routinely and systematically reported, such as breathlessness on presentation to the ED.

The aims of this aspect of the research were twofold. One reason for reviewing the notes was to extract relevant information, such as basic demographics, to reduce burden on the survey participants and to find information that cannot be obtained using the patient survey (for example, details of what assessments and treatments the patient went on to have in hospital). A second reason was to obtain information to enable comparison between patient self-report of breathlessness and the clinician's documentation of breathlessness as a reason for presentation. The information was gathered from the hospital notes of all breathless participants who gave consent to review their notes, rather than apply for section 251 of the NHS Act 2006 (81) access to all patients' case notes without seeking/gaining consent, due to time constraints inherent in the studentship, and therefore there may be some selection bias as consent was not provided by all eligible participants. A standard data extraction sheet by one researcher was used to ensure consistency.

In summary, the choice of the case note review design is justified to answer some of the research questions of this study. This choice of design enabled the researcher to extract information from confidential patient notes and to both add information to that given by the survey participant and to compare the patient's and the clinician's view of the breathlessness.

3.3.5 Interview Methodology

To answer the research questions and gain an understanding of the decision making, beliefs and experience of patients and carers it is necessary to use a qualitative methodology. The design chosen was the linked semi-structured

interview which was carried out with patients, their carer (if they had one) and subsequently with their nominated healthcare professional (if one was nominated and later consented to be interviewed). There are other qualitative approaches which could have been used for this research, for example participant observation, however for methodological and practical reasons the interview was chosen. Participant observation has a number of advantages over interviews, including prolonged experience of the setting of the research, a more naturalistic approach and the ability to observe behaviour directly, rather than rely only on what is said in answer to what is asked in an interview (76). However, participant observation was not chosen as it would not have been feasible to observe people in their homes as they were deciding to present to the ED, nor would an understanding of their thoughts, beliefs and feelings about presentation have been achievable through observation. From a practical point of view this research was carried out by one researcher who wouldn't have had time to observe continually in the ED for the amount of time necessary to generate data from a reasonable number of encounters and so participant observation was not chosen as the approach for these research questions. Participant observation would however have been appropriate for researching into the experience people have in the ED and how the prevailing culture in the ED impacts breathless patients' care.

The semi-structured interview is widely used and can give insight into perceptions and behaviours (82). However it has limitations, for example it may be biased, as it is a social interaction between the researcher and the researched which has a researcher-led agenda (82). Furthermore interviews call for a retrospective reconstruction of events and rely heavily on memory, which may be distorted by the emotions felt by the person, thereby increasing the saliency of some memories over others (83). Interview data is a reconstruction of what happened in the past and may also be biased due to the intersubjective nature of the interview, in that participants may answer in socially acceptable ways or attempt to answer in a way they think the researcher would like them to. However, despite these limitations it is the conscious sense-making or reconstruction of events by the participants which is of interest here and therefore the use of the interview is justified to answer the research questions on what beliefs patients and carers hold about

breathlessness, how patients and carers come to the decision to present to the ED and what is their experience of the ED once they have presented. This will allow the interviewees to make sense of their decisions and experiences in describing them to the researcher.

The philosophical approach taken when constructing the interview topic guides was that of phenomenology, in which exploring the lived experience of the patient, carer and healthcare professional of presenting to the ED is the main aim of the research. Phenomenology is an interpretivist approach to understanding how people subjectively make sense of the world and of their experience in it and how this sense-making affects their behaviour (84). The topic guides were developed using open-ended questions to elicit in-depth answers about their experience and also the sense they made of the situation they were in.

An approach adopted when using the phenomenological perspective is that of imaginative variation, in which aspects of the phenomenon under investigation are altered slightly to gain insight into what the phenomenon is precisely, by seeing how the changes would alter the phenomenon for the person (84). To this end the topic guide had questions on how the decision to present to the ED was made in this instance, as well as questions relating to previous times when the patient felt very breathless however chose not to present to the ED.

A purposive sample of patients with a wide range of specific characteristics (sex, living alone/with others, malignant/non-malignant diagnosis, socioeconomic status, smoking status and number of previous ED presentations) was selected from those who filled in the survey indicating that they experienced chronic breathlessness and that their presentation was due to breathlessness and had also indicated willingness to be approached for the interview, to gain maximum variation in responses and experience. Another approach to sampling that could have been used is probability sampling, in which a random sample of participants is invited for interview; however this approach was not adopted so that variation amongst the participants in key characteristics aligned with the research questions could be achieved. The limitation of choosing to sample purposively is that it can be argued that any findings are not generalisable to the entire population, however this is not the

aim of qualitative research which aims for understanding of the richness of individual experience.

Having selected a sample of patients from the survey participants, some were interviewed alone (if they had no informal carer) and some were interviewed with their nominated informal carer. The nominated healthcare professional was then interviewed separately.

In this study patients with long-term conditions and their carer were interviewed together (where there was a nominated carer) for a number of reasons. To reduce the burden on the patients and also their carer it was decided that it would be beneficial for them to be interviewed together, therefore not requiring the patient to be left alone whilst their carer was interviewed. Whilst this meant that some information which might have been given by either the patient or the carer individually (e.g. feelings of letting the other person down/being a burden) may not have been offered, there was potential to gain insight into the dynamics between the patient and carer which could shed light on how both of them might play a part in the decision to present to the ED. Arksey and Knight (85) argue that joint interviewing may enable the establishment of rapport more easily, as the interviewees may feel safe together. Also a more complete account of their experience may emerge as each fills in the gaps of the other. Seymour et al. (86) recommend the researcher should think carefully about the rationale for interviewing people together or separately, considering theoretical, methodological and practical aspects of the research when making their choice. For this study the joint interview was chosen to allow observation of the interaction of the couple and to allow for practical issues such as lack of suitable spaces in the participant's home. In addition this approach obviated the need for two interviewers if the participants were to be interviewed separately or in the case that the patient could not be left unattended.

However Seymour et al. (86) point out that there are limitations to joint interviewing if the material to be discussed is particularly sensitive or if it is necessary to get each person's individual perspective on the research question. On balance it was felt that the questions asked in this research were about issues that each participant would feel comfortable to discuss with their partner in general. Arksey and Knight (85) also point out other limitations of joint

interviewing, such as one interviewee dominating the other in the interview or the possibility of stirring up antagonism between patient and carer. Therefore care was taken not to pressure either participant into answering any questions they didn't want to and to allow each participant their turn to contribute. Another reason for choosing to interview the patient and carer together was to reduce any possible ethical issues around concerns about confidentiality which can arise when participants are interviewed separately and may say things they do not wish to be disclosed to the other (87). By interviewing them together both participants were aware the other was listening and therefore could choose what they wished to disclose.

3.4 Justification of Mixed Methods Approach

The two main methodologies used in the applied health sciences are quantitative and qualitative research. Quantitative research has its roots in the positivist epistemological tradition in which knowledge is gained by direct observation to test hypotheses and there is an assumption that the researcher can be objective and value free, thus not directly affecting the persons being researched. Quantitative research is often used in the natural sciences and can also be applied to a range of other disciplines including the health sciences where there is a need to quantify certain aspects of the research area. Conversely qualitative research has its roots in the interpretivist epistemological position, widely used in the social and health sciences, in which the focus of study is other human beings and where knowledge is seen as being subjectively constructed through a process of interaction with others (76).

These two methodological paradigms can be viewed as mutually exclusive and incompatible if the nature of the difference between them is seen from an epistemological perspective, in which the nature of knowledge and how it can be generated is of paramount concern. However, if the nature of the difference between qualitative and quantitative research methodologies is seen from a technical perspective, in which the emphasis is on the relative strengths of the research methods generated by each paradigm, then the two paradigms do not need to be seen as mutually exclusive, but rather as mutually supportive and thus a mixed methods approach (one using a mixture of quantitative and

qualitative research methods) can be justified as it results in a greater understanding of the subject under study than would be gained with either method alone (76).

According to Creswell (88) there are four philosophical worldviews which guide research and these are post-positivism, constructivism, transformative and pragmatism. Creswell (88) suggests that pragmatism is the worldview which best supports mixed methods research, with its emphasis on the research questions and on choosing methods to answer them appropriately, rather than focusing on epistemology or ontology. The pragmatic approach to research is to choose methods intentionally, with a clear rationale guiding the choice, so as to fully answer the research problems by using relevant forms of data collection and analysis. The adoption of the pragmatic approach is argued for by Morgan (89) in his paper entitled "Paradigms Lost and Pragmatism Regained" in which he suggests that it is an approach which supports the appropriate use of both quantitative and qualitative research methods by focusing researchers' attention on methodological issues rather than metaphysical ones.

When adopting the pragmatic approach the choice of methods to be used in mixed methods research is driven by the research questions asked (88). The first two research questions of this thesis were asked in order to understand the degree to which presentation due to chronic breathlessness occurs and to track what happens to patients once they have presented. This gives a greater understanding of the impact of chronic breathlessness on the hospital system as well as on the individual patient. These research questions can be best answered by using quantitative methods and for this reason a survey and case note review were performed. The use of closed questions in the survey and the use of a data extraction sheet for the case note review allow data to be gathered from a large number of people for statistical analysis and provide information which is generalisable.

Alongside answering the first research question (measuring the prevalence of presentation due to breathlessness) the survey also provides some information from a large number of people on what state they were in both before and as they presented to the ED and who was involved in the decision to present. Thus the data gathered from the survey goes some way to answering the research

question on how patients decide to present to the ED. However, when designing a survey questions are formed from existing knowledge of the situation to be researched and a limited number of answer options are provided. Whilst this allows for statistical analysis it does not allow for other types of answers that a patient may wish to provide, nor does it allow for complex answers to be given. For this reason findings from the survey were complemented by the use of qualitative semi-structured interviews to enable a richer understanding of the ways in which these decisions are made. Thus the same research questions can be approached using both quantitative and qualitative methods (i.e. mixed methods) to obtain a clearer picture of the situation.

Quantitative methods can only give a limited understanding of why patients present to the ED, therefore a qualitative synthesis of the research literature on the experience of breathlessness and qualitative semi-structured interviews were performed in order to gain a fuller understanding of the experience of and beliefs about breathlessness and how decisions are made to present to the ED. Answering all of the above research questions is important if a greater understanding of how chronic breathlessness results in presentation to the ED is to be reached and therefore a mixed methods approach was adopted, as it allows for multiple methods of inquiry to be used to generate both breadth and depth of data and then the findings to be integrated to obtain a more complete understanding of the area researched.

This research is an example of a sequential design (88) in which initial quantitative research both measures prevalence of presentation and subsequent hospital care and also gives some insight into why patients present, this then being developed further in a detailed exploration by interview of a number of individuals in a purposive sample drawn from survey participants. Finally the results from each of these methods were combined with findings from the qualitative synthesis and integrated at the analysis stage.

The rationale given for mixed methods research varies widely between studies and in a recent content analysis of mixed methods research articles Bryman (76) identified sixteen different rationales given by researchers to defend their choice of using mixed methods research. The three main rationales for using

the mixed methods approach in this thesis are completeness, the ability to answer several research questions and also to aid sampling for different aspects of the research. The first two rationales have been described. The third rationale, the issue of gaining access to a sample, is a vital aspect of this research. At the end of the survey consent was requested to gain access to patients' notes, thus allowing the researcher, who was not part of the patient's clinical team and therefore not allowed to view case notes without consent, to review patient notes. Consent to contact the patient to arrange an interview was also requested at the end of the survey, thus allowing access to a group of patients (who all suffered chronic breathlessness which had lead them to present to the ED) from which a purposive sample could be selected to interview.

In summary the mixed methods approach taken in this thesis is justified as the research questions can be answered with completeness to give a rich understanding of what influences the presentation of patients with chronic breathlessness to the ED.

3.5 Summary

Chapter Three outlined and justified the methodology used in this thesis to answer the research questions arising from Chapters One and Two. To this end a mixed methods study was designed involving a sequence of quantitative followed by qualitative methods, the results of which were integrated at analysis. This approach was required in order to answer the various research questions and also to provide a recruitment strategy for both the case note review and the interviews. The following three chapters will detail the methods used and the data gathered by: systematic literature review and qualitative synthesis; survey and case note review and finally interview.

Chapter Four: Systematic literature review and qualitative synthesis of the literature on the experience of breathlessness

4.1 Introduction

Chapter Two described the experience of living with chronic breathlessness and introduced the concept of “total dyspnea” which will form part of the theoretical framework for this qualitative synthesis. Chapter Three described the methodology chosen to answer the research questions posed in this thesis. This chapter presents the methods used, the findings and a discussion of the findings from the systematic review and qualitative synthesis to answer the research question number four:

What is the experience of people living with daily breathlessness due to chronic medical conditions and those caring for or treating them with regard to their coping with and help-seeking for their breathlessness, particularly with regard to their interaction with healthcare services?

4.2 Systematic literature review method

4.2.1 Search Methods

A systematic search of qualitative studies was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) principles (90). This involved a systematic approach to searching and review allowing transparency and reproducibility.

The search strategy (see Appendix 1 Search strategy for systematic literature review) was guided by search terms, derivatives and related Medical Subject Headings (MeSH) terms for breathlessness (exposure); patient, carer and healthcare professional (population); and experience, interaction, help-seeking, coping and beliefs (outcomes of interest) combined with a validated filter for identifying qualitative research (91).

The search was developed with advice from a supervisor (Miriam Johnson [MJ], UoH) and a university librarian (Catriona Kemp, UoH) experienced in searching the literature. The search was intentionally made very wide and then narrowed down by the application of inclusion and exclusion criteria as there is a large amount of qualitative research on the experience of breathlessness, although few papers have healthcare use and coping as their specific focus.

4.2.2 Search strategy

Searches were conducted on 4/8/14 by Ann Hutchinson (AH) on Medline, PsycINFO, Embase and CINAHL which are extensive, electronic databases, commonly used in the health sciences. In addition studies were identified by hand searching of the reference lists of relevant qualitative reviews and through email contact with experts in breathlessness. Titles and abstracts were independently reviewed by two reviewers (AH and Natalie Barclay-Klingbe (NBK) [a final year medical student on an academic elective]) with respect to the inclusion and exclusion criteria (see Appendix 2 Inclusion and exclusion criteria), any disagreements being resolved in discussion with a third researcher (MJ). Full text articles of all studies included on the basis of title and abstract were accessed and independently reviewed by two reviewers (AH and NBK) and the final selection of studies to be included in the review was made by agreement between AH, NBK and MJ.

Studies were included if they were published in English between January 1987 and July 2014; reported on the experience of breathlessness due to any underlying chronic condition (other than asthma or obesity or in a restricted population e.g. post-transplant) from the perspective of patients, carers or healthcare professionals and presented primary empirical qualitative data in the publication.

4.2.3 Quality appraisal

The quality of the included studies was assessed using the Qualitative Assessment and Review Instrument (QARI) critical appraisal checklist for

interpretive and critical research (92) (see Appendix 3 QARI Critical Appraisal Checklist for Interpretive and Critical Research). This measure was chosen as it enables a general judgement to be made on the quality of the research with respect to the congruity between the research methodology, research questions, methods used, analysis performed and the interpretation of the results in order to decide the weight that was given to the findings when synthesising. Quality appraisal was not used in the eligibility criteria in recognition that valuable findings may be present even in poor quality studies. Quality appraisal was carried out for all selected papers by one researcher (AH) with 5 papers being assessed independently by a second researcher (NBK).

4.2.4 Data extraction

A data extraction tool was developed to extract contextual information about each study and all primary data in the form of direct quotations from participants. Data were extracted from all papers by one researcher (AH), with data extraction from a random sample of 5 papers being done independently by another researcher (NBK). The data were handled using NVivo.

4.3 Qualitative synthesis method

A thematic synthesis (see Chapter Three) was made of the included qualitative literature on the experience of breathlessness from the perspectives of breathless patients and also their carer and healthcare professionals (72). The synthesis was performed in three stages: line-by-line coding of the primary research findings of each included study; organisation of these codes into descriptive themes and finally the development of analytical themes (72). The initial coding of primary data was performed by AH using NVivo which was then discussed and refined in discussion with MJ and Kathleen Galvin (AH). Initial codes were then organised into descriptive themes and confirmed through discussion with MJ and KG. Finally analytical themes were developed in discussion with MJ and KG to provide a broad understanding of the experience of breathlessness and interaction with healthcare services. Transparency of the method, independent selection of and extraction from primary studies and group

discussion ensured that the review and synthesis process was performed with rigour and the product presented valid findings.

4.3.1 Theoretical frameworks

4.3.1.1 Theoretical framework for the widespread effects of breathlessness theme

As described in Chapter Two the effects of breathlessness are wide ranging, encompassing the physical, psychological, social and existential realms and can best be understood when thought of as “total dyspnea” (3). Therefore the framework of “total dyspnea” was used when analysing the data with regard to this outcome.

4.3.1.2 Theoretical framework for the coping outcome

Coping is defined as a set of cognitive and behavioural responses that individuals use in order to manage or tolerate stress (93). Examples of coping responses are problem solving, cognitive restructuring, problem avoidance and social withdrawal.

Lazarus and Folkman (93) hypothesise that coping responses can be categorised as either problem-focused or emotion-focused coping, however Tobin et al. (94) argue that a categorisation of coping responses as engaged or disengaged coping results in a more efficient description. This categorisation by Tobin et al. (94) encompasses both the problem-focused and the emotion-focused categorisation of Lazarus and Folkman (93) as well as the approach/avoidance classification first described by the Greek hedonist philosopher Epicurus (95) and elaborated on by Freud (96) who both considered that the drive to receive pleasure and avoid pain was a basic motivating force for all humans. The weakness of the categorisation that Lazarus and Folkman (93) adopt is that each category has within it responses which employ approach and also those which entail avoidance, whereas the

categories used by Tobin et al. (94) each entail only approach or avoidance responses and therefore Tobin's categorisation of engaged and disengaged coping styles has more explanatory power and will be employed as the theoretical framework for the coping theme in this thesis.

According to Tobin et al. (94) engaged coping involves approaching the stressor and employing problem- and emotion-focused responses which include problem solving, cognitive restructuring, expressing emotion and seeking social support to enable the person to manage the stress effectively. Conversely disengaged coping involves avoiding the stressor and employing problem- and emotion-focused responses which include problem avoidance, wishful thinking, self-criticism and social withdrawal.

4.3.1.3 Theoretical framework for the help-seeking outcome

The definition of help-seeking behaviour for a health problem given by Cornally and McCarthy (97) "a problem focused, planned behaviour, involving interpersonal interaction with a selected healthcare professional" will be used as a framework for the analysis of the help-seeking theme. Using this definition it is possible to break the concept of help-seeking down into its constituent parts and to analyse the differing ways people seek help. Before the help-seeking behaviour is enacted the intention to seek help needs to be formulated and this involves several steps: problem recognition and definition, the decision to act and the selection of the source of help.

4.3.1.4 Theoretical framework for the interaction with healthcare professionals outcome

To better understand the interaction between patient and healthcare professional in any interaction the concept of epistemic injustice, "a wrong done to someone specifically in their capacity as a knower" (98) has explanatory power and was used as the theoretical framework to analyse the outcome which related to interaction with healthcare professionals. Epistemic injustice can be subdivided into testimonial injustice and hermeneutical injustice.

"Testimonial injustice occurs when prejudice causes a hearer to give a deflated

level of credibility to a speaker's word" (98), thus when it arises a person's testimony (or what they know) is not taken into account when a decision is made by another. "Hermeneutical injustice occurs when a gap in collective interpretative resources puts a speaker at a disadvantage when trying to make sense of their social experiences" (98), thus it arises when there is no shared understanding of a phenomenon with which to be able to fully interpret a particular experience.

Carel and Kidd (99) argue that ill persons (patients) are "particularly vulnerable to epistemic injustice". They argue that patients may suffer testimonial injustice as they may be viewed by healthcare professionals as unreliable informants who are emotionally unstable and as such the information that the patient proffers (their testimony) may be downgraded or even disregarded when decisions are made with respect to diagnosis and treatment. Furthermore, Carel and Kidd (99) argue that patients may suffer hermeneutical injustice since much of the illness experience is difficult for others who have not experienced it to fully understand.

4.4 Findings

4.4.1 Included papers

Searches were conducted on 04/08/2014 by AH on the following databases: Ovid MEDLINE (1996 to July week 4 2014), Embase (1996 to 2014 Week 31), CINAHL Plus (1987 to July Week 5 2014) and PsychINFO (1987 to July Week 5 2014). Titles and abstracts were independently reviewed by two reviewers (AH and NBK) with respect to the inclusion and exclusion criteria, any disagreements being resolved in discussion with a third researcher (MJ). Full text articles of all included studies were accessed. The reference lists of all included studies and of relevant reviews were checked for further studies and any relevant titles were screened by AH and NBK with respect to the inclusion and exclusion criteria, any disagreements being resolved in discussion with a third researcher (MJ).

One thousand, nine hundred and fifty nine papers were identified through the database searches, with an additional 32 papers identified through other

sources. These papers were independently screened and after discussion between AH, NBK and MJ 77 full papers were selected to be included in the synthesis (see Appendix 4 PRISMA flow diagram). The characteristics of the included papers are detailed in Appendix 5 Table 11 (Characteristics of included studies).

4.4.2 Introduction to the synthesis findings

Four main themes were identified: i) Widespread effects of breathlessness, ii) Coping, iii) Help-seeking and iv) Healthcare professional responsiveness to breathlessness (see Table 2). These are consistent with the overview of living with breathlessness given in Chapter Two, but distil in more detail the impact of and response to breathlessness itself by the patients, carers and their healthcare professionals.

Table 2 Themes from the systematic literature review

Themes	Subthemes	Codes
Widespread effects of breathlessness	Physical effects Psychological effects Social effects Existential effects	Bereavement, change in relationships, change in roles or identity, impact on carer, isolation, manner of death, restricted freedom, physical limitations, psychological effects, shrinking lifeworld, social limitations, stress of breathlessness, carers needs, hopelessness, loss, self-esteem, social embarrassment, spiritual or existential aspect
Coping	Disengaged coping Engaged coping	Acceptance, adaptation, communication, cooperation with patient needed, helplessness, importance of mobility, lack of understanding, co-morbidities, breathing techniques, attitude to support groups, one day at a time, carer's own health, palliative care, sense of duty, smoking cessation, stagnation, stoicism, carer-support needed, community support, pulmonary rehabilitation, self-management, autonomy, avoidance, being cared for, benefit of air movement,

		benefit of being outside, benefit of fan, benefit of fresh air, breathlessness as a way of life, connectedness, health within illness, hope, hopelessness, importance of mobility, increased activity post PR, increased self-efficacy, injustice, innovation, lack of knowledge, motivation to keep going, need for activity, own pace, perseverance, resignation, self-monitoring, breathlessness is normal, struggling, suicide, support from others, taking one day at a time, stigma, hiding,
Help-seeking behaviour	Recognising breathlessness as a problem to be solved Deciding to take action Selecting a potential helper Disclosing the problem Consequences of help-seeking Help-seeking styles	Help-seeking, reluctance to present to healthcare professional, pride not asking for help, need for information, information seeking for self, lack of information, explaining it away, access to healthcare professional, lack of acknowledgement, consultation constraints
Healthcare professional responsiveness to breathlessness	Testimonial injustice Hermeneutical injustice Consequences of non-responsiveness or responsiveness to breathlessness	epistemic injustice, lack of understanding, nothing more can be done, palliative care, clinician distress, diagnosis, prognosis, holistic approach, management of breathlessness, future care, invisibility, continuity of care, where to present, waiting

4.4.3 First theme: Widespread effects of breathlessness

The framework used to analyse this theme was “total dyspnea” (3), which encompasses the physical, psychological, social and existential effects of breathlessness.

4.4.3.1 Physical effects

Chronic breathlessness exacts a heavy physical toll on those experiencing it, leading to curtailment of activities of daily living, disability, increased dependence on others and poor quality of life. Patients commented, across studies, that activities of daily living such as self-care are severely disrupted:

“The worst thing I think is the stairs, going up and down the stairs. Ordinary household chores I find difficult. Very restrictive, because of your breathing. And now of late... even simple things like having a shower and getting dressed.” (Patient) (100)

Physical limitations have wide ranging effects on a person’s life, for example people suffering from chronic breathlessness find it hard to walk far and to lift things thereby making daily activities such as shopping difficult:

“I can walk around 200 yards and then I have to sit down and rest even on a flat road.

You could walk round the shops but you couldn’t carry anything.” (Patient) (101)

This reduced ability to carry out activities of daily living results in dependency on others which can be difficult to come to terms with:

“Being dependent on somebody used to make me upset in the beginning. Sometimes, although I was forcing myself to the limits not to ask for help, I was trying to manage my own work. But now, both me and people around me got accustomed to this disease.” (Patient) (102)

Not only does breathlessness impose physical limitations on patients, but their carer’s physical health can be affected by their role of carer. Individuals describe how their own health suffers:

“No time to worry about my physical health.” “My health is not too good, I am physically worn out, anyhow I try not to think about it so much ... One has to work put food on the table and take care of the home as well.” (Carer) (103)

As can be seen from these quotes the physical limitations imposed by breathlessness have extensive effects on people’s daily lives, which in turn can have psychological, social and existential effects on both patients and those caring for them which are described in the following sections.

4.4.3.2 Psychological effects

Breathlessness is closely interrelated with anxiety and panic, often leaving patients feeling very vulnerable:

“Then I’d be fine but I am all the time worried—worried when this breathing will attack me again” (Patient) (62)

It can mean that people panic thinking they might be about to die or be very anxious about the manner of their death:

“My worst fear is of slowly suffocating, dying gasping for breath when I’m alone here in my flat on me own, that’s my worst fear.” (Patient) (41)

Equally carers may experience fear about their loved one's death:

"I have this constant fear that he will stop breathing, so I need to sleep near him so I can be on the alert if something happens." (Carer) (104)

Healthcare professionals describe how anxiety can lead to rapid deterioration in the patient's overall condition:

"I think when people get anxious, I mean, they really seem to deteriorate quickly. The anxiety has to be treated because they get ... I mean, they just pant and pant and pant. You can't get a handle on them when their anxiety is over the top." (Family physician) (105)

Not only do patients feel anxiety due to breathlessness but so do those that care for them:

"It ain't just me; it's my family as well. I've got two boys and my wife and they have to go through it as well, people tend to forget them . . . they just think about the person whose got the illness, not the people they've got around them and it does affect them big time, you know, it's um, they get emotional, they're frightened." (Carer) (106)

Breathlessness can also lead to depression as a result of the physical limitations experienced and the subsequent losses felt. Inability to be as active as they had previously been leads many patients to feel sadness and depression:

"Depression is the biggest problem. It is the worst, because if you were an active person all your life and now you're inactive, it's hard to accept." (Patient) (107)

Similarly breathlessness leads to frustration:

"Some days I can't do anything and I get very frustrated. I cry a lot, this happens a few times a week." (Patient) (108)

The strain of looking after someone who is depressed can exact a toll on those who care for them:

"He wouldn't have it that there was anything wrong with him. But that's just a thing, but between us we're we're alright, it just a strain, a constant strain of trying to keep him (...) not happy, but trying to keep him thinking positively and just trying to get through each day and some days it's not too bad and other days it's a real struggle ... he's becoming more and more depressed." (Carer) (104)

This strain on the carers can also lead to them experiencing depression:

"I had become so depressed just after Christmas that I used to sit down at night, just crying ... I went to my GP and he gave me some pills and I think they have helped me a bit ... I have at least stopped crying. Still I am awfully tired mentally, and sad, terribly sad, mentally I am worn out." (Carer) (103)

Understanding the psychological difficulties that are faced by breathless patients and their carers is key to helping them manage breathlessness; unfortunately not everyone feels they get the understanding they deserve:

“The emotional thing is extremely, extremely important. You don’t get the understanding ... you can just like get caught up in a downward spiral and you end up in this little place all by yourself ...” (Patient) (109)

4.4.3.3 Social effects

As previously described chronic breathlessness affects both patients and their carers significantly physically and psychologically, this in turn brings about various social consequences for them; including social isolation, changes to relationships and altered social roles.

Living with breathlessness on a daily basis results in developing ways of dealing with its impact and commonly patients describe how this results in changes in their lifestyle, often including some self-imposed limitations:

“I used to love dancing, I can’t you know, and going anywhere where there’s music now, no, no, because I want to get up and I can’t and it upsets us.” (Patient) (110)

As a consequence many become isolated and live with a constant sense of loss over all the activities they feel they are no longer able to do:

“My husband would say: ‘Shall we go down and see John and Juliana?’ and the thought of walking out that gate into the car, I would be absolutely gasping, I made excuses not to go out and this is what happens, the more you’re housebound, the more depressed you get.” (Patient) (111)

“We often feel lonely and on the edge of things.” (Patient) (112)

This isolation results in psychological distress and changes in relationships with others for both the patient and their carer:

“Gradually we have had less and less to talk about ... gives the impression that he has no interest anymore, neither in myself nor in his surroundings. I think this is some kind of envy of me, in my heart I can feel it ... After he started to go in and out of hospitals we stopped being good friends like we used to be ... The disease has isolated him from the family and myself, and now we have restricted issues to talk about ... it makes me sad when I think about it.” (Carer) (103)

Relationships may change due to having less to talk about, psychological distress experienced by the breathless person or increasing dependency:

“He’s very controlling he’s got me under his thumb. If he thinks I’m going to go somewhere and do something, he’ll find some way to get himself run down so I won’t be able to leave the house. He wants to know where I am 24/7 ...” (Carer) (113)

Also intimate relationships can be affected by breathlessness, however these issues may go untackled:

“I am really in need of some form of intimate contact with him, but I do not want do press him ... and this is something one cannot talk so easily about ... I am afraid he could sense it as an accusation.” (Carer) (103)

Both patient and carer may feel that their roles change when living with breathlessness. The physical effects of breathlessness mean that lifting and movement are constrained and activities like cooking, cleaning, decorating, making love or carrying shopping may become very difficult. When breathless people feel unable to do the activities they associate with their gender role they feel less of a man (or a woman) which can be very distressing:

“It’s the silly things . . . not being able to carry the shopping . . . I was brought up in the Victorian school . . . the man always carries the bags...” (Patient) (45)

“For people like Chris that you can’t actually see any physically wrong with them. I don’t know, it makes life that little bit more difficult when you go out coz people look at you, like if I’m carrying the shopping bags and he’s walking, doesn’t bother me in the least, but people look and then it makes him feel awkward.” (Carer) (54)

“He feels angry about the way breathing limits his life, he has been active all his life and now he can’t do anything about it. He further describes problems with maintaining an active sex life and is deeply concerned about it. His cancer and his breathing are affecting all parts of him not just his lungs; his breathing has been bad enough but this (impotence), he feels not a complete man anymore....” (Carer) (114)

Carers also undergo changes in their roles too, often moving away from having an intimate relationship (e.g. spouse) to having to take on many new roles:

“It’s a hard time I tell you and it gets you down. When you think what the nurse do in hospital, giving him his tablets and everything. I’m doing a thousand jobs as well. I’m just going crazy because you don’t get to the end of it... We’re nurses, we’re doctors, we’re housewives, we’re cooks, we’re gardeners. We’re shopping.” (Carer) (58)

This change in roles may lead to having to give up work and can adversely affect the relationship leading the carer to re-evaluate aspects of their life:

“I usually sleep with half an ear open . . . I put my life on hold . . . can’t talk about free time...” (Carer) (45)

“Over the last 8–9 years, I feel inside that my role’s completely changed. Somewhere in all of this, I’ve lost who I am. I’m more like his nurse or ‘I need you’ kind of thing. That’s it – I need you, and I don’t know how to explain it. I just feel like somewhere me, myself, I’m lost. I don’t know who I am any more. I don’t know if anybody can understand that.” (Carer) (113)

“Well I used to have a part time cleaning job and I mean it used to get me out of the house and bring in a bit of extra money each week like, you know, help supplement the income a bit. But I had to give it up 'cause it was all becoming too much for me, I was exhausted and besides I couldn't leave him on his own. I mean, it's so unpredictable these days that you're scared to leave him, there's no warning like, it comes on so sudden. So I had to give it up.” (Carer) (41)

4.4.3.4 Existential effects

There are many existential concerns associated with chronic breathlessness including inability to carry out religious observance, difficulty determining how best to use their remaining life, the daily struggle sometimes resulting in a lack of will to live and also the fear associated with the imagined manner of death.

Living with the burden of chronic breathlessness can mean that people are unable to continue on with their chosen religious observance at the very time they feel most in need of that support:

“I went down to Mass then in the car and I—my wife said to me ‘You shouldn't go down because you're not able to walk all that far’ and I really couldn't walk from the car park—I attempted and failed—to walk from the car to the church— which is only maybe about 200 yards—and I'd only gone a few yards and I said ‘Look I can't—you're right I can't go any further—I'll have to stop’— so I had to come back and get into the car and go home—but eh-ah well.” (Field Note: Eyes filled with tears and voice became shaky.) (Patient) (62)

Patient's difficulty in determining how best to use their remaining life arises from a number of issues with respect to diagnosis and prognosis. Patients find that there was a lack of information with respect to their diagnosis and that often it meant little to them:

“We were just told that it was COPD. I had never heard of it and in fact, I couldn't remember the sequence of letters for a long time.” (Patient) (39)

Often the relief at not having cancer means that patients do not realise the severity of their condition as this is not clearly described to them:

“I've been to the doctors and they've told me I've got COPD. ‘What is it?’ The doctor hasn't even explained what those four letters mean and the worst thing about it is it starts off with C, and first thing you think: ‘Oh, have I got cancer?’ But this is the thing that is wrong, it's [COPD] not a well-known disease, yet it's one of the greatest killers.” (Patient) (39)

Little attention is paid to describing likely prognosis with patients being left in a limbo, feeling they had an uncertain future and living day by day without planning:

“Erm, you know, I can’t really say [how I see the future] we’ll just take each day as it comes.”
(Patient) (39)

The lack of meaning of the diagnosis and inattention to prognosis means that they are unable to determine how they wish to spend the time left to them:

“At the time we weren’t really told that was a degenerative condition that it would gradually get worse. At the beginning we weren’t told that it was a general decline. We were just told this is what you’ve got, get on with it. Yes, in the beginning I would have liked a little bit more information. At least it prepares you for the general decline in his health.” (Patient) (39)

Many people also feel doubts over whether their life is worth living and express the desire to end their lives in order “to end the struggle to breathe” (Patient) (108):

“When the shortness of breath was at its extreme, I thought I was going to die and saw a coffin beside me and then I was in a tunnel... I did have thoughts about suicide and I envied the dead.” (Patient) (114)

Also fear of the manner of their death can be a concern, with many patients unaware of both how their underlying condition may bring about their death and also how it could be medically managed by appropriate palliative care. With this lack of knowledge many patients (and also carers) believe that they may die with the feeling of suffocating that they regularly experience with increased breathlessness and fear this:

“My worst fear is of slowly suffocating, dying gasping for breath when I’m alone here in my flat on me own, that’s my worst fear.” (Patient) (41)

“I’ve always said I’m not afraid of dying ‘cause I know where I’m going. But when I get short of breath I get scared – I don’t know why – I shouldn’t. I think smothering to death is a hard way to go.” (Patient) (115)

When these issues are not discussed and planned for then the manner of death may indeed be very distressful for all concerned as described by the husband of a patient who died from lung cancer:

“...drown in her secretions sitting upright looking into my eyes crying for help. It was a nightmare and now I can't get those pictures out of my head, I know I did my best but I failed her-it was exactly what we didn't want, my life is in complete tatters.” (Carer) (114)

4.4.4 Second theme: Coping

From the above description of the first theme it is clear that the experience of living with chronic breathlessness causes a considerable degree of stress to both patients and those caring for them. The long-term consequences to an individual patient's health and the health of their carer are influenced by how the patient copes with this stress. Tobin's categorisation of engaged and disengaged coping (94) was used as a framework to analyse the findings for the coping outcome.

4.4.4.1 Disengaged coping with the effects of breathlessness

The qualitative literature reviewed included many examples of patients employing disengaged coping strategies in the face of the stress caused by breathlessness. According to Tobin et al. disengaged coping is characterised by “problem avoidance”, “wishful thinking”, “self-criticism” and “social withdrawal” (94).

“Problem avoidance” is one strategy used in disengaged coping in which the patient may attempt to carry on with life as if nothing had happened. This can take several forms including ignoring the breathlessness as it gradually becomes more apparent and writing it off as being due to another cause such as getting older. This approach may lead to not seeking medical help for the symptom:

“About 30 years ago, I was first told that I had the beginnings of emphysema... So, what's that mean? I mean, how bad can that be? I didn't have time to be sick. I didn't have time to have an ailment, and so I didn't let it bother me...I just continued to let it get worse, and ignored it.” (Patient) (116)

Alternatively a patient may accept they have breathlessness but not be prepared to make any changes or adaptations that could potentially help them:

“To top it all off I couldn’t even walk round bloody Sainsbury’s. And she says [work colleague] ‘Well why don’t you get one of those little motorized things with a basket?’ and I said “I’M NOT DOING THAT!” (Patient) (106)

A second disengaged coping strategy is “wishful thinking” or wishing that the problem will just go away of its own accord. This may involve repressing health worries or avoiding thinking about the future and long-term prognosis for their condition; meaning that issues that could be tackled are avoided:

“First you don’t want to recognize that you’re repressing everything unpleasant...like sweeping it under the rug...but sometimes it all comes out anyway.” (Patient) (117)

“I know when the nurse first said, ‘I’m referring you to [a day centre run by the local hospice]’ I thought oh God! This isn’t terminal! Not me!” (Patient) (118)

A third disengaged coping strategy is the emotion-focused strategy of “self-criticism” which may be a common response in breathless patients as there is a strong link between smoking and the underlying conditions which cause breathlessness such as lung cancer, COPD and heart failure. This self-blame may lead the patient to hide all signs of their breathlessness from others, thus avoiding social embarrassment at not being able to take part in everyday activities without being breathless and also feeling that they are unworthy of support for a symptom they have brought on themselves:

“I resent myself for letting it get to this, for smoking. For being stupid. When I did know better I did nothing about it. It was my own choice.” (Patient) (61)

“Are we wasting valuable time for someone else or... or are we a lost cause - I mean you obviously think that way, don’t you?” (Patient) (58)

Similarly patients displaying the disengaged coping strategy of “social withdrawal” may become isolated due to avoiding social situations:

“Sometimes you think ‘I’d like to go for a pint tonight’. But when it’s time to go for a pint I’ll sit here on the settee without the energy to go out” (Patient) (101)

“But sometimes I think well, why do you want to sit down on walls every five minutes, breathing in and out. People come and say: “Are you alright dear, can I help you?” I say: “No I’m fine thanks,” “Are you sure?” I say: “Yeah.” So I think well, just get a taxi and it’ll drop you outside the house, no people coming out of houses, nobody asking questions and no feeling exhausted when you get in.” (Patient) (55)

Also sometimes patients intentionally hide their breathlessness from others:

“Even if it’s going next door, you can see the anxiety building up because he will never ever show anybody what he’s like. He won’t show it. It’s only me knows, it’s only me knows in the family.” (Carer) (100)

“Because we’re quite private because of what’s happened, his world is imploded and in some respects so has mine, erm, and I really don’t think that perhaps other people outside really truly appreciate what goes on and what the stresses and strains are, because we hide them.” (Carer) (54)

This means they may not be able to bring themselves to access social support from either friends or family, nor from support groups for breathless people:

“I’ve never been one for group activities ... it seems too Americanised to me.” (Patient) (119)

“...she wouldn’t go to a community group, she is not into that.” (Carer) (100)

It may also lead to poorer quality of life due to isolation, psychological stress and lack of social support:

“Sometimes, especially when I’m left in here on me own, I get to thinking: ‘I don’t know what I’m living for’, ‘not worth living like this’, you know, more or less feeling sorry for meself I suppose [laughs].” (Patient) (41)

4.4.4.2 Engaged coping with the effects of breathlessness

According to Tobin et al. engaged coping involves approaching the stressor and employing problem- and emotion-focused responses which include “problem solving”, “cognitive restructuring”, “expressing emotion” and “seeking social support” to enable the person to manage the stress effectively (94).

From the literature reviewed it is also possible to find many examples of engaged coping amongst breathless patients who recognise that they have breathlessness but that it doesn’t need to rule their lives. Engaged coping is characterised by continuing to be active, acceptance, finding ways to adapt to the difficulties caused by breathlessness and remaining calm.

Instead of avoiding activities that cause breathlessness engaged copers use “problem solving” to find new ways of managing their daily lives by adapting their activities or pacing themselves:

“Yesterday, I left my shower until the afternoon and I found that I was much better. I had the water just above body heat—so as not to have too much steam, and I had a draught blowing through.” (Patient) (61)

“I try not to exert myself, but I realise that I still have to exercise. So when the weather is good I can go out and walk back and forward and when I have walked for a while, I notice that I can walk longer distances without becoming breathless. -I know when I have to sit down and try to breathe calmly and deeply.” (Patient) (120)

Alternatively people may problem solve by using various aids or choosing alternative activities which they still can find rewarding:

“There’s a lot I can’t do. I can’t run up and downstairs. I’m on oxygen 16 hours a day, which I have piped through the house. I’ve got an oxygen meter upstairs in the bedroom. But I still get out a bit. I mean we go to [son’s] house at the weekend. I get a prescription from the doctors and send it up to him and he gets some oxygen bottles. I take my plumbing up there.” (Patient) (121)

“I do Shiang Kung (a gentle martial art) in a nearby park at 4pm everyday. I think this is a good exercise for aged people like us. We cannot handle very strenuous exercise.” (Patient) (122)

Engaged copers also employ “cognitive restructuring” whereby they come to look at their situation in a new way so that it doesn’t appear so bleak. This can be achieved by thinking positively and having a ‘can do’ attitude:

“I think far more along the lines of ‘can do’ rather along the lines of what is impossible to do.” (Patient) (58)

“Do the best you can with what you’ve got.” (Patient) (118)

“Cognitive restructuring” can also involve people being accepting of their limitations and their prognosis:

“You just learn to live with what you got... it’s kind of a state of mind. You’re about as happy as you want to be.” (Patient) (123)

“I am not going to live forever, but I am going to live the best I can for as long as I can.” (Patient) (124)

It [COPD] eats up your life, up the time, you know you learn to enjoy what you can and work on what you can’t. (Patient) (109)

They may also develop an informed understanding of their situation by seeking information from others:

“One thing I found useful was the literature and advice... from the right source on the subject. There’s a certain comfort factor in thinking I’m not abnormal.” (Patient) (106)

“If other people have the same thing, I would like to know how they cope with it; it might help me.” (Patient) (107)

If they smoked they may rethink their attitude to smoking and decide to cut down or stop:

“I’ve managed to cut it down to five a day, but it’s hard, blimmin’ hard. I mean I know it’s for me own good, but it’s not bleedin’ easy breakin’ the habit of a lifetime is it?” (Patient) (41)

Engaged copers can consider what/who is important to them and express this to others by using a further type of emotion-focused engaged coping which is “expressing emotions”:

“But that’s normally what I do, I’ll either get angry and I’ll go and bash something or I’ll shed a few tears.” (Patient) (54)

“Well, this is what we’re trying to work out with the counsellor, what we can do with the positive that we can have a relationship that we both are happy with.” (Carer) (54)

“Well you have to talk with people who know what you’re talking about and unless you’ve really walked this trip, you really don’t know what it’s about and that’s why I like RAPS [support group].” (Patient) (109)

This may also involve demonstrating self-compassion, where instead of self-blame patients who have smoked may be able to show their younger selves compassion and recognise that at the time they started smoking it wasn’t well understood that smoking was harmful and so they needn’t take the blame:

“I know it’s self-inflicted. I’m not very happy about it, but you have to accept it. My mother and father smoked, it was a way of life, smoking. We were not aware then of the health damage it could do.” (Patient) (108)

Furthermore engaged copers may “seek social support” from both family and friends and also from others who have breathlessness and have learnt to deal with it:

“To get out and about, that’s the most important.” (Patient) (41)

"I felt comfortable ... all the other people here with the same problems and you find out you're not alone." "You get an incentive to try and help yourself more when you see what other people have done, you say okay, maybe I should try this, maybe I should try that." (Patient) (109)

"You think if other people can do it so can I, it encourages you." (Patient) (125)

"I don't have many friends so I did use it as a bit of social time." (Patient) (125)

Continuing to be sociable may be achieved by various methods including getting out and about with the use of assistive aids like ambulatory oxygen, nebulisers or mobility aids and also by using technologies such as phones and the internet to keep in touch:

"I go to friends sometimes and take my nebuliser with me. She understands and does not mind. I usually have to 'psych' myself up and keep my fingers crossed that I'm ok on the day. Otherwise you could be tied in forever." (Patient) (108)

"The relationship (with family) hasn't suffered, but it's a different kind of relationship. It's a 'telephone relationship'." (Patient) (58)

4.4.5 Third theme: Help-seeking behaviour

By applying the concept analysis of help-seeking by Cornally and McCarthy (97) to breathlessness it can be seen that the patient is therefore required to: (i) recognise breathlessness as a problem that could be solved (ii) decide to take action (iii) select who can be asked to help and (iv) disclose the problem to the potential helper. From this breakdown it can be seen that there are several steps involved in seeking help, each of which may have other factors influencing how they are carried out.

4.4.5.1 Recognising breathlessness as a problem to be solved

The first step in seeking help for breathlessness is that a patient needs to recognise it as a problem that can be solved. Many breathless patients however take a long time to realise that breathlessness is a problem affecting them, since it often develops slowly:

"But the breathlessness as I have now has been creeping on quite insidiously so it's hard to define" (Patient) (126)

Also some may explain away their breathlessness as usual for their age or for a smoker and so not see it as a problem to be solved:

“There were times when I struggled but I just thought it was because of old age and just let it go.” (Patient) (127)

“I didn’t go (to GP) because I always put it down to just me smoking. I didn’t go to the GP, not to that extent, only if I’d got something, you know, wrong with me. But I’d get a bit out of breath and you know as I say I just put it down to smoking like.” (Patient) (41)

Breathlessness can remain hidden from others as patients often feel it is poorly understood and others do not seem to recognise that they have difficulties because of breathlessness:

“Actually I’ve been called a fraud before now you know yeah half joking like but all the same I’ve had it said: you’re a fraud, look at you there’s nothing the matter with you. Tell em you’ve got cancer or that you’ve had a heart attack or something like that and they’re very sympathetic and understanding, but tell ‘em you’ve got emphysema and they look at you blank like... They just don’t seem to understand the extent of it.” (Patient) (41)

It is worth pointing out that breathlessness can rarely be solved, however it can be managed. The wording used by Cornally and McCarthy (97) in their concept analysis may not be entirely applicable to breathlessness, nonetheless the first stage in seeking help for breathlessness is that the person recognises that there is a problem and that it can be addressed, therefore it is worth seeking help for.

4.4.5.2 Deciding to take action

Once the patient has recognised breathlessness as a problem that can be addressed the patient needs to decide to take action. That is they need to actively form an intention to act and whilst some patients do this many breathless patients remain passive and do not decide to take action or have difficulty deciding when to take action:

“I don’t easily go to see a doctor.” (Patient) (128)

“It has to be really bad for me to ... see the doctor” (Patient) (128)

"I'm virtually house bound ... and I don't like to call a doctor out and you know always have a problem with (home visits) coz I never feel as though I'm ill enough to ask them to come out to see me, you know what I mean?" (Patient) (129)

This may be for many reasons including their self-efficacy, locus of control, fears, class and gender norms and past experiences of help-seeking. Patients may also feel unworthy of help as a result of the stigma they feel is attached to their condition:

"Are we wasting valuable time for someone else or... or are we a lost cause - I mean you obviously think that way, don't you?" (Patient) (58)

If a breathless patient doesn't individually decide to take action for their everyday breathlessness sometimes it is left to the family to make that decision:

Interviewer: "Are you confident you know when is the right time to be looking for help?"

Patient: "My son is always here."

Interviewer: "Would you know when to call the doctor?"

Patient: "My son would do." (Patient) (130)

"My daughter asked for him. I didn't ask for him, she sent for him." (Patient) (131)

4.4.5.3 Selecting a potential helper

The next step in help-seeking is selecting a potential helper. In the UK a general practitioner (GP) is usually the first port of call for a health problem and so a patient who sees breathlessness as a problem which can be addressed *and* who decides to act would contact their GP when seeking help:

"Just to know there's somebody out there cares about you, what happens to you . . . he (GP) talks to me and calms me down . . . said he's only a phone call away, he's always willing to come out." (Patient) (45)

"I see my own doctor who understands how I feel and he's always very understanding and I get on very well with him." (Patient) (58)

Some patients, however, may think that they cannot discuss their breathlessness with their GP but instead they are meant to discuss it only with their specialist doctor:

Interviewer: 'Is your GP involved in the care for your lungs?'

Patient: 'No. I'm seeing a respiratory physician...' 'I visit the respiratory physician once a year, and when I'm really ill I go and see my GP. But that can be about something completely different. We don't discuss my emphysema then. It's registered somewhere, emphysema, but we don't talk about it.' (Patient) (132)

In crisis the patient may not feel able to access their GP and so not seek help there, instead feeling that they should seek help from the ED:

"I was working in work and my breathing all that week had been rather haywire...I do maintenance and we were steam cleaning, er, a patio garden in our firm—and I am afraid the steam really wound me up and I couldn't breathe after about 10 or 15 min of this. So I said to the guy "Look I am no good" I said "I've got to go". I said I'm feeling dizzy, I feel as if I'm going to faint'... So I went downstairs for five min and I was no good. I said "look I am going home". So... I sat on the bed for about an hour. I couldn't breathe, and I was in pain and I thought Jesus I've got to get to hospital!" (Patient) (46)

4.4.5.4 Disclosing the problem

Finally when the patient meets the potential helper they need to disclose the problem for which they are seeking help. However there are many factors that can influence this disclosure, for example time constraints and the need to repeat information numerous times impose limitations on the level of detail that can be gone into:

"We thought we would see the senior doctor, but then we came in to see the other doctor. And what do you know? ...nothing more than we knew already. And I was sitting there with my notepad where I had prepared my questions to ask. But I didn't come to asking them, because there is no time. He has to run his clinic of course, that's why he got up in the end and didn't listen anymore. And then you sit there and when he asks you "How are things?", "OK" you say. "No, not OK, why do you think we were there, because I've got serious problems, I sometimes hardly come through the day!" (Patient) (39)

"For the first, say, two or three years, I was under, well I was seeing Dr G all the time and then, all of a sudden, in about a year, I found that I'd seen about four or five different doctors. And I found that a bit of a problem really, 'cause you've got no continuity at all. You've got to explain it all again really, start from scratch each time, and that can be very wearing. 'Cause you're out of breath to start with, and you get more and more out of breath trying to explain why you're out of breath (laughs)!" (Patient) (41)

As this is an interpersonal situation the characteristics and manner of the listener also affect what is disclosed. A patient will also make decisions on what information to disclose to a healthcare professional and may decide that something isn't medically relevant and thus not mention it, even though it is important to them:

"You can't go to the doctor and say "I can't dance." It's a strange thing to say to the doctor."
(Patient) (55)

Similarly if a patient discloses information relevant to breathlessness it may not be responded to and so further disclosure may not happen:

"I wanted people to take notice... I used to offer this information... I'm really quite breathless... they were probably more interested in the pain..." (Patient) (45)

Thus, at this point in the help-seeking behaviour, full disclosure of the effects of breathlessness on the patient's life may or may not occur. It may be that only a limited amount of detail is given and the problem defined in terms of having worsened breathlessness due to a chest infection for example, which will in turn influence the help offered.

4.4.5.5 Consequences of help-seeking

The help-seeking behaviour once performed will then have certain consequences such as problem resolution or management and increased well-being:

"It's fantastic because you have the practical exercise and then you have the education, and that is as important because I knew nothing about it [COPD] until then and I learned so much and how to cope." (Patient) (111)

Alternatively the problem may remain unresolved and result in subsequent dissatisfaction, anger or resentment and increased helplessness, which in turn will affect future help-seeking behaviour. The patient may then decide to seek help from an alternative potential helper, use health services inappropriately or may give up thinking that either their problem is not valid or that there is nothing that can be done to solve it:

“They have given me about all the drugs they can to cope with it. I don’t think they can do anything more.” (Patient) (133)

4.4.6 Fourth theme: Healthcare professional responsiveness to breathlessness

The concept of epistemic injustice (98) has been employed as the theoretical framework with which to analyse the theme of healthcare professional responsiveness to breathlessness. Epistemic injustice can be subdivided into testimonial and hermeneutical injustice and each can shape patient/healthcare professional interactions.

As previously described, a patient who chooses to seek help is performing “a problem focused, planned behaviour, involving interpersonal interaction with a selected healthcare professional” (97) and as such, not only is what the patient chooses to seek help for and what information they disclose important, but so is the responsiveness of the healthcare professional to what the patient says, with the interaction between the two shaping both the present consultation as it unfolds and also future consultations.

4.4.6.1 Testimonial injustice

Patients with chronic breathlessness suffer testimonial injustice (99) due to several factors: including not being seen as an expert; self-censorship of what is disclosed to a healthcare professional; limitations of the consultation itself and who controls the consultation.

Reliance on medical knowledge, observable signs and symptoms, and objective performance tests such as the FEV1 (forced expiratory volume in 1 second) by healthcare professionals may lead them to disregard the patient’s subjective information about their experience of breathlessness and overall functioning. This may explain the experience of this COPD patient:

“It started about 4 years ago, I was visiting next door’s new baby...when I tried to lift him up I couldn’t breathe. I went to the doctors and had all the tests and when they came back normal I

just carried on. There were times when I struggled but I just thought it was because of old age and just let it go.” (Patient) (127)

However, other patients had better experiences. An example of a healthcare professional taking a biopsychosocial approach and attending to the patient’s testimony (testimonial *justice*) is given here by a carer of a COPD patient:

“They were great . . . they sat and listened . . . and explained . . . tried to get to the bottom of things. . . tended to know more than just an ordinary nurse.” (Carer) (45)

Another way in which testimonial injustice may arise is that the patients themselves may select which information to tell the healthcare professional based on their understanding of what is likely to be thought relevant, as was the case with the patient who reported:

“You can’t go to the doctor and say “I can’t dance.” It’s a strange thing to say to the doctor.” (Patient) (55)

It is as if the patient feels the need to adopt medical terminology and present certain symptoms to be taken seriously by healthcare professionals. However not being able to dance any more isn’t trivial to her and this is an example of how patients come to think they can only talk about physical symptoms to a doctor, rather than being able to discuss how a symptom is affecting them in all dimensions of their lives and as a result the breathlessness she is experiencing is going untreated.

Testimonial injustice may also arise as a result of the structure of a consultation. Consultations are subject to time pressure and this may lead to the healthcare professional managing the time available by changing the course of what is discussed away from what the patient wishes to disclose about their breathlessness:

“I wanted people to take notice . . . I used to offer this information . . . I’m really quite breathless . . . they were probably more interested in the pain....” (Patient) (45)

This time pressure may be even more overtly expressed by a healthcare professional by making it clear they control the consultation and showing it is over by standing up for example or hurrying the patient:

“All he is interested in is give me a prescription, how do you feel, yep . . . you have had your 10 minutes . . . on your way.” (Patient) (131)

Equally the time pressure on consultations may be felt to be a hindrance to the healthcare professional too as expressed by this GP:

"I think time's a massive issue. In your ten minute consultation when they've come with a fungal toenail infection and this, that and the other, to actually say 'and we also need to talk about your COPD, and you do realise that eventually you could possibly die from this illness' it just opens a massive can of worms and so you don't really want to go there. And that's the practicalities of the job really." (Doctor) (134):

Testimonial injustice can arise when healthcare professionals take charge of consultations, controlling what is discussed and in doing so do not offering opportunities for patients to express their needs:

I got a car to the doctor's and walked in, it was a sunny day and I just felt very depressed ... I felt sad but he said "But you're here in very good form." I said "Yes, thank you very much, bye doctor" and all smiles, what a nice man. And [I] left to walk to the bus stop and by that time, I was out of breath and exhausted. And I thought "Ah, I remember why I was depressed, getting out of the car to the doctor's was quite easy, but then after the surgery, real life kicked in." (Patient) (55)

Similarly the lack of opportunity to discuss things in a consultation is felt by carers:

"I know I could honestly do this if I could occasionally get a rest, maybe one week, a couple of weeks, three weeks at a time and then I would be happy to have him at home in between ... but I could never go to the doctor and just say, I can't do this anymore'. No, I have not noticed any open door offering help for myself." (Carer) (103)

Conversely some healthcare professionals understand the importance of offering patients the opportunity to discuss what is important to them:

"Of course, I think that the nurse has a very great part to play, particularly for the COPD patient... it's just this, having a chance to, well, talk about one's life situation at all. You must get the chance to see the physician too, there's no doubt of that, but the physician doesn't have an hour to spare." (Nurse) (135)

Testimonial injustice occurs when what the patient says is not believed, a forcible example of which is given by this heart failure patient:

“Now, the oxygen would bring me around by the time I got to A&E and they'd be looking at me like I was a CRIMINAL!—like—that I shouldn't BE there and the first question you heard ‘Are you sure it's not in your own head? Now THEY were telling ME that what had happened to me couldn't happen but it WAS happening and that's the most frightening part—they didn't believe me” (Patient) (62)

4.4.6.2 Hermeneutical injustice

In the literature reviewed there were examples of how difficult patients find it to explain their symptoms to healthcare professionals and the apparent lack of understanding of how breathlessness affects them:

“And he said to me: “Where do you work?” I said “Work.?” He said: “What do you do for a job?” I said: “Well, nothing doctor.” He said: “What do you do for a living?” I said: “Nothing.” And then I left. I thought what a silly question to ask me, “What do you do for a living?” And he said: “Why do you live downstairs?” and I said because it saves going upstairs. And then afterwards I thought, [..], he's seen emphysema on the screen [of his computer] but didn't realize the full extent of it. I mean, there's no way I could get a job or could go to work.” (Patient) (55)

This may be compounded by the patient often appearing comfortable when at rest in the consultation:

And they must say ‘Oh there's THAT one again’ and sometimes I had to stay on the trolley all night and like they'd be looking at me like ‘What's wrong with HER?’ because by the time they see me I'd be alright maybe?” (Patient) (62)

It can be argued that hermeneutical injustice occurs with respect to breathlessness due to insufficient understanding of how it affects people. Gysels and Higginson (55) describe how patients feel their symptoms are very unpredictable, rather inexplicable and their wide-ranging impact poorly understood by health professionals, which results in a lack of support and limited offers of medical advice and help:

I felt so bad, couldn't breathe, had to sit down, couldn't walk from here to the door. I went to the doctor [but] she didn't know what to do with me, so she said “OK, get yourself into casualty, you have to go to hospital and casualty is the only way to get into the hospital.” So all right, in casualty. There, they look at me, [they ask] “What are you doing here?” [They] don't want to admit me. [When] I'm back here, with a prescription for antibiotics, she comes in [and asks] “Why are you not in hospital?” [I answer] “Well tell ME!” (Patient) (55)

This lack of understanding is described by a patient with chronic bronchitis:

“They can’t appreciate what you’re feeling so you are wasting your time talking. They are sympathetic but they don’t really understand. They don’t know the pain and suffering that you go through sometimes” (Patient) (136)

4.4.6.3 Consequences of non-responsiveness to breathlessness

As described above the occurrence of epistemic injustice can lead to healthcare professionals lacking a full understanding of the effects of breathlessness, this in turn resulting in their non-response. Gysels and Higginson (55) describe a pattern of non-response from healthcare professionals to COPD patients’ complaints of breathlessness and there are examples of this non-responsiveness from the literature reviewed.

A common theme was that there was “nothing more that could be done” for the patient and subsequently both patients and carers felt abandoned:

“They have given me about all the drugs they can to cope with it. I don’t think they can do anything more.” (Patient) (133)

“I know there was nothing they could do for him and he knew, but it was a feeling of you’re abandoned, we don’t want to see you no more. There is nothing we can do, no, but there is tender loving care. Even if there is nothing they can do. At least he would have known that someone was out there.” (Carer) (137)

“But then when you leave hospital he knew that there was nothing after that. Nothing there was just me and him.” (Carer) (137)

There was a lack of information on what to do in future or of palliative care or exercise to help with the breathlessness:

“I’ve heard of it [palliative care] but to be honest I never understood what the word meant.” (Patient) (138)

“We’ve never been given any information about that (exercise). We just thought that it was...something he had to put up with. So, no we weren’t, we’ve never been aware that there were things that he could have done to help him. I just thought, well, it’s what he’s got to put up.”(Carer) (100)

Also some clinicians find managing these patients distressing:

I think sometimes it’s overwhelming to be out in the community alone, not having those resources, so that can weigh you down emotionally because sometimes you can feel helpless that you’re going in and you’re doing the best that you can but you don’t have the resources available to help them So, going in to see them over and over again and not getting anywhere other than trying to do basic symptom control for each situation that they’re in can be quite discouraging.” (Doctor) (105)

"I think it is distressing and difficult. I find it very distressing when you come to see someone who is breathless....You don't get the immediate relief like you do with pain relief." (Doctor) (139)

There were examples of clinicians not seeing the impact of breathlessness, nor understanding the difficulties the patients and carers were having:

"No, no one has asked about me. Sometimes I wish someone would ask how we're doing here at home." (Carer) (140)

Consequently there was a clear indication that it would not be discussed and little guidance on the underlying condition or its prognosis:

Mrs. F.: "This was over a year ago they told me there's nothing they could do."

Mr. F.: "but even then he didn't answer me question, did he?"

Mrs. F.: "Well, I don't suppose he could."

Mr. F.: "Well, of course he could."

Mrs. F.: "No, that was a question that I don't think any doctor would want to be asked.

[turning to the interviewer] "He asked Dr. C. how long have I got?"

Mr. F.: "I said how long can I survive with this, well surely."

Mrs. F.: "Well, technically that's the same type of thing."

Mr. F.: "If you ask the doctor you expect an answer, I wouldn't ask you if I didn't want an answer."

Mrs. F.: "Yes but you know, how long is a piece of string."

Mr. F.: "Well, I'd sooner know the truth."

Mrs. F.: [turning to the interviewer] "Yes, he, you know, he's prepared for the inevitable." (Patient and Carer) (39)

This lack of discussion of breathlessness and how to manage it left patients experiencing great difficulty in knowing when to present to hospital:

"There was no mention like that at the doctors about when you should, if you are poorly and you need to send for an ambulance, there was no mention of that." (Patient) (110)

Therefore some patients were reluctant to bother anyone and so desperately coped alone as best they could whilst others felt that hospital presentation was their only route to rescue:

“They’re all terrifying at night—I go ‘Uh oh here we go again’ you just have to get out—put your feet on the floor, and you think ‘Will I ring the ambulance or not?’ or ‘Am I going to die under this one?’ But most times I don’t ring anybody I just sit up all night waiting for it to pass and there’s nobody in the house so that’s really frightening.” (Patient) (62)

“Sometimes you can think, when you’re too sick, that they [medical staff] can tell me what to do, so I don’t have to make all the decisions. I trust myself, but it would be nice if someone just took care of me like that.” (Patient) (141)

The lack of response to breathlessness was accompanied by a lack of information about the underlying condition. For example many suffering COPD were often not told they had COPD, therefore they came to see themselves as having a succession of chest infections. Alternatively they were given a diagnosis which held almost no meaning to them (39) and which resulted in little change to their lives. Commonly the diagnosis of COPD was seen as a relief since it meant they didn’t have the cancer they had feared, only later coming to realise that COPD is also a life-limiting condition.

This lack of discussion of prognosis and likely future quality of life also resulted in some people not seeing the importance of preventative measures such as smoking cessation:

“The doctor said to me it will cut 10 years off of your life. Ten years didn’t mean a thing to me at that age and I thought well 10 years I’d be too old to enjoy life by then. But if I’d been told that you’re not going to be able to walk around your own home, and not play with your grandchildren, you see, I’ve always spent time with my grandchildren, that would have made me give up smoking immediately.” (Patient) (39)

It also results in people only seeing themselves as ill when they have a chest infection, the rest of the time seeing the breathlessness as normal:

“People like Mr X who doesn’t really bother us that much, we really only see him when he’s not well.” (Doctor) (118)

“Getting breathless has become normal for me, I don’t even notice it.” (Patient) (119)

4.4.6.4 Consequences of responsiveness to breathlessness

There were also examples in the literature of patients finding that their healthcare professionals were responsive to their breathlessness. In these cases the patient felt listened to and understood as a result of being treated in an epistemically just manner. Knowing that a healthcare professional is available and responsive to breathlessness provides great peace of mind to both patients and their carers:

“They are very good and I know I can ring them up. The doctors are great, they are marvellous; you can ring or he’ll even ring to see if you are alright. That means an awful lot. When he is doing well I don’t like to bother them. When you need a person, that’s the time that you ring, when he is not great.” (Carer) (138)

When a healthcare professional takes the time to understand the complexity of a patient’s concerns it can be very beneficial:

“It makes you much more relaxed, and we don’t feel so intimidated. You feel more comfortable—like having a warm bath instead of a cold shower.” (Patient) (61)

Having the impact of their breathlessness recognised by the healthcare professional resulted in offers of management of breathlessness and a palliative care approach being taken even if the patient was not deemed to be at the end of life. Being offered the opportunity to talk means that decisions can be made about future care:

“I don’t think people [with COPD] realise you can do this, can make wishes or choices of what happens, to say ‘I don’t want to go into hospital, it doesn’t matter what’, things like that, so that in a way they’re prepared for it... I just don’t think a lot of patients realise that they do have these choices, and if you don’t bring up the subject they’re never going to find out.” (Doctor) (134)

Similarly a responsive healthcare professional can enable the patient to counter any self-blame there may be over having smoked and potentially contributed to their present breathlessness:

“Well, you often meet patients who say: ‘It’s my own fault for smoking for so many years’– but then I usually answer: ‘You mustn’t say that, because when you started smoking, no one knew how dangerous it was. It’s no use crying over spilt milk,’ and I think they understand that’s how it is.” (Nurse) (135)

Taking this approach results in patients being more able to cope with their breathlessness:

“She has got me organised and now I understand how the disease works. As a result I have had a good summer. It makes me feel more resilient.” (Patient) (142)

Not only is this approach beneficial to patients and their carers but it also results in greater satisfaction for the healthcare professionals working with them:

“I still think we can make a major difference to their quality of life through various interventions aimed at symptoms, um [...] so certainly the feedback that one gets from patients is that they certainly feel they've gone from being hopeless that that what they were suffering was what they had to suffer and and just through the implementation of some very simple symptom based remedies one can make a big difference to how they feel.” (Doctor) (104)

And here a healthcare professional describes her aim when working with breathless patients:

“It's a matter of trying to manage them the best we can at that level and help them make the most out of that time and not just lie down under it.” (Healthcare professional) (143)

4.4.7 Breathing Space: a concept to describe life with breathlessness

In this thesis the ‘Breathing Space’ concept is used to represent the findings of the systematic literature review. It is the overarching analytical theme resulting from an integration of the three descriptive themes: coping style, help-seeking behaviour and healthcare professional responsiveness to breathlessness. The phrase breathing space (also called breathing room or breathing while) dates back to the 1600s (144) (145) and it has several connotations including:

“A period of rest from a difficult activity that allows you to get your energy back or try a different solution” (146)

Thus a breathing space can be seen as an opportunity to rest from the relentless difficulties thrown up by breathlessness and plan how you'll achieve the things you most want to do.

“Sufficient space in which to move, work, etc.” (147)

“Enough area to permit freedom of movement/a pause for rest” (148)

Here breathing space denotes a space in which activity can continue, work can be done and things can be achieved by the patient.

This quote from *Life without work* by Christine Ingham (149) illustrates how a breathing space can allow a person to find out what is important to them and to be themselves:

“Circumstances may have conspired to give you the breathing space in which you can meet your real self.”

Similarly Alfred, Lord Tennyson (1842) in his poem *Locksley Hall* (150) writes:

“There the passions cramp'd no longer shall have scope and breathing-space.”

Here Tennyson uses breathing space to denote space in which one can follow one's desires and act upon them, rather than keeping them hidden.

Taken together these various definitions allow the phrase Breathing Space to be used as a metaphor for the experience of living with breathlessness; with the connotations of rest from the constraints imposed by breathlessness, space and time to recoup strength and plan further action and the circumstances under which one can find one's priorities and then fulfil them. It is argued in this thesis that the concept of Breathing Space extends and adds to the concept of “total dyspnea” (3), which usefully describes the multifaceted effects that breathlessness has on the lives of those living with it. Breathing Space describes the entirety of the experience of living with breathlessness, going beyond the widespread effects breathlessness causes, to encompass how the patient copes with their breathlessness, how they seek help for it and also how they are responded to by their healthcare professionals. The concept of Breathing Space draws on the definition of quality of life provided by Raphael et al. (1997) (66) which is “The degree to which a person enjoys the important possibilities of his or her life” and thereby emphasises that health goes beyond the absence of disease and extends to the person being able to find meaning in their life and be able to achieve what is important to them by the use of appropriate coping and help-seeking strategies alongside a responsiveness to breathlessness by their healthcare professionals.

Therefore, the degree of Breathing Space achieved represents the overall experience a person and those caring for them have of living with breathlessness. It is clear that breathlessness causes widespread limitations to the lives of both patient and carer, however it is argued here that their overall

experience of living with breathlessness will result from a complex interaction between the patient's coping style and help-seeking behaviour and the responsiveness of their healthcare professional to their breathlessness.

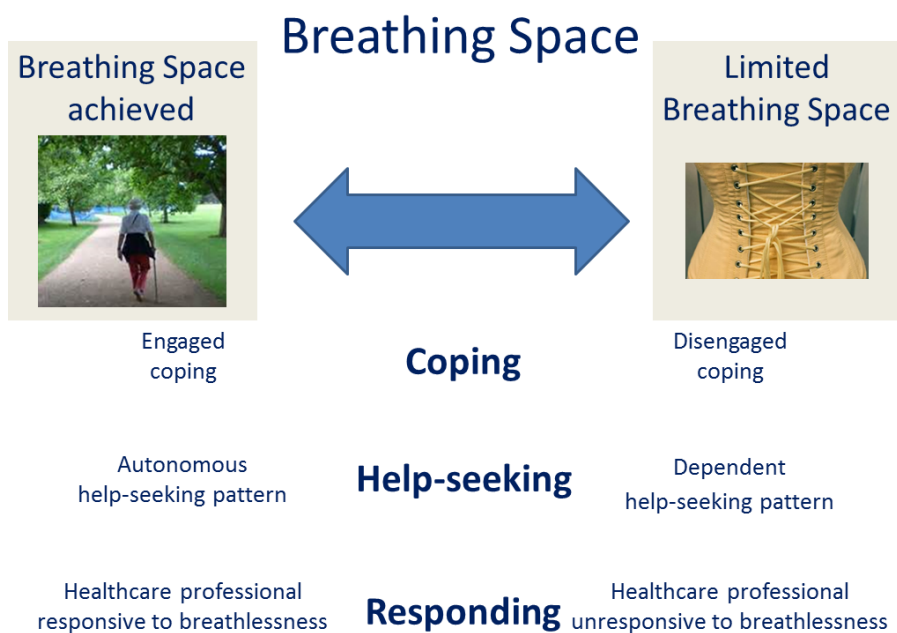


Figure 4 The Breathing Space concept

Breathing Space is a continuum with some patients having restricted Breathing Space, whilst others are able to achieve a considerable degree of Breathing Space. Restricted Breathing Space is characterised by avoidance, resignation and stagnation; together summarised in this thesis by the phrase “Life stops”:

“It just stops your life, stops you from living.” (Patient) (100)

“No, this isn't living, it's just existing...I just am.” (Patient) (117)

In this case patients may feel they have no control over their breathlessness:

“I have no activities, it controls me...it controls my life.” (Patient) (151)

It is argued here that this restricted Breathing Space would result from a combination of a disengaged coping style, dependent or delayed help-seeking behaviour and a lack of responsiveness to breathlessness by the patient's healthcare professionals.

Whereas achieving a considerable degree of Breathing Space is characterised by acceptance, adaptation and participation and is summarised in this thesis by the phrase “Life changes”:

“I’ve sort of changed my life. You can’t do the things you used to do, so you’ve got to say “well, okay, what can I do?” and do it.” (Patient) (61)

“All these experiences teach you to appreciate what is important in life especially things like good friends, books, good TV programmes and yes, what is important.” (120)

“I make the most of it and take it as it comes.” (108)

One patient describes how she is able to get out and have a good outing with her children and despite some difficulties have a good time together, thus achieving a considerable degree of Breathing Space :

“Walking was so difficult and we were supposed to bring our swimming gear and bottles (referring to oxygen tanks), so I got a wheelchair and the children pushed me and then parked me somewhere...I sat there and drank coffee and read...and occasionally they came over to touch base...it was great...but they could hardly reach the handles to steer and people didn’t get out of the way...so I had to call out beep beep (laughter)...it probably looked pretty funny...but we had an outing anyhow, and that was the main thing.” (Patient) (117)

It is argued here that a considerable degree of Breathing Space would result from a combination of an engaged coping style, autonomous and timely help-seeking behaviour and responsiveness to breathlessness by the relevant healthcare professionals. Consequently it may be that changes to a patient’s coping style and help-seeking behaviour and the responsiveness of their healthcare professionals to their breathlessness could all affect the degree of Breathing Space achieved and interventions aimed at changing those three aspects could be beneficial to the patient and those caring for them.

4.5 Discussion

This synthesis of 77 qualitative papers identified an overarching analytical theme of Breathing Space. This is built from the four descriptive themes identified from the literature: i) Widespread effects of breathlessness, ii) Coping, iii) Help-seeking and iv) Healthcare professional responsiveness to breathlessness. The concept of Breathing Space involves interaction between the various subthemes and this will be explored here.

4.5.1 Widespread effects of breathlessness, Help-seeking and Healthcare professional responsiveness to breathlessness

Breathlessness causes wide-ranging effects on the lives of patients and carers; physical, psychological, social and existential effects consistent with the concept of “total dyspnea” (3). It is important to realise that each of these realms affects the other, for example social isolation can result in depression and not being able to do physical activities can lead to changes in roles. Thus the concept of “total dyspnea” enables patients to be seen as complex, whole people in need of a holistic understanding of how breathlessness affects their lives on which effective management can be based.

However despite these manifold effects breathlessness is often coupled with epistemic injustice and may remain largely invisible to both the public and healthcare professionals; thereby greatly affecting the experience of those living with breathlessness and the Breathing Space they can achieve.

Gysels and Higginson (55) use the term “the invisibility of breathlessness” to describe the many difficulties breathless patients face in the recognition of breathlessness and their receipt of help for it. They go on to describe how this invisibility derives from: the slow onset of breathlessness; intentional hiding of the symptom and a lack of response from healthcare professionals.

The slow onset of breathlessness (particularly in COPD) can affect help-seeking in that breathlessness may not be recognised as a problem to seek help for until it becomes extreme, because it is often discounted by the patient as being due to aging, industrial exposure or smoking. Furthermore patients who smoke or have smoked in the past may not decide to take any action to seek help for their breathlessness due to considering that they had brought it on themselves through smoking and so are not worthy of taking up the doctors time.

Additionally some patients who are smokers may be reluctant to visit their healthcare professional for fear that the response they get will be judgemental and since they have been advised to stop smoking previously the healthcare professional may not respond well to them. Not seeking help for the above reasons will result in restricted Breathing Space as the breathlessness is not

being brought to the attention of healthcare professionals and therefore cannot be managed.

4.5.2 Widespread effects of breathlessness, Epistemic injustice, Help-seeking and Healthcare professional responsiveness to breathlessness

Breathlessness may be hidden intentionally because often it doesn't look like much is wrong with them if they are at rest and they may be made to feel a fraud by others. Additionally because there is a lack of public understanding of the underlying conditions such as COPD and heart failure, unlike cancer which is well known to the public, people may not realise the full extent of the problems caused by these conditions and so consider breathless patients a fraud. Therefore the intentional hiding of the effects of breathlessness is related to hermeneutical injustice; a lack of a collective understanding of the symptom and its effects. Also they may not seek help for their breathlessness even if they recognise it as a problem because they do not know that it is a problem *that could be solved* (97) due to poor public and professional understanding of the symptom and its management; this being related to hermeneutical injustice.

Additionally hermeneutical injustice may occur if the patient does seek help from a healthcare professional since the response can be variable, with those who both know about the extent of the effects of breathlessness and how it can be managed being responsive to it, whilst those with both a lack of awareness of the effects of the symptom and of its management being unresponsive (152).

Intentional hiding of the symptom of breathlessness, alongside the fact that at rest they may not appear to have anything wrong with them, means that breathless patients may not appear to need any help or treatment and this could contribute to the lack of response from healthcare professionals; the third aspect of the Invisibility of Breathlessness. Even when seeking help they may suffer testimonial injustice and not choose to disclose the effects that breathlessness is having on their lives considering it not medically relevant.

Carel and Kidd (99) argue that testimonial injustice arises partly as a result of the epistemic privilege healthcare professionals enjoy, due to their training and

expertise. When healthcare professionals see themselves as experts (i.e. more accurate knowers than patients) they may concentrate on what they themselves know about the illness, instead of listening to what they the patient has to say.

A stronger focus on tests rather than the information offered by patients is unlikely to be a conscious response from the healthcare professional, but may arise from a biomedical mind-set acquired in their training that involves emphasis on gaining medically relevant facts from a patient and in which parts of a patient's testimony may be seen as irrational, irrelevant, overemotional or inarticulate. This is not to say that all healthcare professionals intend to ignore what patients have to say, it may simply be that their training leads them to seeing themselves as experts whose job it is to select out information that they deem to be relevant and thereby they may miss other potentially useful information that they could get from the patient who is after all expert in how the condition is affecting them. A healthcare professional adopting a biomedical approach may listen with empathy to a patient, but not see the relevance of their testimony. In contrast one adopting a biopsychosocial approach may garner vital information about how the patient is functioning socially and psychologically, which when taken into account in decision making would alter treatment offered.

From the literature reviewed both testimonial and hermeneutical injustice towards breathlessness patients and their carers occurs. When epistemic injustice occurs healthcare professionals are not in full possession of the facts about their patient's condition and this leads to a lack of response from the healthcare professional, resulting in patients and those caring for them not being offered the full range of potentially beneficial treatments for their breathlessness.

4.5.3 Widespread effects of breathlessness, Coping and Help-seeking

Breathlessness may also be invisible due to the intentional hiding of the symptom by patients due to embarrassment over being breathless and their inability to do many things they previously could. This hiding of the symptom is part of a disengaged coping style involving avoidance and will lead to isolation

and restricted Breathing Space. Additionally whilst adopting disengaged coping strategies may appear to get around problems caused by breathlessness it is ultimately maladaptive in that decreased activity will lead to deconditioning of the patient's body and thus steeper decline in both their underlying condition and their overall functioning. An explanation of why disengaged coping appears a common reaction to the experience of chronic breathlessness may be that breathlessness increases on exertion and is often accompanied by feelings of anxiety or panic. Therefore it may appear intuitively right to patients to avoid any activity that could bring on their breathlessness.

A greater emphasis could be put on enabling patients to use engaged coping styles as is common in pulmonary rehabilitation programmes and breathing technique sessions. Problem avoidance strategies may go beyond avoiding activities which would increase breathlessness and also include ignoring the symptom and reluctance to present to healthcare professionals for help with their breathlessness unless they are in crisis. They may also be unwilling to adapt their activities so as to be more manageable, instead allowing themselves to become very dependent on others to fulfil their needs. Patients may also indulge in wishful thinking and hope that the problem will take care of itself if ignored. In this case patients may repress their health worries; not seek information about their condition or how it might be managed and treated, nor what its likely prognosis is and may continue with damaging behaviours including smoking; believing the damage has already been done.

However there are many engaged coping strategies which could be taught to people to help them avoid the pitfalls of disengaged coping. By adopting engaged coping strategies patients retain some independence and control over their lives, continue to be active and sociable, gain social support and actively adapt to their situation and therefore enjoy a better quality of life than those who adopt disengaged coping strategies.

4.5.4 Help-seeking and Healthcare professional responsiveness to breathlessness

From the previous analysis of help-seeking behaviour for breathlessness it can be seen that there are many variables which may affect whether or not help is sought, what it is sought for and when and from whom it is sought. Living with chronic breathlessness and a chronic underlying condition, which may be accompanied by comorbidities, will necessitate help-seeking over a considerable period of time and so the response that the patient gets when seeking help will mould future help-seeking and a pattern will develop unless changes occur in subsequent help-seeking episodes e.g. a different helper being involved and responding in a different way. Patterns of help-seeking for breathlessness could vary between autonomously seeking help (97) for their breathlessness and receiving a response which enables them to cope better, to dependently seeking help regularly for the problem of chest infections/breathing crises and receiving a response which only solves the current issue but offers no long-term solution involving symptom management.

Autonomous help-seeking behaviour for breathlessness may result in the patient learning new techniques to cope with their breathlessness and also receiving help such as pulmonary rehabilitation, referral to a specialist, medication and assistive devices. Whereas dependent help-seeking behaviour for worsened breathlessness may result in receiving medication to solve the immediate problem and also provide reassurance at a time of crisis, but no offer of other forms of help that may ease the chronic breathlessness long term. Furthermore people not only vary in their help-seeking type, but also in the degree to which they will seek help, with some people having a very high tolerance before they perceive the need to seek help and others seeking help for minor problems.

From the literature reviewed it is clear that when a patient does seek help for their breathlessness, whether it be in crisis or a general deterioration, the way in which the healthcare professional responds is very important. Pendleton (153) asserts that "the consultation is the central act of medicine, and as such, it deserves to be understood". It is important to recognise that a medical consultation is an interpersonal act not just a transfer of information without

context. A dialogical relationship is established with each response (e.g. silencing or careful listening) shaping later stages of the interaction and also future interactions (99). Thus the interaction between patient and professional shapes not only the patient's understanding of the symptom and what help is available to them, but also their future help-seeking behaviour.

4.5.5 Healthcare professional responsiveness to breathlessness and end of life issues

The responsiveness of the healthcare professional to the patient's breathlessness and also to their underlying condition can have a huge effect on the patient's understanding of their health and also the existential distress they experience. The lack of meaning associated with the terms COPD or emphysema and the often associated relief that they don't have cancer can lead to patients not realising the gravity of their diagnosis and therefore not making the best of the time left to them.

Even when a diagnosis was given often prognosis was not discussed and consequently palliative care and advance care planning wasn't offered. The lack of discussion of prognosis leaves patients unable to engage in decision making about their end of life preferences. This may contribute to the continued use of acute treatment up until death and consequently death occurring in hospital, which may not have been their preferred place of death if they had had the chance to discuss it earlier.

The underlying conditions of which breathlessness is a feature are life-limiting and yet this is not always recognised by the patient, nor discussed by their healthcare professionals (55). This may be because healthcare professionals feel they do not know how quickly the condition will progress or may be part of a general reluctance to discuss the more difficult aspects of conditions, instead preferring to concentrate on medication adherence as was found in an ethnographic study on the practices of district nurses by (154).

As a result of this difficulty in talking about death and the uncertainty about prognosis it appears that many patients continue to think of themselves as being ill only when they have exacerbations and put to the back of their mind

any thoughts of death. Unfortunately this can then lead to lack of discussion of end of life issues and increase the distress to patients and their families if worries about the end of life are not addressed and palliative care is not made available to them.

People vary in their attitude towards their own death, with some not facing it even when death may well be immanent, whilst others live their lives in accordance with the awareness that they will die. Living with this awareness of one's own death (that our lives are finite) is described by Heidegger as 'being-towards-death'(67). Heidegger considers mortality a defining feature of human existence and that an awareness of one's own death allows one to live authentic lives, whereas living without the awareness of one's own death leads to inauthenticity. This authenticity can be described as the ability to use one's time and resources wisely and to respond appropriately to others, enabling us to make life meaningful to ourselves and it can be related to Carel's concept of Health within illness.

People suffering from chronic breathlessness vary in their awareness of their own death, just as all people do, however the opportunity to live authentically may be denied them if the healthcare professionals they rely on do not address their prognosis and inform them that theirs is a life-limiting illness. The state described by Gysels and Higginson (57) of patients feeling they have a past and present but no future is an indication that they have an inauthentic attitude to their death, probably related to lack of discussion of prognosis with healthcare professionals.

Heidegger describes how commonly people intimate that a very ill person won't die, but will be cured and return to normal, rather than facing the fact that they are dying and preparing for that. If this thinking is applied to people with life-limiting underlying conditions then it can lead to patients, carers and healthcare professionals all continuing to want acute treatment as opposed to accepting that palliative care would be more appropriate, allowing the patient to experience good quality of life as they near their death and also to make decisions about their final months and their preferred treatment options. Heidegger continues to explain that this non-acceptance of death means that people don't feel free to express their anxieties about death. Furthermore when

holding an attitude of being-towards-death one's death is not fled from or covered up, thereby leading to less existential suffering through facing the fears one has about impending death and the implications of one's death.

4.5.6 The Breathing Space concept

The concept of Breathing Space is used in this thesis to describe the interaction between coping, help-seeking and healthcare professional responsiveness to breathlessness and the concept forms the answer to research question number three of this thesis; What is the experience of people living with daily breathlessness due to chronic medical conditions and those caring for or treating them with regard to their beliefs about, coping with and help-seeking for their breathlessness, particularly with regard to their interaction with healthcare services?

It is an application of the common English phrase breathing space to the symptom of breathlessness and is based on Raphael's concept of quality of life "The degree to which a person enjoys the important possibilities of his or her life" (66) introduced in Chapter Two. Thus achieving Breathing Space allows patients and their carers to be able to do more on a daily basis, to continue to belong to their family and community and to choose their priorities as to what they become in the future and how they choose to live the rest of their lives. This concept may well be applicable to other long term conditions and could be used as a framework for future research.

4.6 Implications for clinical practice

When in consultation with a patient suffering from a condition in which breathlessness is a common symptom the healthcare professional should first assess the degree to which breathlessness is a problem to the patient and also their carer by encouraging them to speak about their experience, so the patient and carer are aware that such concerns are legitimate to present to their clinician and thus counter the invisibility of the symptom.

At this point the healthcare professional should consider the coping and help-seeking style that the patient is using and recognise the degree of Breathing Space the patient and carer have achieved thus far. From the Breathing Space concept it may be that a healthcare professional responsive to breathlessness could work with the patient and carer to help them learn engaged coping strategies and also give guidance on how and when to seek help and that this would then potentially increase their Breathing Space.

Health care professionals need to be up to date on the current management of breathlessness and aware that there are evidence based interventions targeting breathlessness in its own right and liaise with other colleagues as necessary to help their patient achieve a greater degree of Breathing Space.

4.7 Strengths and limitations of this study

The systematic literature followed the process described in PRISMA (90) and three researchers worked in an open and transparent way to ensure rigour. All titles and abstracts and full papers were double reviewed adding to rigour and making it less likely that a relevant paper would not be selected. The qualitative synthesis was conducted following guidelines from Thomas and Harden (72) with discussion amongst the researchers at regular intervals during the process. Direct quotes were chosen as the raw data for the synthesis, rather than the reflections of the authors, so as to keep to the primary data as closely as possible rather than twice reflected which may have made the original meaning more distant.

There are a number of limitations of the study including language restrictions as only papers in English were searched for, however the selected papers include studies from a range of countries each with their different cultural contexts. The date restrictions for the search mean that it is possible some recent studies have been missed.

4.8 Summary

The fourth chapter described the findings of the systematic literature review and qualitative synthesis, the four main themes of which were: Widespread effects of breathlessness, Coping, Help-seeking behaviour and Responsiveness of the healthcare professional to breathlessness. The overarching analytical theme was the concept of Breathing Space which is used to answer research question number three. The fifth chapter will describe the survey and case note review methods and findings.

Chapter Five: Survey and case note review

5.1 Introduction

In Chapter Four the experience of living with breathlessness was described and the Breathing Space concept developed. This chapter addresses the following research questions with respect to prevalence, clinical pathway, predictors of admission and decision to present to the ED:

- 1 What is the prevalence of presentations to the ED at Hull Royal Infirmary (HRI) that are due to acute-on-chronic breathlessness?
- 2 What clinical pathways are followed by patients who present to the ED due to acute-on-chronic breathlessness?
- 3 What predicts hospital admission (ED departure status) in people presenting to the ED with acute-on-chronic breathlessness?
- 5 How do beliefs about, coping with and experience of help-seeking in the community influence their decisions to present to the ED?

The hypothesis for the primary objective was that:

Acute-on-chronic breathlessness will be a reason for presentation for at least 3.2% of presentations to the ED.

5.2 Research setting and study governance

The survey and the case note review were conducted in the ED at Hull Royal Infirmary, Kingston upon Hull, UK. The project obtained both sponsorship and research governance from Hull and East Yorkshire Hospitals Trust (HEYHT). The principal investigator (AH) had an honorary contract with the HEYHT in place prior to the start of recruitment. Ethics approval 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.

5.3 Survey method

5.3.1 Setting

The original research question on prevalence related to prevalence of presentation due to breathlessness to the *entire* ED, however to efficiently obtain a consecutive sample, with minimal disruption to the department, this was revised to measuring the prevalence of presentation to major emergencies only. Therefore the survey was only administered to eligible patients who presented to the major emergencies section of the ED instead of to all patients presenting to either major or minor emergencies. This was justified as in the experience of my second supervisor, a consultant in emergency medicine, the vast majority of breathless patients present to the ED by ambulance and therefore are seen in major emergencies, not minor emergencies. From this measure of prevalence to Majors an estimate of the prevalence to the entire ED could be derived by assuming that most breathless patients had presented to Majors and with reference to routinely recorded information on the total number of adult presentations to the department in the time period.

5.3.2 Participants and eligibility criteria

Eligible patients presenting to the ED within the study period were offered a survey to complete.

Inclusion criteria:

- Patients presenting to the major emergency area of Hull Royal Infirmary
- Deemed stable enough by the clinical staff to complete the survey
- Sufficient use of the English language or has a carer who has
- Able to provide implied consent by virtue of completion

5.3.3 Development of the survey

In developing the survey many aspects were taken into consideration, including the process of delivery, content of the survey, ethical considerations and recruitment (see survey in Appendix 6 Survey).

5.3.3.1 Design and flow

The layout and flow of the survey was designed in a way to maximise response rate, minimise patient burden and facilitate data analysis in a number of ways (155). The survey was designed as a four page paper survey, starting with a short introduction to explain the saliency of the survey to the potential participants (155), followed by a number of closed questions using tick boxes to answer each item, one open question inviting any further comment and finally requests for consent to view their hospital notes and to contact the participant for interview. A paper and pen survey was considered suitable as participants were waiting in the ED and would be likely to feel that they had the time to fill one in there and then.

The front page had immediately recognisable logos of the main parties involved in this study to demonstrate their sponsorship, and therefore the legitimacy, of the research (155), an introductory paragraph in an easy to read font, three basic items gathering demographic information and an initial question on whether or not the patient experiences chronic breathlessness. Polite language was used thanking them for their participation, as well as giving clear direction on whether or not they need continue with the following pages. The front page was designed in this way to appear attractive and engaging, give a clear rationale as to why they should consider filling the survey in and maximise response rate for at very least the primary outcome measure. As the primary outcome measure of the survey was prevalence of presentation to the ED due to chronic breathlessness this question was put on the first page in the hope that as many people as possible would fill that question in even if they didn't feel like completing the entire survey. Patients for whom chronic breathlessness was not a problem were only required to complete the first page thus minimising

participant burden. If a participant had answered that they experienced chronic breathlessness then they were invited to continue filling in the rest of the survey.

The following two pages consisted of a number of closed questions divided into sections with clear headings to make it easy to follow. To simplify survey completion a consistent method to answer by using tick boxes, was used. For example question B4 and B5 had only four tick boxes with categories from none to severe, rather than using a NRS. Straightforward wording in a reasonably large font was employed and the lay out had plenty of white space to make the survey appear simple and uncluttered. Careful consideration was given when wording the questions to use simple language taking into account the relatively low educational levels in this region (156). Thought was given to the flow of the questions in the survey, including the use of subheadings, clear indications of how to answer each question and the inclusion of a question on smoking status towards the end of the third page, as this was a rather sensitive question which might have brought about feelings of stigma or self-blame and therefore possibly have put people off participating if it had been one of the first questions.

The fourth page of the survey had a final closed question about diagnoses and then a general open question enquiring if they had anything else to add, thus giving the participant an opportunity to write any further information if they wished. Finally after thanking them for participating in the survey there was a section inviting them to give written consent to their hospital notes being reviewed and/or being contacted for interview.

5.3.3.2 Content: survey questions

The content of the survey aimed to incorporate important relevant questions without putting off or overburdening the participants. Questions included date of birth, gender, postcode, whether they experienced chronic breathlessness (defined as experiencing breathlessness most days in the last month), if breathlessness was one of or the main reason for their presentation, severity of their breathlessness when they decided to present and also currently, the MRC dyspnoea scale which measures disability due to breathlessness, who was

involved in the decision to present, how long they have experienced chronic breathlessness for, the number of emergency presentations due to breathlessness they have made, how long their episodes of breathlessness last, who they talk to about their breathlessness, smoking status, whether they live alone or not, who filled in the survey and finally any known cardiorespiratory diagnosis. Initially several other questions were included in the survey e.g. standard scales to measure self-efficacy and helplessness in COPD, however following advice from the RSG it was decided that inclusion of these questions lengthened the survey considerably and might therefore put people off completing the survey. Care was also taken not to include any questions about information which would be available from hospital notes, so that the patient was only asked for information that only they could offer. The final content of the survey was designed to obtain relevant information without overburdening the participant, with the aim of resulting in a well performed survey rather than a burdensome one with a low response rate.

5.3.3.3 Review process

The initial survey draft was developed by AH using published literature and expertise from supervisors MJ and AP. Peer review was sought from the SEDA research group, health sciences researchers, experienced survey designers and statisticians. Public and patient review as recommended by Lowes and Hulatt (157) was provided by the RSG. Following this the language used was simplified further and some of the questions were removed or altered to make the survey as user friendly as possible. The survey was then piloted in the ED to assess the feasibility of the proposed method of delivery, acceptability of the survey to participants and performance of the survey questions. After the pilot was conducted a number of minor administrative changes were made to the survey.

5.3.3.4 Sample size

The number of completed surveys that were necessary to be able to accurately estimate the primary outcome measure of presentation to the ED due to chronic

breathlessness was calculated based on the prevalence of 3.2% of presentations due to breathlessness found in a study in America (23), using the following calculation:

$$N = P(100 - P) \div SE^2$$

$$N = 3.2(100 - 3.2) \div 0.51^2 \text{ (Where SE = } 1 \div 1.96 = 0.510 \text{ [95\% CI])}$$

$$N = 1,191$$

This calculation resulted in the sample size of 1,191 completed surveys needed in order to measure the prevalence of presentations to the ED due to breathlessness in the region of 3% to a degree of accuracy of +/-1% with 95% confidence intervals.

5.3.3.5 Ethical considerations

The main ethical considerations taken into account when developing the survey were: minimising patient burden, gaining consent and ensuring confidentiality. As the participants in the survey were all in the ED and therefore ill, vulnerable and possibly anxious, minimising participant burden was essential. Patients were only offered the survey by clinical staff if in their judgement the patient had capacity and would not be unduly burdened by completing it. Filling in the survey did not present a clinical risk to the participant, as they were only given the survey at a point when they would be waiting anyway and they were judged to be stable and therefore it did not interfere with their treatment or recovery.

The participants were free to choose whether or not to complete the survey and were not offered any financial or other incentive. It was made clear that their treatment would be unaffected by whether or not they took part. In order to ensure that the potential participants did not feel coerced into completing the survey it was handed out by clinical staff, rather than the main researcher who had a vested interest in successful completion of the survey. Completion was taken as implied consent.

Burden was further minimised by having a screening question on the very first page about whether or not they experienced chronic breathlessness, thus the

majority of patients only had to answer four questions. For those patients who experience chronic breathlessness burden was minimised by ensuring that there were only an acceptable number of questions to be answered and that the survey could be completed reasonably quickly. Also, although the survey was designed as a patient self-report survey it was made clear that if they had someone with them that they could help fill it in if the patient wished.

Maintaining confidentiality was also a high priority when developing the survey. All surveys were handed out with an opaque envelope for them to be returned to the staff in, thus ensuring that the participant's name and personal details would not be visible to others before collection and storage by the research team. The completed surveys were stored in a box in the major emergencies section of the ED which was regularly emptied by a researcher and then stored in a locked room. When data from the survey was entered into a database each participant was only identified by their survey number. The only patient identifiable data held electronically was that in the master index file, a database of those participants who were later interviewed, which was stored separately on an encrypted memory stick.

5.3.3.6 Pilot One

5.3.3.6.1 Patient identification

The patient-report survey was offered by triage nurses to all adults who presented to the major emergencies section of the ED, with mental capacity and deemed clinically stable, to complete if they wished. The process of delivery of the survey was decided upon by taking the layout of the ED and the working patterns and workload of the staff into account. As patients arriving by ambulance all enter the triage area and are then immediately assessed by the triage nurses, it was decided that an appropriate method of delivery for the survey, that would both minimise burden on the staff and would be acceptable to patients, would be to request triage nurses to hand out a paper and pen survey to all eligible patients as they finished off their initial assessment. To this end the survey was designed to be handed directly to patients with only a very brief request by the nurses that they take a look at it and fill it in if they wished.

5.3.3.6.2 Consent

To simplify the process of delivering the survey, a process of implied consent was used, rather than requiring the triage staff to first give a separate information sheet about the study and then gain written consent before the survey was given to a patient. Thus, the survey, which had a brief introduction explaining the study, was offered to all eligible patients and the participants were considered to have given consent to taking part in the survey if they chose to fill in any part of it.

5.3.3.6.3 Data collection

The surveys and pens were placed in an easily accessible place in the triage area and staff were made aware of the study rationale and requested to hand them out to all eligible patients. A collection box, with the study logo on to make it easily identifiable, was placed in the main area of the ED and staff were requested to collect completed surveys from patients and place them in the box. Both boxes were regularly checked to ensure surveys were always available to staff and that completed surveys were then stored securely.

5.3.3.6.4 Changes resulting from Pilot One

In order to assess the feasibility of conducting the survey it was piloted for seven days in December 2013, during which the researcher (AH) monitored the process of delivery, enquired about patient acceptability and analysed the completed surveys to assess appropriateness of content and layout. The results of conducting the pilot are outlined in table 3:

Table 3 Outcome of Pilot One

	Problems identified:	Solutions offered:
Process of delivery:	Triage nurses did not hand out the required number of surveys: 840 presentations, but only 33 handed	Other clinical staff, including medical students attached to the unit, could hand out the

	out	survey.
Patient acceptability:	Patients found the survey acceptable.	None necessary.
Content and layout:	<p>A few items did not have enough options or were confusing.</p> <p>A number of participants only filled out the front and back pages as they appeared to be unaware of the middle pages.</p>	<p>Options for answering items were added or altered to reduce possible confusion.</p> <p>A note was added to the bottom of the first page indicating that there were four pages in the survey.</p>

The results of the first pilot demonstrated that although some minor adjustments to the content and layout of the survey were needed, the survey was acceptable to participants and did not present a burden to them. Some participants even commented that they had enjoyed filling in the survey as it passed the time whilst waiting and they were happy to do anything to help with the research and contribute to improved patient care in future. It appeared that this method of recruitment to the case note review and to interview was feasible (see table 4).

Table 4 Recruitment to case note review and interviews

Number of completed surveys:	Number completed by people with chronic breathlessness:	Number giving consent to view hospital notes:	Number giving consent to be contacted for interview:
Pilot One	9	7	3

The major problem identified in the first pilot was that the proposed method of delivery was not effective and had to be reconsidered. Even so, several patients gave consent for their notes to be reviewed and to be contacted for interview and therefore the data extraction form for the case note review could be piloted and a number of people were interviewed to allow piloting of the topic guide.

The revised survey and method of delivery was then Piloted for a second time.

5.3.3.7 Pilot Two

A second pilot, with the amended survey, was undertaken in late January and early February 2014 for a total of 11 days. The setting, consent and participant eligibility were unchanged.

5.3.3.7.1 Patient identification

Triage nurses were no longer asked to administer the survey, but instead a group of medical students on placement in the ED were offered the opportunity to experience the research process and give out the survey to consecutive clinically stable adult patients who had been judged by ED clinical staff to have the capacity to complete it.

5.3.3.7.2 Data collection

The surveys and pens were placed on top of a filing cabinet in an area where patients were waiting having been assessed by triage. Once completed the students collected the surveys and placed them in the filing cabinet. This cabinet was regularly emptied and the surveys were stored securely in a locked office.

5.3.3.7.3 Changes arising from Pilot Two

In order to assess the revised process of delivery a second pilot was undertaken for 14 days in April 2014, during which time the researcher (AH) monitored the process of delivery, enquired about patient acceptability and analysed the completed surveys to assess whether the modifications made to content and layout after Pilot One were appropriate. The results of conducting the second pilot are outlined in table 5:

Table 5 Outcome of Pilot Two

	Problems identified	Solutions found
Process of delivery:	The medical students were inconsistent in their delivery of the survey. 129 handed out /1,320 presentations.	Funding for dedicated staff to deliver the survey was sought and obtained from the local CCG.
Patient acceptability:	Patients found the survey acceptable.	None necessary.
Content:	No further problems were identified and the previous amendments resulted clarity of all questions to the participants, none of whom missed out the middle two pages.	None necessary.

Though more successful than the first pilot in which triage nurses had been requested to hand out the survey, the second pilot was delivered inconsistently by medical students and it was still not possible to work out the prevalence of presentations due to chronic breathlessness from the number of completed surveys (106) as in the 11 day period approximately 1,320 presentations to major emergencies had occurred.

It became clear from the two pilots that the survey was well designed, not burdensome to participants and the sampling method for the whole study was effective in that many breathless patients were prepared to have their notes reviewed and to be interviewed (see table 5).

Table 6 Recruitment to case note review and interviews

	Number of completed surveys:	Number completed by people with chronic breathlessness	Number giving consent to view hospital notes:	Number giving consent to be contacted for interview:
Pilot Two	106	32	29	10

However the major stumbling block was the method of delivery and it was decided that dedicated staff time specifically for this purpose would be required. In order to overcome this problem a successful grant application to the Hull Clinical Commissioning Group (CCG) funded dedicated clinical staff to deliver the survey, covering all shifts for the time period necessary to achieve the required sample size. The full survey was then conducted during a two and a half week period in May 2014.

5.3.3.8 Final survey and delivery method

Setting, participant eligibility, method of consent and survey remained the same.

The survey was administered by a team of clinical staff specifically employed to deliver the survey. During their shift they approached all patients who in their clinical judgement would be able to fill out the survey. Thus a consecutive sample was obtained, with an ongoing tally of how many patients had presented without the capacity to complete the survey and of those who refused to complete the survey. The survey was given out on a 24 hour a day basis in the period between 7am 12/5/14 and 9pm 22/5/14 and then again between 7am 23/5/14 and 7am 29/5/14. (This was because unfortunately no one was available for one shift from 9pm 22/5/14.) The survey had been designed to be filled in by the patient themselves or possibly by a family member if present, however due to the eventual process of delivery many patients told their answers to the staff administering the survey who then filled in the survey for them, thus reducing participant burden further. Another change in the process of delivery of the survey was that all completed surveys were stored in a locked cabinet in the ED, rather than an open box, before being transferred to a locked research room. The survey was halted at the end of the shift in which the predetermined sample size (1191) had been reached.

5.4 Case note review method

5.4.1 Setting and participants

The hospital notes of eligible survey participants presenting to the major emergencies area of the ED at the Hull Royal Infirmary who provided written consent on the last page of the survey were accessed both on paper and electronically in a hospital research office. Data were extracted and then stored on a password protected computer.

Inclusion criteria:

- Survey participants have chronic breathlessness and presented due to breathlessness
- Written informed consent given

5.4.2 Development of the data extraction tool

In developing the data extraction tool several aspects were taken into consideration including content, ethical issues and process of extraction.

5.4.2.1 Content and format

The format of the data extraction sheet (see Appendix 7 Table 12 Case note review data extraction sheet) was designed to enable the researcher to extract data from the hospital's electronic patient administration system in a straightforward and logical manner. The items to be extracted were of aspects of the index presentation including time and date, presenting complaint and known history, observations and investigations performed, treatments given in the ED and whether or not the patient was admitted to hospital. Information was also extracted on the number of previous presentations in the last year and the length of any ensuing admissions to hospital. These items were chosen to gain insight into patterns of presentation to the ED due to breathlessness and the consequences of those presentations.

5.4.2.2 Ethical considerations

The main ethical considerations involved in the case note review were minimising participant burden, consent and confidentiality.

The data extraction form was designed to include all items that a patient could have offered but that were available from the notes (e.g. time and date of presentation) so as to minimise the burden on the participant whilst in the ED.

Consent for the researcher to view hospital notes was necessary as AH was not involved in the patient's care and therefore notes were only accessed if written consent had been given on completion of the survey.

To maintain confidentiality the paper surveys with personal details of the participant were stored and accessed in a lockable research office in the hospital. No patient identifiable data were recorded on the data extraction sheets which were numbered using the relevant survey number and stored on a password protected computer.

5.4.2.3 Review process

The initial data extraction form was developed by AH using published literature and expertise from her supervisors MJ and Alastair Pickering [AP]. It was then piloted to assess the feasibility of the proposed process and format.

5.4.2.4 Piloting the data extraction sheet

The data extraction form was piloted in December 2013 with the case notes of two consenting pilot survey participants. During data extraction it became clear that it was necessary to reorder the items on the sheet to avoid going back and forth through the hospital notes. The order of the items was altered to follow the order in which they are recorded in the hospital notes. The content of the form was appropriate and it was possible to identify most items from the notes. One item, the Charlson Comorbidity Index, was not routinely recorded and needed to be deduced from information that the doctor had taken on medical history. The written notes were, however, both hard to read and also difficult for the

researcher to understand, due to the use of medical terminology and abbreviations.

As a result of the pilot the order, but not the content, of the items on the data extraction sheet was altered and directly inputted into the SPSS spreadsheet.. The process of data extraction was also altered to be performed by the researcher working alongside a research nurse who was experienced in the use of case notes.

5.4.3 Final case note review

The case note review was performed from May to October 2014 by the AH together with a research nurse (Paul Williams [PW]) to assist with medical terminology. A full case note review was conducted for all patients with chronic breathlessness who indicated that their presentation was due to breathlessness. Data were extracted from the case notes and inputted directly into an SPSS spreadsheet.

5.5 Analysis plan

Research questions:

- 1 What is the prevalence of presentations to the ED at Hull Royal Infirmary (HRI) that are due to acute-on-chronic breathlessness?
- 2 What clinical pathways are followed by patients who present to the ED due to acute-on-chronic breathlessness?
- 3 What predicts hospital admission (ED departure status) in people presenting to the ED with acute-on-chronic breathlessness?

The data to answer research question one were extracted from the survey and the data for research questions two and three were from both the survey and the case note review.

The survey data and case note review data were inputted and analysed in SPSS (Released 2011. IBM SPSS, Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp). The primary outcome measure of the survey was prevalence of presentation to the ED due to acute-on-chronic breathlessness (research question one). Descriptive statistics (proportion, mean, median, IQR, range) were used to present clinical and demographic data from the survey and clinical record review. Inferential statistics (Z test, Fisher's Exact test and 95% confidence intervals) were used to calculate the primary outcome of prevalence and compare the sample with people presenting who were not breathless and also with the surrounding population.

Binary logistic regression was used to predict post ED departure status (research question three), a binary outcome reported as discharged from the ED (usually within 4 hours) or admitted for inpatient management in patients with acute-on-chronic breathlessness. Independent samples Z-tests were performed for all continuous predictor variables (including age, respiratory rate and oxygen saturation), Pearson Chi squared test for unordered categorical data with more than two groups, Fisher's Exact test for binary categorical variables and Kendall's Tau-b when dependent variables were ordinal with more than two levels. Variables with no significant univariate association with ED departure status ($p > 0.05$) were excluded from subsequent analyses. Variables which had an effect identified in the unifactorial analysis were included in a binary logistic regression using stepwise analysis with backwards elimination. At each stage the variable with the largest non-significant P value was eliminated and the step repeated until there were no non-significant associated factors.

5.6 Findings

5.6.1 Study participants

There were a total of 2,041 presentations to Majors during the study period. Of these presentations 1,345 (66%) were eligible to be given the survey. 1,212/1,345 surveys were completed; a response rate of 90%. The characteristics of the survey and clinical record review participants are

summarized in Tables 7(below), 13 and 14 (in Appendix 8 Table 13 and Appendix 9 Table 14). Of the 424 survey participants who experienced chronic breathlessness 350 consented for their notes to be reviewed. Of the 245 patients presenting due to breathlessness 177 consented to case note review with complete data available for 171 cases.

5.6.2 Characteristics of survey participants

Of the 1,212 presentations, 424 were made by people with chronic breathlessness; a prevalence of 35.0% (95% CI 32.2% to 37.7%). People with chronic breathlessness were older than those without (mean difference 6.1 years; 95% CIs 3.7 to 8.6 years; $p < 0.001$), however there was no significant difference in the gender balance (see Table 7).

Table 7 Presentation to Majors

	Chronic breathlessness - NO	Chronic breathlessness - YES	P value (No compared with Yes)
Presentations to Majors (n=1,212)	n=788	n=424 Prevalence 35.0% 95% CIs 32.2% - 37.0%	-
Age mean (SD) (n=1,212)	59yrs (22)	65yrs (19)	Mean difference 6.1 yrs (95% CIs: 3.7-8.6) $p < 0.001^*$
Gender (n=1,212)	355 M (45%) 433 F (55%)	189 M (45%) 235 F (55%)	$p = 0.856^{**}$

* Z test- difference of two independent means

** Fisher's Exact test

5.6.3 Primary outcome

Breathlessness was given as one of the reasons for presentation in 20.2% of presentations (245/1,212, 95% CI 17.9% to 22.5%). Hospital activity records show that there were 4,692 presentations to both Majors and Minors during this period, therefore breathlessness sufficiently severe to necessitate an assessment in Majors comprised *at least* 5.2% (245/4,692, 95% CI 4.6 to 5.9%) of all ED presentations. Therefore our hypothesis that acute-on-chronic breathlessness will be a reason for presentation for at least 3.2% of presentations to the ED was supported.

5.6.4 Characteristics of patients with chronic breathlessness

The prevalence of presentation to Majors by people with chronic breathlessness due to COPD [121/1,212 (10%; 8 to 12%)] or heart problems [165 (14%; 12 to 16%)] was higher than the prevalence of presentation to Majors by people with chronic breathlessness due to asthma [54/1,212 (4.5%; 3.3 to 5.7%)] or by people with chronic breathlessness due to cancer [42/1,212 (3.5%; 2.7 to 4.3%)]. A full summary of the characteristics of patients with chronic breathlessness and those with acute-on-chronic breathlessness is shown in Table 14 (Appendix 9).

5.6.5 Characteristics of people with acute-on-chronic breathlessness

Details of those who presented due to breathlessness can be seen in Appendix 9 Table 14 General characteristics. Of those presenting due to breathlessness the median modified Medical Research Council (mMRC) Dyspnea scale grade was 4 with three quarters (188/245; 77%) at grade 3 or above, and nearly half (112/245; 46%) had experienced chronic breathlessness for over 2 years. Most presentations were by people with a non-malignant diagnosis [COPD 63/245 (26%) and heart conditions 104/245 (42%)] compared with cancer (21/245; 9%).

5.6.6 Factors relevant to the decision to present to the ED

Survey data (n=245)

For this presentation the median level of breathlessness severity at the time of the decision to present was “severe”, in contrast whilst waiting in the ED the median level was “mild”. When asked who was involved in the decision to present that day 92 (37%) said that they themselves were, 98 (40%) mentioned family or friends, 47 (19%) a GP and 43 (18%) said a paramedic was involved.

When asked who they talked to about their breathlessness three quarters (178/245; 73%) said that they talked to their GP and one in ten (29/245; 12%) said they talked to a specialist doctor. Fewer talked to nurses of any type, a quarter (64/245; 26%) said they talked to their family or friends and one in seven (34/245; 14%) said they didn’t talk to anyone at all about their breathlessness.

Clinical record review data (n=177) (see Appendix 10 Table 15)

Approximately two thirds (121/177; 68%) of presentations were made outside of working hours defined as 8am-6.30pm Monday to Friday excluding public holidays.(158) Half (94/177; 53%) were re-attenders, having presented to the ED at least once in the 12 months before the index presentation. The median number of previous presentations in the last 12 months was 1 per person (IQR 0 to 2 times).

5.6.7 ED assessment

Breathlessness was documented by the triage nurse as a primary presenting complaint in one third of people (56/177; 32%). Doctors documented difficulties

with breathing (primary or one of the reasons) in two-thirds of case records (112/177; 63%). In total, notes in relation to breathlessness were documented by a doctor and/or a triage nurse in 69% (122/177) of presentations all of which were characterised as due to breathlessness by the patient.

One quarter (48/177) of the diagnoses made by ED doctors for the cause of the index presentation were an exacerbation of COPD/chest infection, one third (60/177) were a heart condition with the remaining 39% (69/177) of presentations due to a range of other causes.

There was a known history of COPD in 30% (53/177) of presentations and a known history of a cardiac condition in 44% (77/177) of presentations, compared with 16% (19/177) of presentations with a known history of cancer. The median Charlson comorbidity score was 1 (IQR 1 to 2).

Observations made in the ED included respiratory rate (mean 20 per minute; range 12 to 40) and oxygen saturation (mean 96%; range 72 to 100). Frequently given treatments included; oxygen (53/177), a nebuliser (40/177) and antibiotics (26/177). Tests including an electrocardiogram, venous blood tests and a chest x-ray were performed in the majority of cases (see table 12, Appendix 10).

Factors relevant to admission

From hospital activity records the number of admissions from both Majors and Minors was 1,615 therefore acute-on-chronic breathlessness was a contributing factor in *at least* 7.6% (122/1,615, 95% CI; 6.3 to 8.9%) of all admissions.

Seven out of ten (122/177; 69%) of presentations due to breathlessness resulted in admission. The median length of stay was 1 day (IQR 0 to 5). The proportion of presentations due to breathlessness from all presentations to both Majors and Minors which resulted in admission in the survey time period was 34% (1,615/4,692).

5.6.8 Predictors of ED departure status

In the regression analysis, the dependent outcome was a binary measure of ED departure status (discharged from the ED or admitted for inpatient management to the acute assessment unit (AAU) or a ward).

Selection of potential variables associated with ED departure status: unifactorial analysis

Approximately 60 independent variables were initially assessed for significant univariate associations with ED departure status ($p < 0.05$).

The independent variables assessed for univariate associations with ED departure status are shown in Appendix 11 Table 16 Predictors of admission. These included variables extracted from both the patient survey and clinical record review. The following variables were found to be significantly associated with ED departure status: age, oxygen saturation, whether they talk to a specialist doctor about their breathlessness, self-reported diagnosis of heart condition, known history of heart condition or heart failure, Charlson comorbidity score, the doctor's diagnosis of the cause of this presentation, whether the doctor documented and breathlessness-related notes, whether oxygen was given and whether venous blood tests, arterial blood gases and a chest x-ray were performed.

Predictors of ED departure status: multifactorial analysis

Applying the recommended rule of at least 10 positive cases and 10 negative cases (159) per predictor variable and a sample size of 171 complete cases (120 admitted and 51 discharged) the acceptable number of independent variables that could be entered into a binary logistic regression was calculated to be no more than five. Only variables with significant univariate association with ED departure status which were characteristics of the presenting patient, as opposed to those relevant to how they were responded to in the ED, were included as candidate factors in the binary logistic regression. These candidate variables were: age, oxygen saturation, whether they talked to a specialist doctor about their breathlessness, a known heart condition (by self-report or in

the clinical record) and the Charlson comorbidity score (see Appendix 12 Table 17 Unifactorial analysis). The final multifactorial model is shown in Appendix 13 Table 18 Final regression model. ED departure status was associated with age, oxygen saturation, talking to a specialist doctor and a known history of a heart condition. The odds of ED departure status being admission into hospital are increased with every extra year of age, with every percentage decrease in oxygen saturation, previously having talked to a specialist doctor about their breathlessness and having a known history of a heart condition.

5.7 Discussion

5.7.1 What is the prevalence of presentations to the ED at Hull Royal Infirmary (HRI) that are due to acute-on-chronic breathlessness?

This study found that over one in three presentations to the major emergency area of the ED was by someone living with chronic breathlessness, and nearly one in five presentations were reported by the patient to be due to breathlessness. If the management of the underlying disease is already optimal and there is no acute exacerbation of that disease, acute-on-chronic breathlessness is likely to be driven by other factors. Therefore there may be a group of people with acute-on-chronic breathlessness for whom the ED may not be the best setting to manage their needs; the ED can be a stressful experience and the service is not designed to address issues regarding chronic care better provided in the community.

This prevalence estimate of at least 5.2% from Majors *and* Minors is higher than previous reports (23, 24). The 9% reported by Langlo, Orvik (25) excludes presentations to the minor injuries unit. This makes the prevalence of self-reported breathlessness as a reason to attend Majors, in those stable enough to complete the survey, of 20.2% all the more remarkable. However, previous studies used clinical record review rather than patient self-report and only examined cases in which the *primary* presenting complaint was breathlessness. In this study the prevalence measure is by patient self-report and includes breathlessness as “a reason”. In presentations due to breathlessness, only one

third had breathing difficulties documented by the attending nurse as the primary reason. In the others, “chest pain” (23%) and a non-specific “illness” (27%) were noted instead. Even when the clinical records were carefully scrutinized for any documentation which might indicate that the clinician had recognized that breathlessness was a reason for presentation, this was noted in only two-thirds.

When participants made the decision to present to the ED their median breathlessness rating was “severe”. However, whilst waiting in the ED, this settled to a median rating of “mild”. Therefore, depending how quickly their breathlessness improved, by the time they were assessed by the doctor, they might have had no visible signs. This is consistent with previous comment that breathlessness can be invisible to others until severe enough to be a clinical sign (160) (161). Clinicians’ attention to breathlessness as a symptom is variable; often considered significant insofar only as it points to a underlying medical condition (152).

Most presentations by patients with chronic breathlessness were made by people with non-malignant cardio-respiratory disease. Although this is a single site study, the proportions of presentation by people with cardiorespiratory conditions are similar to the findings from the National Hospital Ambulatory Medical Care Survey (162). However compared with the prevalence of such diseases in the community served by the hospital ED in this study, these are over-represented in the ED (163). In contrast, the survey data regarding presentations by people with cancer was very similar to Quality Outcomes Framework (163) data relating to cancer in the local community. The reasons for this discrepancy are not clear, but it is interesting to reflect that the multi-disciplinary, cross-setting coordinated approach to the management of chronic non-malignant conditions in the UK has been slower to enter policy (164-166) and service delivery than for cancer care (167).

This study prevalence is also disproportionately high compared to the prevalence of breathlessness in the general population; 8.9% of adults reporting restricting chronic breathlessness over at least 3 months at MRC Dyspnea scale grade 2 or above and 2.6% experiencing more limiting breathlessness at grade 3 or above in Australia (6) and 15% of men and 23% of women reporting breathlessness, grades 2 to 5 on the MRC Dyspnea scale(at any point in the last year) in the Health Survey for England (5).

Given such over-representation, it is unsurprising that the prevalence of breathlessness as a reason to present to the ED is higher than that found for documented reason to attend the family practitioner (at least 5.2% versus approximately 1%) (168). In the nationally representative Australian retrospective cohort study of routinely collected data if breathlessness was the “reason for encounter”, patients were 2.5 times more likely to be referred urgently to hospital by the family practitioner.

The concentration of people with acute-on-chronic breathlessness presenting to Majors (20.2%) represents distress for patients and their families and a large burden on both the resource intensive, high cost, Majors area of the ED and on ambulance services.

5.7.2 What clinical pathways are followed by patients who present to the ED due to acute-on-chronic breathlessness?

Three quarters of those presenting due to breathlessness scored grade 3 or above on the MRC Dyspnea scale representing levels that are significantly physically restricting, with accompanying negative consequences of limited activity, function and psycho-social wellbeing. Optimal care for such people should include quality management for both their underlying medical condition and their breathlessness (169).

Although most participants say they discuss their breathlessness with their family practitioner few said they talked to specialist doctors, nurses or friends

and family about their breathlessness; again consistent with breathlessness remaining hidden from others (160). Importantly, it identifies the family practitioner as a pivotal health professional with potential to co-ordinate optimal management (160). Although the survey did not collect data on the number of participants who had accessed other services such as respiratory nurses, long term condition nurses, community matrons or pulmonary rehabilitation services, the low numbers of those saying they discussed their breathlessness with such clinicians implies that these services are not being used consistently for symptom management by this cohort. This is surprising since nearly half of the patients (46%) report that they have experienced chronic breathlessness for over two years giving time to have been referred to services embedded in healthcare policy as part of best practice.

In keeping with the pivotal role of the family doctor, two thirds of presentations to the ED occurred at times when their regular healthcare professional (family doctor, specialist nurse or physiotherapist) was not available. These out-of-hours presentations might be reduced if individual management plans included breathing crisis management, and training was given to both the patient and their carer (170). Healthcare professionals in the community available outside usual working hours also need to be skilled in the recognition and management of those with acute-on-chronic breathlessness episodes which can be treated in the community without recourse to an ED attendance.

5.7.3 What predicts hospital admission (ED departure status) in people presenting to the ED with acute-on-chronic breathlessness?

The prevalence of hospital admissions for people attending the ED due to breathlessness was estimated at 7.6% of all admissions; lower than that found in the study by Pearson (28). This is likely to be an underestimate as patients who were too sick to complete a survey are likely to be at higher risk of admission and to be those who have breathlessness as a significant problem. In our study 69% of presentations due to breathlessness in people stable enough to complete the survey, resulted in admission; twice the proportion admitted from the ED as a whole in this time period (34%) (-this figure included those who would have been too sick to be eligible for the survey).

The finding that breathlessness as a reason to attend the ED is associated with increased risk of admission is consistent with previous findings (35) (171). Our finding is comparable with that of Fedullo et al. (24) who reported that 52% (84/162) of presentations by breathless patients resulted in admission.

Several studies have aimed to find clinical predictors of admission in breathless patients in order to expedite care and post ED departure. Both Fedullo et al. (24) and Parshall and Doherty (30) found that tachycardia is associated with admission in both CHF and COPD patients. Saracino et.al. (35) found that arrival by ambulance to the ED coupled with tachycardia and increased breathlessness by self-report predicted hospital admission. Increased distress due to breathlessness itself also predicted admission (35). When comparing these studies to our study it is important to note that heart rate was not extracted from the case notes and also our measure of severity of breathlessness is not comparable with that of Saracino et al. (35) as theirs was assessed at triage on entry to the ED, whereas ours was assessed by the patient once they were stable and waiting in the ED to be seen by a doctor.

Our results suggest that four factors independently predict admission: increased age; decreased oxygen saturation on presentation; having talked to a specialist doctor about their breathlessness; having a known history of a cardiac condition.

5.7.4 How do beliefs about, coping with and experience of help-seeking in the community influence their decisions to present to the ED?

The median level of breathlessness severity at time of decision was “severe”, contrasting with “mild” whilst at rest in the ED, indicating that the decision was generally taken at a time of crisis. In only 37% of presentation did the patient mention themselves as being involved in the decision to present to the ED, however, this decision commonly involved others including family or friends, a GP or a paramedic. This finding resonates with the findings of Green et al. (172) in which the decision to present was felt burdensome to patients who felt relief when others made the decision for them.

5.8 Implications for clinical practice

It is important that ED clinicians assess a patient's breathlessness routinely.

Breathlessness is a stronger predictor of five year survival than tests of pulmonary function (169) . It is also associated with ED re-attendance and hospital admission (35) (171) and can therefore identify a group of people at higher risk for repeat attendance/admission. Knowledge of patients' self-rated breathlessness can enable optimal care and symptom management; routine assessment of breathlessness in hospital is feasible (36). Routine assessment of breathlessness in the ED may enable better management of patients both in the hospital and post discharge. Additionally approximately a third (55/177) of presentations due to breathlessness resulted in discharge home from the ED; suggesting that their acute-on-chronic breathlessness might have been most appropriately managed with improved breathlessness care in the community, and with optimal management planning between primary and secondary care (173).

5.9 Strengths and limitations of this study

This survey was consecutive, including 24 hour days and weekends, thus minimizing selection bias. There was a very high response rate (90%) and minimal missing data. The survey was administered in a single site during spring, however although there will inevitably be findings specific to this site, there are sufficient similarities to other published work to support their relevance. This study was performed in a city in the northeast of England which has a higher prevalence of both COPD than the rest of England (163). Owing to the wide variation in prevalence of these conditions nationally the study would need to be repeated before assuming generalizability. Furthermore, primary care is under-resourced in the study area; in the lowest quintile for number of family doctors per 100,000 of the population (174) and this may influence the number of presentations to the ED.

The survey was in English with no resources available for translation and therefore some patients may not have been able to take part. Only patients presenting to Majors were surveyed and therefore some patients who presented to Minors but who were not re-directed to Majors may have been missed. Only 72% of the potential participants gave consent for clinical record review, which may have caused some selection bias in the clinical record data.

As the study required self-report breathlessness and no provision was made for proxy observation, we have no data with regard to those who were too unstable to participate. This group are likely to include people with significant breathlessness which contributed both to their attendance at the ED, and any, again likely, admission. Our prevalence therefore, if anything is an underestimate further underlining the importance of breathlessness as a symptom in the ED. In addition, to minimize participant burden, we did not collect any further data on people who said they did not have chronic breathlessness. We therefore have no comparative data from this group.

5.10 Summary

This fifth chapter described the methods for and the results from the survey and case note review, finding: a high prevalence of presentation to the ED due to breathlessness; that most commonly patients discuss their breathlessness with their GP; that breathlessness is associated with admission and that increased age; decreased oxygen saturation on presentation; having talked to a specialist doctor about their breathlessness; having a known history of a cardiac condition are predictors of ED departure status. The sixth chapter will describe the methods of and the results from the semi-structured interviews on the experience of presenting to the ED.

Chapter Six: Interviews

6.1 Introduction

Chapter Five described the prevalence of acute-on-chronic breathlessness, pathways to ED presentation and predictors of ED departure status. This chapter presents the methods used, the findings and a discussion of the findings of the semi-structured patient, carer and healthcare professional interviews which were designed to answer the following research questions:

- 2 What clinical pathways are followed by patients who present to the ED due to acute-on-chronic breathlessness?
- 5 How do coping with and experience of help-seeking in the community influence their decisions to present to the ED?
- 6 What is the experience of patients and their carers when presenting with acute-on-chronic breathlessness to the ED?

6.2 Research setting and study governance

The project obtained both sponsorship and research governance from both Hull CCG and East Riding of Yorkshire CCG. The principal investigator (AH) had a NIHR research passport in place prior to the start of recruitment.

6.3 Interview method

6.3.1 Setting

Interviews were conducted in the homes of patients and their carer in Hull or the East Riding. Healthcare professional interviews were conducted in their workplaces.

6.3.2 Participants and eligibility criteria

Inclusion criteria:

- Survey participants who have acute-on-chronic breathlessness and have agreed to be contacted further after they had completed the survey
- Written informed consent
- Sufficient use of the English language to contribute to an interview
- Able to take part in an interview
- Healthcare professional participants were eligible if they were nominated by their patients as being a supportive healthcare professional and gave written informed consent

6.3.3 Development of the interviews

6.3.3.1 Design

The interview was designed to be semi-structured and last approximately one hour. Once selected as a potential interview participant the patient was phoned by AH to check consent to be approached, explain the study in brief and arrange a time to visit. On arrival at the participant's home/workplace the researcher introduced herself and gave the participant(s) an information sheet to read (see Appendix 14 Participant information sheets). Written consent to interview was sought after any of the participant's questions had been answered (Appendix 15 Participant consent form). Audio-recordings of all interviews were made.

6.3.3.2 Content: topic guide questions

A topic guide of key prompts was used to guide the researcher during the interviews. The guide was sufficiently flexible to allow emergence of relevant but unanticipated responses and thus the formation of new prompts for subsequent interviews. The topic guides were derived from the current literature and the research process and covered areas such as thinking about breathlessness and coping strategies, as well as their experience of the ED.

The semi-structured interviews followed the topic guide (see Appendix 16 Topic guides) which was developed from the literature and expertise of the

supervisory panel. The topic guide contained questions about how the participant's health and how breathlessness in particular was affecting their life, how they cope with breathlessness, their experience of presenting to the ED and the circumstances surrounding their decision to present, their view of their future, which healthcare professional (if any) they find most supportive and finally any suggestions they had for improving services for breathless patients.

The semi-structured interviews with healthcare professionals followed a topic guide which was based on that used with patients. The healthcare professional was asked to reflect on what they knew of the effect breathlessness had on their patient's life, how the patient coped, what they knew of the circumstances surrounding the patient's presentation to the ED, their view of the patient's future health and their suggestions for improvements to services for breathless patients. In addition to these questions the healthcare professionals were asked about how they experienced treating their patient, their view of the patient's use of healthcare services, what would help the patient avoid presenting to the ED another time, what things they had discussed with their patient with regard to breathlessness management and expectations and what, if anything, had happened in the period between their presentation to the ED and the time of the healthcare professional's interview (see Appendix 16).

6.3.3.3 Review process

The topic guides were reviewed by supervisors, peers and from patients in the Respiratory Support Group (RSG), based at the Freedom Centre, Hull. As a result of the feedback the language used was simplified. Also as the interviews progressed items were added to the topic guide in an iterative manner.

6.3.3.4 Ethical considerations

A number of ethical issues were considered when designing and performing these interviews, including minimising participant burden, gaining consent and maintaining confidentiality.

Minimising participant burden was a key consideration when designing the interview process and patient topic guide. Participants were offered the choice of interview venue, however all chose to be interviewed at home. The interview lasted approximately one hour and breaks were offered as required. It was made clear that the participant could withdraw from the study or end the interview at any point if they chose.

Healthcare professionals were interviewed in the workplace, which minimised travel burden and allowed easy access to patient notes should they wish to refer to them. The interview lasted approximately 30 minutes and it was made clear that the participant could end the interview at any point.

The flow of the patient interview was carefully considered to help the participant open up and discuss issues about their health in general initially, leading to more directed questions aimed at understanding their decision to present to the ED and their future, then finishing with less personal questions to round off the interview in a less emotional way. The researcher monitored the participant's emotional state and reactions, allowing rest breaks whenever necessary. At the end of the interview if any issues had arisen requiring clinical attention the researcher recommended that the participant contact their clinical team for review.

The flow of the healthcare professional interview was also given careful consideration. Although the emotional content of the interview was less likely than for the patient, they may have felt defensive or uncomfortable when being asked questions about their care of their patient.

The issue of consent was treated with prime importance all through the study. Initially the survey participant had been asked to give written consent to be contacted for interview at the end of the survey they had filled in. When the researcher then phoned the potential interview participants verbal consent to meet at their homes for an interview was gained. Then at the beginning of the interview written consent was gained from the patient and the carer, if present, to take part in an audio-recorded interview and permission sought to publish anonymised quotes. The patient was also asked to give consent for the

researcher to inform their GP that they had taken part in this research, so that the GP would know with whom they had been discussing their health. Finally towards the end of the interview the patient was asked to verbally consent to the researcher contacting their nominated healthcare professional for interview.

Consent was a particularly important concern of the healthcare professionals, as obtaining consent and guarding confidentiality are key aspects of their professional practice. When seeking an interview by telephone the researcher made it clear to the healthcare professional that their patient had nominated them and had given verbal consent to be allowed to contact them.

To preserve confidentiality, names and contact details were stored in a master index file on an encrypted USB as the only record of identifiable data; filed in a locked cabinet. The audio-recordings were stored on an encrypted hard drive at the university and a password protected computer and were then immediately erased from the recorder used in interviews. When sending the recordings for transcription, the encrypted service Drop Off was used. Finally all transcripts were anonymised, including circumstantial details which may inadvertently identify the participant.

No reimbursements were offered to the patients or carers. Healthcare professionals were reimbursed for their time spent taking part in the study. Those employed by a GP surgery were paid NIHR rates, whereas community trust employed staff received a £25 book voucher for participation.

To minimise the risk of harm to the researcher the SEDA research group's lone worker policy was followed.

6.3.3.5 Patient identification and sampling strategy

Of those survey participants presenting with acute-on- chronic breathlessness, who lived in Hull or the East Riding of Yorkshire and who had given written consent to be contacted for interview, a purposive sample of approximately 20 participants was selected to gain wide variation in respondent types. The sample was selected on the basis of gender, socioeconomic status, diagnosis,

whether they lived alone or not, smoking status and on the number of previous ED presentations in the past year.

During the patient or patient and carer interview the patient was asked to nominate a healthcare professional who they felt was most supportive of them. The patient was then asked if they gave their consent for the researcher (AH) to contact the healthcare professional to seek agreement to take part in an interview. Verbal consent was recorded and a note taken of the relevant contact details. A letter inviting the healthcare professional to take part in an interview, along with an information sheet was then sent. A week later the invitation letter was followed up by a phone call to answer any questions about the study and to arrange a suitable time and place for the interview, if agreed to by the healthcare professional.

6.4 Analysis plan

The method of analysis chosen was thematic analysis first described by Boyatzis (73) and then elaborated on by Braun and Clarke (175). This is a flexible method of analysis that can be employed across a range of epistemological approaches and can result in a rich and detailed account of the data. Thematic analysis can be used with the size of sample that was chosen to give maximum variation, whereas other methods of analysis e.g. Interpretative Phenomenological Analysis (176) would not have been appropriate as they require a small homogenous sample.

6.5 Findings

6.5.1 Study participants

The interviews took place between December 2013 and September 2014. In total 18 patients were recruited to interview, nine of whom were interviewed with their nominated carer. None of the patients or carers withdrew from the study or asked for the interview to be stopped.

Of the 18 patients, 12 nominated a supportive healthcare professional and 11 gave consent for them to be approached for interview. Of the 11 healthcare professionals nominated 8 were interviewed whilst three did not consent to be interviewed. None of the healthcare professionals withdrew from the study or asked for the interview to be terminated.

6.5.2 Characteristics of interview participants

The characteristics of the patients recruited to interview are shown in Table 8. It proved difficult to recruit to interview more than one non-smoker who had presented to the ED due to breathlessness as several patients I contacted explained that they were ex-smokers or if they were non-smokers that their reason for presentation was not due to breathlessness. The healthcare professionals recruited included two Macmillan nurses, two respiratory physiotherapists and four GPs.

Table 8 Characteristics of patients interviewed

Interviewee identification number	Gender (M/F)	Socio-economic status (Low/Medium/High)	Diagnosis (Malignant/Non-malignant)	Lives with (Others/Alone)	Smoking status (Current/Ex/Never)	Previous attendance at the ED (Few [2 or fewer]/Many [3 or more])
4	M	Low	Non-malignant	Others	Ex	Many
5	F	Low	Non-malignant	Alone	Ex	Few
7	M	Low	Non-malignant	Alone	Ex	Few
8	M	Medium	Malignant	Others	Ex	Few
18	F	Medium	Non-malignant	Others	Ex	Many
19	M	Low	Non-malignant	Alone	Ex	Few
39	M	High	Non-malignant	Others	Ex	Few
84	F	Low	Non-malignant	Others	Ex	Many
88	M	High	Non-malignant	Others	Ex	Few
169	M	Low	Non-malignant	Others	Current	Few
258	F	Low	Non-malignant	Others	Ex	Few
338	M	High	Malignant	Others	Ex	Few
430	F	High	Non-malignant	Others	Current	Few
476	F	Low	Non-malignant	Others	Ex	Few
508	F	High	Non-malignant	Others	Current	Few
577	F	Low	Non-malignant	Others	Never	Few
603	M	Low	Non-malignant	Alone	Ex	Many
1209	F	Low	Malignant	Alone	Current	Few

6.5.3 Findings from the thematic analysis

Six main themes were identified: i) Widespread effects of breathlessness, ii) Making the best of it or making it worse, iii) Community healthcare professional approach to the patient and their breathlessness, iv) Knowledge, information and communication, v) System/service issues and vi) Decision to present to the ED. Several themes from the interview data overlap with what has already been reported in Chapter Four and so this chapter will focus on the new findings. The overlapping areas are: Widespread effects of breathlessness; Making the best of it or making it worse; Community healthcare professional approach to the patient and their breathlessness and Knowledge, information and communication.

Table 9 Themes from the interviews

Theme	Subthemes	Codes
Widespread effects of breathlessness	Physical effects Psychological effects Social effects Existential effects	Anxiety and breathlessness, Existential effects, Feelings about breathlessness, Future, Lifespace, Manner of death, Panic, Physical effects of breathlessness, Thoughts when breathless and Uncertainty Change in relationships, Change in roles, Effect on carer, Effect on others, Lack of understanding from others, Social embarrassment, Social limitations, Stigma
Making the best of it or making it worse	Ways of coping well Limited coping Carer support Fresh air Mobility	Acceptance, Adaptation of activity and environment, Attitude to exercise or PR, Attitude of family, Autonomy or dependence, Avoidance, Breathing exercises, Day by day, Fan, Fresh air, Health within illness, Hope for a cure, Mobility, Motivation to keep

		living well, Nihilism, Not telling anyone about fears, Reluctance to ask for help from others, Responsibility for health, Retaining independence, Self-help, Social support, Stagnation or movement, Stoicism, Struggling, Support from carer
Community healthcare professional (HCP) approach to the patient and their breathlessness	Biomedical approach Holistic approach Awareness or lack of awareness of the effects of breathlessness Management or lack of management of breathlessness Palliative care	HCP aware or not of extent of breathlessness, HCP experience of treating the patient, HCP on need for holistic approach, Pattern of treatment offered by HCP, HCP support, HCP on taking underlying condition approach, Interaction with HCP, Management of breathlessness, Nothing more we can do, Palliative care, Prognosis
Knowledge, information and communication	Diagnosis Knowledge of inhaler use Lack of information or too much Communication in consultations	Attribution of breathlessness to other factors, Clarity of explanation, Decline or not, Diagnosis query, Epistemic injustice, Information from HCP, Joint decision making, Knowledge about inhalers
System and service issues	Access to GPs Continuity of care Appointments Access to tests Comorbidities Referral Improvements needed	Access to healthcare professional, Comorbidities Continuity of care, GP access, GP relationship, HCP on services or improvements needed, Malignant vs non-malignant, Referral, Tests
Decision to present to ED	Breathing crisis Reasons to present to ED	Carer monitoring, discharge experience, ED attendance tension, ED chaos, ED experience, ED experience

	Attendance tension Effect of carers/others on ED presentation	previous, Not presenting to the ED, Recurrent ED presentation, ED staff, Paramedics, Exacerbations, Help-seeking, Sudden crisis, Told to present to ED, unsafe/unheard, View of ward, Result of ED presentation
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6.5.3.1 First theme: Widespread effects of breathlessness

As reported in Chapter Four chronic breathlessness causes widespread effects on the lives of people living with it including physical, psychological, social and existential effects and these data were also found in the interview findings.

6.5.3.2 Second theme: Making the best of it or making it worse

Many ways of coping with breathlessness were described in this theme as was also found in Chapter Four, with the addition of findings on the support given by carers and the importance of mobility and fresh air to aid making the best of living with breathlessness.

6.5.3.2.1 The importance of carers

Carers support those living with breathlessness in more than just physical ways, for example providing social support and encouragement to get out and about:

“That was my daughter in law that rings, yeah, yeah. Oh she rings me every morning, sees how I am and, you know; and she'll probably want to say to me "Are you gonna come up this afternoon?" because when it's nice, we go and we sit in the garden, and it's lovely.” (Patient 1209)

However, there was an evident tension when the carer, from good motives, stopped them doing things that they could manage for themselves:

"I was thinking well I could have done that and I could have done that and why aren't I doing it? And then when she goes home and I try and do things, I've got me grandson on me back saying "Sit down (laughter) you're not supposed to be doing that, leave it alone"." (Patient 84)

Carers can also support the patient by being aware of their breathlessness and doing breathing exercises together with them:

"And, you know, we've got this thing, if she's having a hard time breathing we have a breathing session and I do breathing with her." (Carer of patient 258)

"When I'm, when I'm having a bit of a do, shall we say, with my breathing, and I know he's in the garden, then I'll just shout to him, can you come and he'll come across and say "What's the matter?" And I'll say "Just breathe with me for two minutes". And we do, we hold hands, face each other, and we breathe together; and I would say within three minutes I'm on top knock again, you know, it's just...So we do all these little things together. (Patient 258)

Another task that carers take on is liaising with healthcare professionals (HCP) on behalf of the patient, sometimes helping the patient to understand and sometimes giving valuable information to the healthcare professional:

Patient: I can't, hard to understand him much easily.

Carer: That's why I go. He's foreign but, he can understand him but sometimes he talks a bit fast for dad, so I have to try to explain to him afterwards what he'd said.

Carer: Oh he's, he's fine, he seems real concerned and stuff, mm, always checks him out. (Patient 603 and carer)

"Very up and down I think and again just because of just how bad it does get when he is bad, he is particularly bad with it and I don't think he admits sometimes just how bad it is. You're talking to him and he's clearly suffering with the cough and the breathlessness but then he can seem to be particularly bad and he doesn't quite admit that yet and then she (partner) will come and say just how he's been and then he, eventually, he will then admit how bad things have been at times." (Macmillan nurse of patient 8)

6.5.3.2.2 Getting out and about

Fresh air and mobility aids were found to help patients to make the best of their situation. Mobility aids included scooters, walking frames, wheelchairs and cars. For example the use of a mobility scooter can lead to being able to get out and about more, have social contact and also breathe fresh air:

"Yeah, I feel better being out, you know, the fresh air does help, you know, and seeing people around yer." (Patient 19)

Also a walking aid can be of great help, providing physical relief and also some reassurance while walking enabling increased confidence:

"We provide them with walking aids; so a lot of patients, or a lot of people think walking aid means (a) I'm getting old, and (b) I'm unsteady on my feet, but for a breathlessness patient it actually takes a huge load off their quads muscles so they don't actually, their oxygen demand is a lot lower so actually they can walk further." (Respiratory physiotherapist of patient 508)

"Oh, our granddaughter said "Gran, you're gonna be racing up the road". I said "Yes, I am pet" (laughter). I can just see it..." (Patient 1209)

The many ways of coping that patients adopt can lead them to experience better quality of life as described by the following patients:

"I'm looking forward to the summer and thinking I can get out and about and be a little bit more active, and I feel that if I can get me limbs moving a little more and I learn to control me breathing a little bit better, it's pacing yourself. You know, one step one breath, one step one breath. I mean I might go a little bit slower, but yeah, I'm feeling fairly optimistic and hopeful." (Patient 8)

"I 'ope it's as good as it is now. If I stay as I am now I can do little things meself you know without getting puffed even though it'll tek me a lot longer because I do pace meself and I felt fine where before all I did was do a little thing, sit down (draws breath) breathe." (Patient 5)

6.5.3.3 Third theme: Community healthcare professional approach to the patient and their breathlessness

Some healthcare professionals demonstrated a biomedical approach to their patient's breathlessness which focussed on the underlying medical condition:

"Q: How do you feel that breathlessness can be treated? What would you do with a breathless patient to help them?

A: Depends what's caused it. So if they're, if they've got a condition where you know what it is and it's treatable, you can treat it, so in his case he would almost always get antibiotics and steroids; usually it's the steroids that, that do the, the good bit, and the antibiotics may or may not help. But every now and then people don't get better and you feel like an idiot if you haven't given them antibiotics and they, and they get worse." (GP of patient 39)

The participant did not go onto discuss management of the persisting breathlessness once the steroids and antibiotics had been used. The GP goes on to say that his impression is that the patient only consults when there is an exacerbation of the underlying condition:

“My sort of recollection of him is that he generally sort of gets on with things and then comes to see us when he’s got a, either a, a mini crisis or a; so he’s got COPD, so just when he gets exacerbations, and I think he’ll come and see me.” (GP of patient 39)

Other healthcare professionals describe their experience of others having taken a biomedical approach:

“And that’s the biggest thing we get from all our patients that come to us, in that, well I wasn’t told, all I was told was you’ve got COPD, here’s an inhaler, off you go, and not looked at the other options and encouraged to do things, because as soon as you’ve got breathless the last thing you want to do is exercise, but it’s just like the rest of us, if you’re unfit you’re gonna be breathless.” (Respiratory physiotherapist of patient 508)

It was clear from these interviews that some healthcare professionals were not aware of the extent of the effect of breathlessness on the life of their patient even when their patient had reported that they experienced severe problems due to breathlessness:

It wasn’t, it wasn’t something that I’ve highlighted as being a problem for her because it wasn’t an, an issue or an apparent issue when I first met her, it was the pain was the issue... I don’t, it wasn’t something I acknowledged as being a great issue to her, because otherwise I, you know, would have discussed it more I think...It probably was a problem to her, but her problem, her main thing was probably the pain... ..and they don’t always initiate other things that are concerning them. (Macmillan nurse of patient 1209)

Interviewer: So could I ask you how, how you feel breathlessness has affected his and his wife’s lives?

GP: ...I think he’s learned to live with it actually and, and, sort of recognises when it’s probably getting worse and, and seeks help then. But otherwise I think he generally gets on with it.

Interviewer: So if we think about him again then, in particular, what kinds of things do you think he has done to manage his own breathlessness?

GP: Um, apart from just kind of getting on with life I don’t, I don’t know of anything else specifically he’s done. (GP of patient 39)

However, some healthcare professionals did recognise the need for a holistic approach to breathlessness irrespective of underlying condition:

“I think it’s probably come from other services and the Department of Health, in a way, turning round and saying, look, we’ve got an excellent service for end of life for cancer but we’ve got other chronic respiratory patients who are just left and they, they don’t get that care and support and neither do the family and carers, which is just as important for them. But funding goes into heart attacks, goes into cancer and what not, but it doesn’t go into chronic lung disease, which is such a shame cos you can actually do so much for them.” (Respiratory physiotherapist of patient 508)

Such professionals demonstrated considerable understanding of the effects of breathlessness on their patient's lives when asked how they thought that breathlessness had affected them:

"Oh massively, yeah. She's quite an independent lady, as much as she possibly can be, so I think it's really, really restricted her a lot, I think she would go out a lot more than she does if she wasn't so breathless, and she's really keen on, well you, you've been to her house so she, you know, her housework, her house always looks pristine anyway...I think it's sort of the bigger picture that she struggles a bit more with, sort of her life in general, not being able to get out, perhaps not being able to do as much around the house as she used to be able to do, you know. It's that sort of independence gradually becoming less and less isn't it?" (Respiratory physiotherapist of patient 5)

"When it's particularly bad obviously the main thing is just quality of life itself. He has no energy cos he doesn't get any rest. When we saw him the other week it was literally 24 hours a day, he was coughing and breathless non-stop and even when his partner rang me to discuss it I could hear him in the background and it was the worst I'd heard him. He really sounded that bad and it just has a knock on effect because he can't, he likes to get out in the garden, he likes going out with the family and he was restricted to not going anywhere." (Macmillan nurse of patient 8)

Those healthcare professionals who both understood the widespread effects of breathlessness on their patient's lives and who also understood the need for a holistic approach offered appropriate management for breathlessness as well as treating the underlying condition:

"Yeah, 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 obviously 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, so we try and get the carers to attend programmes, or be there when we do home assessments, so that they can see what their loved one can actually do and what to do when they do get breathless, so they don't panic as well. (Respiratory physiotherapist of patient 508)

We use quite a few different techniques with them. So from a breathlessness point of view, we'd teach them positions to adopt to, to make their breathing easier and to recover, we use fan therapy an awful lot, acupuncture, distraction techniques, such as the breathing square or breathing rectangle as well, and also the calming hand. So we try to give them a range of different modalities to use because not everyone will find certain things helpful." (Respiratory physiotherapist of patient 508)

"If people are particularly struggling we've got the training ourselves so we'll go through some training with them, breathing techniques with them and we've got the fan therapy that we use for our patients so we go through that with them. We try to recommend the breathlessness clinic to as many, well to all of our patients if they are suffering with an element of breathlessness and we try and encourage that earlier rather than later so that they've then got the techniques on board to use in the future if and when they need to." (Macmillan nurse of patient 8)

These healthcare professionals offer management of the symptom of breathlessness in the context of its effect of the whole person; taking a palliative

care approach. Some participants described excellent supportive care from professionals who were available and who understood their concerns:

Patient: "Well (name) has, she's been very good and, you know, and, as I say, from day one, and she said "Any time (name), it doesn't matter when it is, you ring". You know, and, as I say...

Interviewer: Yeah. And you feel you can ring?

Patient: Yes, yeah. In fact, she sometimes rings me and if, if she doesn't get hold of me, she'll ring (name) , cos she's got (name) 's number as well and, cos she's met (name) every time she's gone with me. So yeah, it's good. As I say, I've, I can't complain about anybody, to be honest I really can't." (Patient 1209)

"Well the one is a lung nurse, and she's been very helpful in the administration of various things, and she's been pretty good; and she, she phones up every now and again to see, and whenever I have an appointment at the hospital, she, she knows I've got an appointment there, she always comes through to see us, to see if I've any problems or anything else, yeah. So she's very good, yeah." (Patient 338)

"I have got the best of help and the best of treatments and me consultants have been absolutely fantastic and um I've got loads of friends who are nurses and matrons and things like that so I have had the, I mean even me sister said Nobody could get what you've had and I couldn't, oh I've got the best team going which they say even in hospital you've got everything what you need and I have." (Patient 5)

As opposed to those who see breathlessness only as a symptom of an underlying condition rather than something to be managed in its own right and in this kind of scenario the patient also thinks that this is all that can be done:

"No, as I say, when, when you've, when, when you've got CPO (COPD), I mean you just help yourself really with yer sprays and take it easy. There's nothing much; as I say, the only thing that, that anybody can ever do is, if you're really bad, is for 'em to put you on the nebuliser to get you breathing again, that's about the only, only thing I could think of." (Patient 169)

Carer: Yeah, well yeah, because that's all we can do...there's nothing they can do for her, they've told us that anyway, you know, there's...

Interviewer: When you say they, who's they?

Carer: Sorry, the specialist, the hospital, the doctors, they can't do any more for her apart from try and keep her on an even keel, you know. The thing is when we do go they don't tell her anything that they haven't already said the previous time...

Patient: They say that there's nothing else they can do...

Carer:: There's nothing they can do.

Interviewer: So can I ask, in, in this time that you've been particularly unwell in the last few years, have you been offered to, to see, you know, like respiratory nurses or any kind of...

Patient: No.

Interviewer: ...breathing, breathing technique training or anything like that?

Patient: No.

Carer: No, nothing.

Interviewer: Are you aware of any kinds of services or help that you could have at all?

Patient: No, no. (Patient and carer 84)

Often healthcare professionals find it is difficult to decide when it is the right time to discuss palliative care and this seems especially true of non-malignant conditions:

“GP: And so am I right that, at this point, you haven’t yet discussed with him anything about sort of palliative care or sort of end of life or anything, have you discussed?”

Interviewer: No, I don’t, no, I don’t think he’s, no, I don’t, I think some of those services, you know, would, would help him but I don’t see him as sort of end of life. He’s only sixty-three and he hasn’t got an identified definite life threatening condition.

GP: ...and, to be honest, with a, a cancer patient you actually have a trajectory that you can kind of follow, you can see, they’ve got the diagnosis, they follow a certain pathway, and then they literally come to a point and die at that point, whereas COPD, they’ll have a flare up of their condition, so they’ll lose some of their lung function, but then they’ll bounce back but never get back to where it was. So you never know when the end is, so trying to prepare for it is very difficult.” (GP of patient 19)

When this approach is taken then no discussion of end of life care wishes and funeral plans takes place leaving patients in a position where they cannot consider their wishes and often their care may not be as they might wish:

“I think, you know, again just thinking about a lot of the patients that we see, it’s an area that isn’t often discussed and then when it does come to the point where patients are really quite unwell, you know, nobody’s asked them, you know, where they would like to be when they die, there’s nothing in place in the home for if they do become more unwell in terms of, I don’t know, palliative medication and things like that it’s not been discussed, looked into, either with the patient or including their family as well. I think the other thing is a lot of patients do end up going into hospital and they end up dying in hospital, and that’s not what they wanted.” (Respiratory physiotherapist of patient 5)

Alternatively those healthcare professionals who adopt a holistic approach to the management of breathlessness also open the door to conversations about end of life planning and thereby potentially improve their patient’s quality of life:

“No, the fact that she was deteriorating quite rapidly with her breathing and doing less and less, we then started discussing palliation and looking at getting wills and, sorted out, end of life care, things like that. And although it’s not an easy conversation to have, the door kind of opened on that one day, and her husband was there as well, so we had the conversation.

And, to be honest, it was probably the best conversation we could have had at that time, not a good conversation to have, but it's actually spurred her on and she's actually become much more positive in wanting to do things and getting out there.

She, she wasn't happy about confronting the end of life, in a way, and it, it was something that she actually brought up, so it was her opening the door on that conversation, so it was like "Well I can't tell you how much longer you've got, but if we carry on in this vein actually your length of time still alive is going to be a lot shorter than if we actually start getting you eating a bit more, getting you exercising a bit more, and if we can get you outside these four walls and interacting with real life again, then actually that will improve your quality of life. I can't see it's going to improve the length of life but actually the quality will be much better". (Respiratory physiotherapist of patient 508)

There are benefits and drawbacks for the healthcare professional involved too, with those working in a holistic way with patients with malignant diagnoses finding their job predominately positive, whilst those working with patients with non-malignant diagnoses whose care is usually not so well coordinated finding it rather frustrating:

"Because the prognosis is often not long with some of our patients, it's about making sure that they've got the other support mechanisms, which play a much bigger role than we do. You know, if patients are wanting to be at home to, preferred place of care, about making sure the right services are in and, and the liaison between the different services to update people, it's, you know, it's all about that patient at the end of the day isn't it?" (Macmillan nurse of patient 1209)

"I think it's frustrating. I, I, I can see his frustration and I feel as, as frustrated; that you can see what needs to happen but you can't make it happen, but I guess you get a bit philosophical, I suppose. But I actually do think there are a lot of, there are a lot of things we should be doing a bit more with him, I don't think that we, so I do think we can improve what we're doing, even within what's available." (GP of patient 19)

6.5.3.4 Fourth theme: Knowledge, information and communication

Due to the slow onset of breathlessness especially in COPD it can take people some time to realise there is anything wrong with them for which they should seek help for; with many instead attributing their breathlessness to other factors such as smoking, dust exposure or getting older:

"I think, like most patients, you accept, as you get older, that you're getting more breathless, and put it down to the fact that you're getting older and you're not as fit, and I think it then gets to a stage where actually 'Betty down the street can do a lot more than me and she's a bit older than me, so why can't I do that?' and that's when it starts to come through. It definitely

creeps up on a lotta people. It can be going for twenty years before they actually notice they've got a problem." (Respiratory physiotherapist of patient 508)

Once a patient has recognised that their breathlessness is not normal and cannot be attributed to other factors they may seek medical help for it, but still be none the wiser as either they receive no definite diagnosis or the diagnosis they receive has little or no meaning to them:

"Well they, they diagnosed that about eight year ago but they didn't tell me for some unknown reason. I thought that I had bronchial asthma and then when I went in hospital one of the doctors come and said "Oh you've got COPD". I said "What the hell's that?" Then I went on the internet and looked it up and I frightened meself to death." (Patient 577)

"And that's, that's the biggest thing we get from all our patients that come to us, in that, well I wasn't told, all I was told was you've got COPD, here's an inhaler, off you go." (Respiratory physiotherapist of patient 508)

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

Patient: "No, no, you see the doctors don't, do they? They just say, oh yeah, they say, well it's COPD, boom." (Patient 258)

Having received a diagnosis which holds little meaning for them people also have little knowledge of what the condition entails, often being unaware that it involves a decline in overall functioning over time and that it is life-limiting:

"Well I'm going to be as positive as possible because I have to get better, I need to get as well as I possibly can, I really do need to, so I'm going to try my level best to stay, to get well and to stay well." (Patient 258)

"Oh I can't see there being much change, to be honest, so, just keep on me medication and everything will be kept at bay, as you might say." (Patient 338)

Patient: Well I'm hoping they're gonna pick up like, but realistically I can't see 'em picking up much.

Interviewer: Why do you say that?

Patient: Well cos, I don't know, you seem to get in a rut where every month or so you, you seem to go down with your breathing and everything, it seems to get on top of yer, but this is what I'm hoping this class is, this course is gonna help me sort out like, you know, so I don't know. Well I mean that I can carry on at least like I am now, at least, I don't want it to deteriorate like, you know, so I just wanna, I don't know. (Patient 39)

Only people with some personal experience of family members with the condition have much idea that it involves a necessary decline:

“Yeah, cos I’ll have, I’ll be all right for a coupla weeks, won’t I, then I’ll have a bad week and then, cos it, it goes like in steps. Like I’m all right, like that other level of like seven weeks off, OK, and then I’ll go, I’ll have a bad week and then on that, that level again, then it goes down again. So it’s, it’s deteriorating that little bit every time, it gets worse. At this rate I think I, I might be back in ‘ospital again, I hope not but I might do. (Patient 4)

But life in a general ’ll end up the same way as my dad did, and also me auntie, they started out exactly how I did, and even they say, they goes, well I’m going through all the same process as what they did. So I know what the end result will be, but yeah you’ve got to accept it. I think it’ll get progressively worse over a few years.” (Patient 4)

“I know in my own heart I will get worse and I will get worse and I’ll get worse and worse and worse until I can’t control it but at the moment while I can control it I control it meself do you understand what I mean?” (Patient 5)

In addition to patients seeming unaware of interventions to help breathlessness as well as treatments for the underlying disease, many also seemed to lack knowledge on the correct way to use the treatments necessary for their medical condition which is appropriately identified as a key first step:

“But funding goes into heart attacks, goes into cancer and what not, but it doesn’t go into chronic lung disease, which is such a shame cos you can actually do so much for them and just sometimes tiny little tweaks, just even changing their medication, or teaching them how to use their inhalers, cos most of them in giving an inhaler, never shown what to do with it, how to take it, how often to use it, and that’s one of the biggest things that we do is we’ll go through that make sure they know exactly how to use it, when to use it, and that in itself can turn a lot of patients round.” (Respiratory physiotherapist of patient 508)

Additionally there are a whole range of things that patients can use when they have good knowledge of them:

“Despite her slight frame and her breathlessness, her inhaler technique is fantastic; it’s taken a while but we’re, we’re there now, so it is fantastic. But also just getting her knowledge regarding when she can use things like a nebuliser and her inhalers and when she just needs to use her breathing positions and fan therapy.” (Respiratory physiotherapist of patient 508)

When some patients are unwell they seek information from healthcare professionals, friends and family, books and the internet:

“Then I went on the internet and looked it up and I frightened meself to death. (laughs)” (Patient 577)

“I mean I keep asking the questions, I get the answers gradually.” (Patient 8)

Whilst others choose not to find any further information:

Patient: I can be stubborn, if you like, and I just don't want to know, and I would, I want to do it my way.

Interviewer: By not knowing, how does that help you?

Patient: Well that gives me, ignorance is bliss. (Patient 1209)

Those who look for information often find themselves swamped with lots of pieces of paper which don't mean much to them or are seldom looked at:

"I was gonna say I can't, there's that many, they give me that many pieces of paper, but I know I've got it somewhere." (Patient 169)

Interviewer: I was just wondering, have you had a chance to have a look through that, that booklet, the self-management plan, have you had a look at it at all?

Patient: No, not yet love, I will do. (Patient 169)

"I don't exactly know what the nurses do, and even their leaflets don't, are not very clear to me." (Patient 338)

Alternatively some patients work very hard to find information themselves:

Carer: We've had to learn or we've had to find out for ourselves...

Patient: Yeah, right down the line.

Carer: Things, why, what for, why should we do this, why not do that, and why we don't do this, and you find out for yourself, nobody tells you." (Patient and carer 258)

Sometimes information is taken in best when it comes directly from a healthcare professional who take time to talk things through with the patient:

"I've got all the information I want and they've told me what's what, and this new doctor is, he, he, he's one of them where you can talk to 'em straight and say "Look, I wanna know" and he'll explain it to yer." (Patient 577)

Communication between patient and healthcare professional can be clear or alternatively problematic. There are time constraints on GP consultations which can cause difficulties for the GP by not allowing time to talk with patients as much as might be necessary:

"Our consultation time from when I started, it's actually increased; but there's, there's never been enough time to do everything for everybody and almost always you run late, but it's just a

fact of life and you kinda get on with it. And if somebody does need longer, you can do one of two things: one is to say, all right, well here's your whatever and I'll see you next week, so you, you basically put things off, or you just deal with it and run late." (GP of patient 39)

Also there are pressures in the consultation due to the administrative burden GPs have:

"The work in, in hours has definitely got busier; nowadays I come in over an hour before surgery starts to, to sort of do admin while nobody's coming in and asking you to sign things, and really working straight through till six. It is definitely more busy, there seems more stuff to do, many more boxes to tick; and because the box ticking is partly our money, you end up sort of, you know, you're going to see a patient, you have a look before you see them, what boxes have I got to tick whilst they're with me, almost to the point where what they've come with is a secondary issue. It's not quite like that but it's definitely on your mind. So it has an effect." (GP of patient 39)

Patients clearly pick up on the fact that their GP is using their computer a lot whilst in a consultation and can read it as rudeness:

Patient: This is what I find wrong with my GP, he'll sit and look at that screen, he never looks at me. I can be sat here, he looks at that, he never, and I've been his patient for thirty to forty years and he never turns round and says, how are you Mr...? Never.

Carer: He, he never says anything, he's just writing as he's looking at his computer.

Patient: I don't doubt his ability as a doctor, I think he's an excellent doctor, but he doesn't have any bedside manner, no.

Carer: To the point, well, to the point of being rude really, it's manners that comes down to it. (Patient and carer 8)

Misunderstanding can arise when communication between patient and doctor is not clear over what is happening in the consultation as is apparent in the above situation. Another area of possible misunderstanding is the now common practice of joint decision making, whereby a GP takes into account the wishes of the patient when decisions are made on treatment. However, some patients misunderstand the purpose of it and feel that they just want direction from their doctor:

"He [GP locum] just says "Well what do you want me to do?" I thought well you're the doctor, you should be telling me what you can do for me." (Patient 19)

"Well the last twice I've been to see him, I've been and I've seen him, he's asked me what I want him to do; well to me that's not, I'm going to him for a remedy or advice and everything, so; any, anybody could come in and say "Well what do you want me to do?" And so I, I always avoid him." (Patient 338)

6.5.3.5 Fifth theme: System and service issues

Access to primary healthcare professionals especially GPs was a key issue for many patients. Some patients felt they had good access to their own GP and valued the continuity of care it afforded them:

“Well he’s the only one I can go to on a regular basis. If I was to ring up say now and just say, it’s can I see the doctor, I can’t breathe; yes, if you’ll come down straightaway, they see me immediately. If he, if for some unknown reason he couldn’t see me this morning I know I would be there at four o’clock this afternoon; I am seen within a six to eight hour space. Cos I can go to him any time.” (Patient 258)

“Because he listens to me and he knows me condition, you know, his dad tret me for years and, you know, when I was introduced to him he says “Oh yeah, me dad’s told me about you.” And I’ve been with that practice now thirty odd years, so, you know, I trust ‘em as well, do you know what I mean? And they know me condition and they’re really, really obliging with me, you know. They’re really caring with me, if you know what I mean?” (Patient 476)

Developing a good relationship with a GP was seen as very important to many patients:

“Oh he’s fantastic. I know it don’t matter what problem I’ve got I can go in there and he will do his level best to sort it. I went in to see him one day and I just said to him “Doctor I’m restricted, I can’t leave the house because I’ve got to use me nebuliser.” “Haven’t you got a mobile one dear?” I said “No.” He said “Well you will have.” And within ten days I had my mobile nebuliser in this house. He said “Now you can go on holiday.” You know, he’s absolutely fabulous.” (Patient 258)

“I can go to him any time, and, and, and as I’ve already said, I’m seen to, I, I only have to ring up and within an hour I’m being looked after, and if he feels that I need to go into hospital then he’ll sell, send me regardless of whether I want to go or not, he’ll say you’re going and I go with his wishes because I know he’s only doing the best for me. If he says to me “No, go home and rest” then I take his advice and I’ll come home and rest.” (Patient 258)

Interviewer: Can I ask you how you, how you feel about your GP in general, do you see him or her sometimes?

Patient: I see him quite a bit, yeah, yeah, and I, I think he’s very good myself, personally, yeah.

Interviewer: Right. In what way is he good, what does he do?

Patient: Well the advice he gives you and (...) he take, he seems to take, you know, it, a bit of thought goes into what he’s telling yer to, as far as I can make out like, you know, he seems to know what he’s talking, he can relate to me, as far as I know like, you know, it’s like...

Interviewer: Do you feel he listens to you carefully (...)? (talking together)

Patient: I think so, yeah. The, the, the GP I had before was, I don’t know, didn’t relate to them at all, till I swapped to this one and, as I say, I, I think he does listen and...

Interviewer: In what way do you find him helpful?

Patient: Well he suggests different things, he'll, he'll ask me, do you think that's working, do you think, you know, he'll discuss it and he'll put me on different antibiotics and that, do you feel as though they're better than the other type I used to give you and, I think we'll try you on this now, and different things like that like, you know, he's quite good I think, I think anyway like, you know, he seems to have a bit of time for yer, you know, where you've usually got the, your ten minutes allocated slot and you're in and out, he will discuss things with me. (Patient 39)

Other patients perceived they had inconsistent access to their own GP, but they felt happy with the access they had to any one of the doctors in their practice:

Interviewer: So you wouldn't say that you have one particular GP that you see often?

Carer: No, seen about three or four, haven't yer, last few visits?

Patient: Yeah, but I'm not bothered, as long as they know what they're doing that's, that's fine with me. (Patient and carer 508)

Conversely some found that the lack of continuity of care bothered them and they would have preferred consistent access to one GP who knows them well:

"It was this locum that I saw when I went, you know, he didn't know me records or anything. And he was the only one I could see at the time." (Patient 19)

Interviewer: So can I ask you, you, you haven't really talked very much about your own GP, do you, do you go to your GP very much or...?

Patient: Not a lot, no.

Interviewer: Do you have a GP that you've seen for quite a long time or...?

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

Carer: No, but when you do you never see the same doctor twice anyway...

Patient: No, I never see, you don't, no.

Carer: It's just whoever's available. So you, you don't build up a rapport with your GP anyway, you know. (Patient and carer 84)

Interviewer: So you find it sometimes difficult to actually get a GP appointment?

Carer: Absolutely, to get the GP you want, not to get a GP, but to get the GP that you want. I would say that possibly eight times out of ten you can actually get in to see him if you ring up on the morning. And sometimes if you go to a different one, I mean there's so many doctors at our practice so you can get anyone, if you really need to go at that point you sorta say, right, well you'll see them. But I always think if you go to the same one they get to know you and they know what you're all about; like his doctor knows what he's like and how things go on, because they know your history of it they're not having to read it up when you get there and they know who you are and what you're like sorta thing. (Carer of patient 39)

Whilst some reported that getting appointments at their practice was easy others found that receptionists raised barriers:

"But I just think sometimes receptionists can be a bit mighty, almighty sorta thing, well what is it you want and all this business, and I think that sort of puts you off going any further; does he really need a doctor, does he really, there's no appointments." (Patient 39)

"Or then again if you tried ringing up and they say, well we can't get you in till next week or you'll give the receptionist your symptoms and they'll say, well we suggest that you go to hospital. It's like, well you're not a GP. So that gets yer back up as well, so that's why, sometimes it's why you don't bother going." (Patient 4)

Others reported that even when the receptionists were obliging it was difficult for them to get appointments except in an emergency:

Interviewer: Do you feel it's quite easy to get an appointment if you need to go and see him?

Patient: No, it is a bit difficult lately.

Interviewer: Right. In what way?

Patient: It's, well it's the same every doctor I think, innit, you know, they're always full up. If it was an emergency I could, yeah. If it was an emergency they'd, they'd fit me in somehow, you know, the ladies they're, they're pretty good that way. If, you know, if I say to 'em "I'm just not well at all and I need to see the doctor." They say "Well can you ring us back later, we'll try and get you fitted in somehow." They're really good that way. (Patient 476)

GPs themselves also recognise that better access to the practice would help in patient care:

"I think being able to have easy access to the practice, you know, to be able to speak to a doctor fairly quickly, being able to, to get him in quickly and to be seen in that situation would be helpful." (GP of patient 7)

In keeping with the report that receptionists sometimes suggested going to hospital, the lack of access to a GP may be linked to presenting to the ED:

Interviewer: What lead you to go to the ED?

Patient: Well I think it's panic more than anything else, you know, because you don't really know what's going wrong, you don't know yerself. If you ring the doctors up, they don't come out do they?

Interviewer: Can I ask you why, why you, don't think of going to the GP?

Patient: Because if you ring, if you ring up for an appointment and it's after eight o'clock you don't get one that day, and they can't make you an advance appointment for later on or next day, which'd be too late anyway. I have had a visit, I have had a visit from me doctors, but they only have certain times that they come don't they?

Interviewer: And if you do, well do you try to get appointments at the GP sometimes? How is that?

Patient: Nearly impossible. (Patient 84)

Access to other community healthcare professionals was variable with some patients feeling they had excellent access their healthcare professional only a phone call away, whilst others felt there were great difficulties:

Interviewer: Has your doctor said anything to you about when you're feeling very breathless that you should go to the hospital, or has he told you to ring him or...?

Carer: Just ring conditions nurses.

Patient: Long-term conditions.

Interviewer: The long-term conditions nurses. So you have a long-term conditions nurse that comes to visit you regularly do you?

Carer: No. (laughs)

Patient: Not really, not really. They're supposed to come...

Carer: ...they're supposed to come, they're supposed to come once a week, once a month, and I don't think they do.

Patient: They don't do they? (Patient 603 and carer)

Access to diagnostic tests in the community can be an issue too. Whilst some tests e.g. chest x-rays arranged by the GP, are possible the results usually take days to arrive and result in delay to treatment:

"What I find is quite annoying is the fact that if you go to hospital, if you have an accident or whatever, and you get an x-ray and within seconds they can see that x-ray and see what's what. You go for an x-ray because you've got a really bad chest infection, and it takes, I don't know a week/ten days before it comes back to the GP, to me that is absolutely ridiculous. He went for his x-ray, didn't you, at the Community Hospital? And he said "Come and see me a week later". It was nearly ten days and he went to see the GP and there was no results of the x-ray back again. I think that is absolutely disgusting, because in that time you can get so much worse can't you?" (Carer of patient 39)

Patients suffering from breathlessness frequently have a number of comorbidities which can be difficult for patients to bear:

"I was finding, with the COPD and the rheumatoid arthritis I was finding it hard to breathe and because all my joints had swollen I was finding it difficult to walk and it was one thing on top of another." (Patient 258)

"Well it only just upsets you that, I mean three or four years ago I wasn't like this and it just seems to have escalated, you know, and it's oh why? The doctors keep saying it's this, it's that and different things, and now, I mean I went for a scan yesterday and they've told me I've got this asbestos on me lungs and that now I've got a sort of a small growth or something and they're having to check that, and all these things get on your mind." (Patient 39)

“Not any one specific thing, but it does, does get, it takes a lot to withstand it, as it were, you know, you, you feel, God, when’s this all gonna end? Can we have one thing sorted out at the time and get back to normality?” (Patient 8)

“My problem is, and the one that sort of affects me more mentally is that I have a cardiac problem which I consider to be more serious than the actual lung cancer. The lung cancer’s serious and it can blossom and it can go elsewhere and it does kill people, I know, but the pressure that it’s putting me under with this coughing at the moment, I feel that I’m more liable to die from a heart attack than anything else, because it gets so distressing at times and real violent, and not being able to breathe is quite frightening, and it’s you, you sort of get mixed emotions on that one.” (Patient 8)

Patients may be seen in a number of different clinics each focusing on a different speciality which can be burdensome for the patient:

“Because it’s going on for so long every time I go in there I go into a different department; like saying going to ear, nose and throat, then to chest clinic and then to cardiology and then somewhere else. Yeah, so they’re all saying, oh well it’s cos of this, but then it’s like well no because that’s getting sorted out so they have to go down a different avenue, and then, it’s just one thing after another. So they end up saying well it’s an accumulation of everything, even though the breathlessness in its own right has got worse over the years, and it is getting worse as well.” (Patient 4)

Comorbidities also make diagnosis and treatment difficult for healthcare professionals and can result in patient’s receiving conflicting medical information:

“I would say that he does have a number of complex medical problems and his management of them is complicated a little by patterns of anxiety, particularly health anxiety, and so, that’s not uncommon for people with complex medical problems.” (GP of patient 19)

“One doctor says “Oh there’s nothing wrong with your heart, your heart’s OK, we’ve checked everything, you know, we think it might be a chest infection.” And they said, you know, I’ve still got, still got the fluid on me lungs, he says, but there’s nothing wrong with the heart. And another doctor says “Oh yes, it’s heart failure and your kidneys have failed a little bit as well.” So then another doctor says “No, it isn’t, you’re OK, your heart’s OK.” And I mean, you know, I’m like that, you know, I don’t know what’s causing it.” (Patient 19)

Healthcare professionals can refer patients to many other services in order to get their valuable input:

“I probably took half an hour talking about different things, and managed also to persuade her to let me get Macmillan involved as well, so that she had another point of contact, but also so I had another point of contact for looking at palliation.” (Respiratory physiotherapist of patient 508)

“We can refer into the pulmonary rehab service, and I get the smoking cessation team out to see patients in their own home, if that’s more appropriate.” (Respiratory physiotherapist of patient 5)

However often there are access problems and lengthy waits involved:

“They only take COPD on pulmonary rehab, and, and, you know, as on optimal treatment, and even then there’s a wait. So yeah, there’s a, and cardiac rehab similarly, well I don’t have any control about who gets cardiac rehab but it’s not available enough, so there are a lot more people that would benefit than do get it.” (GP of patient 19)

“But I can see that that would help him, psychological support. A single point of access is a, a triage phone call in a month’s time followed by a sometime/never appointment. So in practical terms it’s not really...” (GP of patient 19)

Interviewer: And presently do you find that you can, that you can easily refer to psychological help?

Healthcare professional: No, not at all. We can refer in, but then again, they have a capacity issue and their ability to see the patients is few and far between, so at the moment, no. (Respiratory physiotherapist of patient 5)

Additionally it is not always clear to healthcare professionals what the other services entail or who exactly can refer to that service:

“I think that, you see the breathlessness clinic we haven’t had an awful lot of information about it, so I’m only picking up snippets of information, you know, so we haven’t had an awful lot of stuff to work with really.” (GP of patient 19)

“It’s (pulmonary rehabilitation) normally accessed through the hospital and people who are attending because they’re quite severe and go through the clinic. I have used it but my experience is it’s not that easily accessible. To be honest, it’s not something I often consider, so it might not be as difficult to access as I perceive it to be.” (GP of patient 39)

A number of suggestions for improvement to services for people with breathlessness were made by healthcare professionals including greater continuity of care from the GP practice:

“Better support from GPs. A more consistent approach from GPs. Yeah, one who has looked into her situation prior to coming to visit her. I just think then they’d get to know her better, and she’d perhaps get more appropriate treatment at home. It’d be quite nice if she was maybe being monitored on a weekly basis, maybe one of the nurses popping in on her every week to see how she is, and just giving that support if she needs it, just keeping a bit of an eye on her really. (Respiratory physiotherapist of patient 5)

Greater provision of psychological support for patients was also seen as a key area for improvement:

“Well yeah, I think there definitely would be scope for more from the mental health side and coping with breathlessness. And I think the mental health side, we, you know, the, the services, you know, they would, they would say it’s not but the reality is it’s really hard to get hold of and patients have to go through hoops and, you know, they have a telephone call and if they get engaged with somebody from the mental health team it can be really good, but to actually get

them engaged and get them on board is absolutely tough battles, and, there is that perception of a serious lack.” (GP of patient 7)

“Having the psychological professionals there as well would be extremely helpful for, for those, cos I think we can address a fair amount of it, cos a lot of the anxiety and depression with the COPD patients especially, is the fear of what's going on, cos they have no idea what their condition is or what to expect and we can address all that and we can teach them how to manage that. But for those with more deep-seated problems we do need more specialist staff.” (Respiratory physiotherapist of patient 508)

“Well a lot of them want to talk, a lot of them have got issues in their lives that they want to offload and tell you all about and I’m not qualified to, you know, I’m not a counsellor and, you know, I’m quite happy to listen and offer as much help as I can but sometimes I do feel a little, little bit out of my depth, and you just sort of think, ooh, you know, if there was just somebody that we could refer to that could come out and see these patients and perhaps give them a little bit more support than we can give them.” (Respiratory physiotherapist of patient 5)

Another area that could be improved for those with non-malignant conditions would be improved access to specialists, as is already common in cancer services:

“I think more quick access to outpatient appointments, when you think well I’m struggling to manage this, am I missing something, or could we be doing something better, we have the two-week wait system if you suspect cancer, or three months, and there doesn’t seem to be anything in-between; and sometimes, you know, you don’t think people have got cancer but you could just do with, you know, something, whether it’s to help with their symptoms or because you feel you might be missing something, if you could get them seen in the next couple of weeks in the clinic would be fantastic.” (GP of patient 39)

Generally the care offered to breathless patients with malignant conditions was considered better than that offered to those with non-malignant conditions:

“I think it's probably come from other services and the Department of Health, in a way, turning round and saying, look, we've got an excellent service for end of life for cancer but we've got other chronic respiratory patients who are just left and they don't get that care and support and neither do the family and carers, which is just as important for them. It's not fair, and I think COPD itself has always been seen as, well you brought it on yourself, you know, because you've smoked you brought it on yourself, but then the majority of lung cancers are brought on by smoking but the same stigmatism doesn't seem to go with smoking and lung cancer as it does with smoking and COPD, and it's always seen to be a bit of a Cinderella service of, oh well we've got a little bit left over, we'll throw it that way. But funding goes into heart attacks, goes into cancer and what not, but it doesn't go into chronic lung disease, which is such a shame cos you can actually do so much for them.” (Respiratory physiotherapist of patient 508)

6.5.3.6 Sixth theme: Decision to present to the ED

6.5.3.6.1 Reasons for presentation to the ED

The trigger for presentation to the ED usually appears to be a worsening of the patient's breathlessness and general condition. This situation is often accompanied by a feeling of panic:

"The pain was more intense and the breathlessness was more intense, and really out of breath and, you know, feeling weak with it as well. Breathlessness as well, I was just frightened you know." (Patient 19)

Despite having realised their breathlessness is worsening some patients are reluctant to present to their primary healthcare professional; not wanting to bother them unnecessarily. Therefore their condition declines to crisis point by the time they decide to make an emergency presentation to their primary healthcare professional or to the ED. Some patients feel unsupported by primary healthcare professionals and so resort to presentation to the ED when they reach crisis point, not knowing where else to turn.

In this sample of patients there were broadly three reasons that people presented to the ED: i) they were told to by a primary healthcare professional; ii) their usually supportive primary healthcare professional was unavailable (out of hours) or iii) they felt unsupported by community healthcare professionals and in their panic turned to the ED.

On perceiving that they have a breathing crisis some patients seek help in primary care first:

"She has had COPD for a number of years so she's quite an experienced user of the different services that are available, and I think she tends to use the services quite wisely. She comes to us when she feels that she's not coping with the resources that she has at hand, so she has oxygen at home and she has a nebuliser, and she is known to the long-term conditions teams, so she normally taps into all of that first and I think when she still finds that she's more symptomatic than is her normal then she, she comes, she gets in touch with us for the alternatives. I think she's quite a good, a good patient, if you like, in that sense." (GP of patient 476)

They may then be told by their healthcare professional that they should present to the ED. This may be for a number of reasons: the healthcare professional may feel they are missing something and refer the patient to the ED so that they may get timely test results and specialist opinion:

"We try and control it as much as we can in the community and with antibiotics, steroid nebulisers and one tries to avoid admitting to hospital as much, but if we really don't get on top of it then I think one's obliged to make sure we're not missing anything." (GP of patient 476)

"So he said to me "I think you could do with a day in hospital, a day or two in hospital, if I arranged it would you go in for me?" So I said "I don't think I need hospital doctor." He said "I think you do. He said "Well to be honest, you'll get x-rayed, you'll get your blood done and then I'll know exactly what's going on." You know, so I said "All right then." So anyhow, he said "Go home, get yourself a bag ready, they'll come about a couple of hours." So I said "All right then." So that's what I did." (Patient 476)

Alternatively the primary healthcare professional may feel that treatment in the community has met its limits and that treatment in hospital may be warranted:

"Yeah, I went to the GP and he examined me and he said "Well" he said "you've got a very bad infection on your lungs by the sound of it" he said "I'm gonna give you some antibiotics and" he said "some steroids" he said "I want you to take six of these as soon as you get home" he said "there's enough for"; I think there was enough for five days. He said "I want you to take 'em for five days and I want you to take the antibiotics for six days and" he said "if there's no improvement" he said "I'm afraid it could be a hospital job. So I said "What do I do?" He said "Ring for an ambulance or get in touch with them at Hull Royal." And I still didn't feel that good, you see, so that was why I went. I was really badly I thought this is not getting any better, that's when I had to ring an ambulance." (Patient 169)

Also some patients were told that if their oxygen saturation was low or that they felt their breathing was worsening in future that they should present to the ED:

"When I go to my GP with my breathing problems, they say the same every time I go "Wendy, if your oxygen is any less than 89 you don't mess about with this 111" or whatever it is" it is 999 for you and you get yourself there immediately, because he said "once you start on your downward spiral" he said "you go very, very quick" he said "and you can't hang around." So, so yeah, I am instructed by the doctor not to hang around." (Patient 258)

Once a patient has perceived a breathing crisis they may attempt to contact their primary healthcare professional but find they are unavailable to and therefore decide to present to the ED. Primary healthcare services in the UK tend to be open in working hours (approximately 8.30am to 6pm) Monday to Friday only and so at night or weekends there is usually no one available and patients have to attend out of hours services or the ED if they require medical assistance before the next working day. Several of the patients in our sample fell into this category, including patient 508:

"She got herself into such a tizz and I think the first time was just after midnight and then again about three o'clock in the morning. Well she knows she won't get me at that time and so she'd used the paramedics." (Respiratory physiotherapist of patient 508)

Had this crisis happened during working hours then the physiotherapist would have been available and could have avoided the need to present to the ED by offering support and advice:

"The paramedics said to her, you know "In the morning, let your physio know" and I popped in to see her and she was doing fine. She'd just got herself into a bit of panic and again I think, like all of us, when you're panicking over something, you don't think logically and, you know, I'd said "Well you could just put your nebuliser on". "Oh I was just using my blue inhaler and I didn't seem to be getting any relief". "Well if you'd sat with that it would have helped"...I think her seeing what they did, and again myself going in the following morning and reinforcing, saying "Actually you could have just done this and you would more than likely have been OK in bringing things back down yourselves". And she was like "Oh right, I'll remember next time to use that, next time I can do that". (Respiratory physiotherapist of patient 508)

Other patients in our sample felt unsupported by primary healthcare professionals and so turned to the emergency services not knowing where else to get support when they were panicky and in crisis. Patients may feel unsupported in primary care due to difficulties in accessing one trusted clinician who can offer them continuity of care. For example one patient had great difficulty getting appointments with his GP and saw a variety of other doctors including a locum and this left him feeling unsupported:

"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." (Patient 19)

These patients would then turn to the emergency services to help them in their crisis often feeling safe in the hands of paramedics:

Carer: The paramedic came and gave her some gas and air and that calmed her down really quickly. But he was, he was really good, wasn't he, the way he spoke to yer?

Patient: Yeah, oh yeah, he was brilliant.

Carer: The way he dealt with yer was absolutely brilliant. (Patient 84 and Carer)

Paramedics make people feel safe and calm and also provide quick access to a healthcare professional:

"Well yes I think, but having a cardiac problem, obviously the first reaction when the paramedics come, all they said, you know, we're not, not messing about with your GPs and so forth, straight into hospital. So yes if I dare to ring for paramedics or any sort of panic I mean that's my first reaction is to ring for a paramedic rather than a GP because I could be waiting forty-eight hours to see a GP." (Patient 8)

Interestingly one family demonstrated that they had learnt from the paramedics who had added previously and so were able to avoid a future presentation:

“It's watching what they're doing. For me, personally it's watching what they're saying and, well listening to what they're saying and watching what they're doing with her that helps me, cos at first when she started having these attacks I was, I was panicking, oh I'll have to get an ambulance, I'll have to get an ambulance, now I just think right, think first, calm her down a bit, sit with her for a while, talk to her, find out everything what's going on and then decide. So that when she had another do a couple of nights ago I just did the same as what I'd seen him doing, apart from the, the medicines and the gas and air, yeah. Yeah, just the calming and the cold flannel and talking to her, but without patronising her, you know what I mean? And it helped me, he helped me to cope with this last one. She didn't need to go. I calmed her down and the pain went away. I sat with her and then she fell asleep.” (Carer of Patient 84)

6.5.3.6.2 Attendance tension

Attendance tension is felt by patients when trying to decide if they should consult a healthcare professional since there are a number of considerations to be taken into account. Whilst patients may realise their breathing is worsening not all of them will seek the help of a primary healthcare professional promptly, showing considerable reluctance to bother a healthcare professional when they feel they can manage themselves:

“She doesn't like to feel like she bothers anybody, she quite likes to get on and be independent and try and manage her condition as well as she can herself. So from that point of view she's quite reluctant to alert people if she's poorly and not feeling as well.” (Respiratory physiotherapist of patient 5)

However on reflection some patients realised that they may have left it too long to present to either their GP:

“Well whenever I've gone into hospital I've usually gone past that point where I can do any good meself, you know, I've left it too late, and I know in me mind I have, you know, but you keep thinking it can't last, I'm gonna get better and it doesn't, and that's it. I don't know, I'm thinking well you're a bloody fool really you should have gone a few days ago to see the GP, it might have saved all that like, you know, but I don't know.” (Patient 39)

Additionally many patients demonstrated attendance tension as to whether they should present to the ED, being uncertain whether it is best to present to the ED or whether to avoid it at this point in time. This may be for a number of reasons including not knowing if they were bad enough to warrant a visit:

"I'm always reluctant, because I think it's bad enough, if you know what I mean." (Patient 39)

Some patients felt it was a defeat for them to have to go to hospital and would rather have managed at home:

"I feel a little defeated whenever I have to go to the hospital, that I'm not being able to control myself and it, yes, sometimes it's a little bit frustrating mentally, physically, because I do know that if I've had a particularly bad night and, and if I've had a bad night the mornings are terrible, this is when it becomes obvious and distressing for anybody around, but I know that if I'm allowed to relax in my way that gradually, throughout the day I settle down, and then usually by late afternoon, early evening I've rallied round." (Patient 8)

Others felt they preferred their home surroundings to being in a hospital and so were reluctant to present to the ED:

"I'm not one for hospitals because I like my own surroundings." (Patient 5)

"So I think well do I really want to be in a hospital bed. No, I don't, I'd much rather be in my home environment where I'm more relaxed, I'm able to relax more, it's not easy to relax in a hospital. I can control what's happening to me at home better, because I'm in my own environment and it's always a much better place, it feels a safer place." (Patient 8)

"I don't like going to hospital (laughs) so I'll hold off as long as I can, which is pretty stupid really. I just like my own space, you know, yeah, which once again, as I say, is a bit stupid, when you know all they're trying to do is look after you, you know, but I think we all like our own environment don't we?" (Patient 1209)

Previous experience of the ED, AAU and wards influences the decision to present to the ED and adds to the attendance tension. Typically those who have had some experience of the resuscitation area of the ED (where patients with high needs are treated) feel that it was a good experience and they felt safe there:

"They are so quick, everybody knows their job, everybody has a job, specific job, they know what that job is, they move in, they put the cannula in, they take your bloods, you know, that's within minutes of you arriving, so they can get to work. From those blood tests they know within minutes what to start giving you, which they do. But, as I say they get you in, they put the cannula in, they take your bloods, within five minutes of being there you're on the nebuliser, everything's in place, they've done a heart trace, they've got you plugged up to oxygen, or whatever it is they, at that minute, think you need...and within an hour to an hour and a half your whole body is settled and then you can move onto the next section." (Patient 258)

Carer: If you know what I mean, they fast tracked him into what's like the emergency thing, Resus. I think the quickest they've ever been actually, they were really, really good.

Patient: Yeah, even though you panicked a bit and you wanted it to be sooner, you know, deal with me straightaway, you know, that's not, not the case like, there's other people and all that. But yeah, I think I got good treatment, you know, yeah. (Patient 39 and Carer)

In contrast those who had experience of the main part of the ED were considerably less positive having waited for very long times in what was sometimes a rather chaotic and frightening place:

"They was very busy, you know, they was flying all over the place. And then we had a young lad, I think he must have been on drugs or something, shouting and bawling and, they had security running all over the place for him. So, you know, it was a bit chaotic." (Patient 19)

"Oh, oh it was very frustrating because, and things took longer than you thought they were going to. You think goodness me, am I ever gonna get through this, sort of thing, you know." (Patient 18)

"It takes a long time, even though if you're patient, it takes a bloody long time. And waiting, waiting, waiting, it's bloody terrible." (Patient 603)

Under these circumstances patients felt they needed some reassurance but often felt abandoned instead:

"You don't want to be just left there gasping for breath and thinking there's nobody bothering here, which you do, you know, so. As far as I can see, when you're in that state you wanna be told that, don't worry, you're gonna be all right, we've got this in hand, and a lot of the times they don't do that, they just put you in a bed and then leave yer while the doctor's ready, which I understand they've all got, he's got his duties to do as well, but I'm thinking what I need is reassuring. Just check on yer, exactly. Yeah, he'll be along in a moment is there anything you need." (Patient 39)

"Because I d'int like being on that corridor and I was frightened you 'ear so many people about drunks and you know drugs people and people arguing and it frightened me and I even said Don't leave me 'ere." (Patient 5)

Poor communication is often seen as an issue by patients:

"Or if you asked 'em a question they don't, I know it's busy, every time I'm in there it's always busy, they don't seem to have time for yer, oh I'll get you in a minute, yeah, I'll get you in a minute, and then it's like, well you've asked them half an hour ago and you've asked someone else, oh yeah, well... Yeah, they're too busy, some of 'em are too busy talking at their desk, so. They haven't got the time to listen to yer." (Patient 4)

"If I was an emergency patient brought in here why is nobody looking at me, why is nobody communicating and it's very, very frustrating. I think quite often the frustration sets in when you're laid in a room and you're opposite a nurse's station, or doctors, and you see 'em all stood about chatting and, you know, and I think why aren't you looking at the patient instead of all talking about what went on last night." (Patient 8)

The desire to have an explanation of what is going on and to be communicated with is high:

“Just to treat you as an individual and not just a number, or like to meeting a target. If you go over your target just by giving someone the respect and dignity they deserve, if it’s their fault or not, that goes a long way, cos then you won’t get the complaint saying, well I was in there four and a half hours. But if you was in there four and a half hours because they had to explain summat to yer you’d think well hang on, well they did explain it to me, I did take up a lot of their time.” (Patient 4)

When staff did talk with patients it was mostly thought of positively:

“There was one doctor there, I couldn’t speak highly enough about her, cos every time she came to speak to me she explained what she was doing and why she was doing it, and then she explained to me the reasons why I’m staying in there, but then you get the other ones that just come in and they’re just in and out, in and out.” (Patient 4)

“He seemed real nice, and he had that calming thing, a calming voice with him, and everything he said was, you know, putting you at ease sorta thing, you know.” (Patient 39)

“Out of fairness, the doctors that I’ve had recently, and they’ve mostly been foreign, I’ve found them to be excellent. They’ll answer your questions, they treat you like a human being. They announce theirself, they declare who they are, exactly what they do and, and I found ‘em to be very, very good.” (Patient 8)

Previous experience of other parts of the hospital including the Acute Assessment Unit (AAU), wards and the discharge process also produce attendance tension with respect to the decision to present to the ED. Generally the AAU and wards were considered safe places, if a little noisy and so it was worth getting through the poorer ED experience knowing they’d get to the safety of the ward:

“I felt a lot safer being there, you know, and thought well if anything’s gonna go wrong, you know, I’m in the right place, you know. But, as I say, they was ever so busy, even in there.” (Patient 19)

“All right, but once again, as I say, everybody are lovely, but the thing I find, another thing about hospitals though, why do they make so much damn noise at night?” (Patient 1209)

“I was always in Castle Hill and I know so many of ‘em I mean even when I went in this time everybody knew me and you feel easier you know because they do know ya, at ease and they was so good to me.” (Patient 5)

However safe the patient may feel in hospital there is a desire to get home once they no longer need to be there:

“When you get into hospital, and particularly if you’ve had serious sort of illnesses, there’s a, there’s a feeling of security in the hospital, because you’re not necessarily being looked at every five minutes but they’re there, aren’t they, and it’s, you become, I suppose, partially institutionalised. You, it’s, you, you feel safe, it’s like a safe haven. And, and then if you spend any length of time, and this is why I don’t like to be in too long, because it’s easy to slip into that mould where you’re becoming reliant on that environment of hospitals and nurses, there’s

somebody available, even if not instantly, they, they are there, it's very reassuring when you're not well. But when you feel that you are getting well it's, I, I think I want to be out fast." (Patient 8)

However the discharge experience can be extremely lengthy:

"The only thing what was a bit disappointing was when you was getting discharged it was ten o'clock in the morning when they said you'd be going home like, but it was after six o'clock by the time they brought your medication down that was the only thing, but I mean it don't matter. It just seemed a long, a long wait to be just sat there for a couple of medicines." (Patient 169)

6.5.3.6.3 The role of carers/others in ED presentation

Carers have a significant role in presentation to both primary healthcare professionals and also to the ED. They become vigilant and constantly monitor the patient's breathlessness and general state of health:

"So I do say, right, I'm going, and we keep in constant touch anyhow, you know, on the phone, so I know all throughout the day that she's, she's all right. I know when she's poorly, when she's bad, really bad, you know, if she was really bad I'd just turn round and say, no I'll, you know, I'll stay today, I aren't going out." (Carer of patient 258)

"It just makes him so tired that after he's had one of these spells he just lays back, mouth open and he goes off, well semi-sleep, he's not asleep but he's sort of out of it, you know. So I don't talk to him in those stages because he'd have to answer me and he hasn't got the strength to answer me. Yeah, so just leave him to relax and, you know, just keep an eye on him." (Carer of patient 8)

Additionally this vigilance can lead to their having a part in the decision to present to the ED since the patient may be reluctant to make that decision themselves:

"And when it gets really bad then I know when he gets really bad and his colour changes and then I call the paramedics, as I've been told to do, don't bother with the doctor, just call the paramedics. Oh I get anxious when he can't breathe, of course I do, yes. I'm the one that panics, I think, when he, I'm the one that's, let's get the paramedics in, let's, you know... Yeah, it's, the patient always says, oh leave it a bit I'm all right, I'll be all right in a bit, but they're not all right and you've got to make that decision whether it is time to call the paramedics or not." (Carer of patient 8)

The attendance tension experienced by the patient can make it hard for them to decide whether or not to present to the ED and so when others make the decision they may seem like they don't want to go, but in fact be relieved that someone has taken the decision for them:

"Well, as I say, that was scary a bit really cos you know, I couldn't get me breath at all like, you know, to using me inhalers and everything but nothing seemed to work, and I were starting to panic a bit, even I'm saying, no, I don't want no bloody ambulance and things like that, but in

here I, I was glad I was getting it because it could have got a lot worse. Yeah, yeah and I'm thinking yeah, you get it your way, I'm hoping they get their way, yeah, you know, really."
(Patient 39)

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

Interviewer: So how did you feel when your daughter insisted that she called the paramedics?

Patient: I was quite pleased really, didn't let on that I was but kept saying I don't want to go, you know, but it was a relief actually. (Patient 39 and carer)

Not only are carers involved in the decision to present to the ED but so are others such as primary healthcare professionals and paramedics:

I have had it really really bad but I still wunt ring doctor or the long-term and they do go mad at me, they said you know if you ring us we could get this nipped in the bud before it started really really bad. I've been going down and down and I know I have until I 'ad to go in 'ospital, but I mean even when they come I said I don't want to go and they made me go." (Patient 5)

"Well I was gasping for breath, and me youngest daughter, she was here at the time, and I was sat here and I was gasping and I wanted to go to the loo; so I managed to get meself upstairs but I was so gasping for breath that she said "Oh to hell with this, I'm phoning for an ambulance" which she did do. And the ambulance responder came and then the ambulance itself, and then they just told me I should go straight away to A & E." (Patient 338)

Additionally paramedics can be relied on to make a decision that it is not necessary to attend the ED:

"She hasn't been back in the ED; she's had the paramedics out, she had them out twice in one night because she got very breathless; and basically all they did was came along, put her nebuliser on, sat, calmed her down, and she was fine, and they did that both times, and they were able to say you don't need to go." (Respiratory physiotherapist of patient 508)

6.6 Discussion

This thematic analysis of 18 patient interviews, nine with their carer and eight primary healthcare professional interviews identified six themes: i) Widespread effects of breathlessness, ii) Making the best of it or making it worse, iii) Community healthcare professional approach to the patient and their breathlessness, iv) Knowledge, information and communication, v) System/service issues and vi) Decision to present to the ED. The findings from the thematic analysis of the interviews overlap extensively with those of the

qualitative synthesis described in Chapter Four with additional findings on these overlapping themes and also new findings with respect to ‘System and service issues’ and ‘The decision to present to the ED’.

6.6.1 Applicability of the Breathing Space concept to the interview findings

Extensive evidence for the theme of ‘Widespread effects of breathlessness’ was obtained in the findings of both the qualitative synthesis and the interviews. In both analyses the concept of “total dyspnea” (3) was found to have explanatory value.

The interview findings theme of ‘Making the best of it or making it worse’ had considerable overlap with the qualitative synthesis findings theme of ‘Coping’ and the concepts of engaged and disengaged coping (94) were found applicable to both.

The interview findings themes of ‘Community healthcare professional approach to the patient and their breathlessness’ and ‘Knowledge, information and communication’ overlapped considerably with the qualitative synthesis findings theme of ‘Healthcare professional responsiveness to breathlessness’. In all these themes the concept of epistemic injustice (98) was found to be applicable. The concept of ‘the invisibility of breathlessness’ (160) involving the slow onset of breathlessness and the lack of response from healthcare professionals was also applicable to all these themes.

There was some overlap between the qualitative synthesis theme of ‘Help-seeking’ and the interview findings theme of ‘Decision to present to the ED’ with the concept analysis of help-seeking by Cornally and McCarthy (97) being applicable to both.

Thus the Breathing Space concept has explanatory power, both in the existing qualitative literature and in these new interview findings, when describing the context of living with breathlessness within which the decision to present to the ED sits. In future the concept could usefully be explored on a case by case basis, examining a patient’s coping and help-seeking styles and the

responsiveness of their healthcare professional to breathlessness, in order to obtain a fuller picture of their overall experience of living with breathlessness which may then give context to their decision to present to the ED, as well as aiding in the understanding of how best to manage the patient's breathlessness subsequently.

6.6.2 Additional findings from the interviews

Additional findings from the 'Making the best of it or making it worse' theme were with respect to the carer's role in supporting breathless patients and also with respect to fresh air and mobility.

Additional findings from the 'Knowledge, information and communication' themes were with respect to knowledge of correct inhaler usage, information and communication issues.

Additional findings from the 'Decision to present to the ED' were reasons for presentation, attendance tension and the role of carers/others in the decision to present to the ED. The interview findings theme of 'System and service issues' was a new finding. All these additional findings will now be discussed in greater detail.

6.6.2.1 The carer's role in supporting breathless patients and in the decision to present to the ED

Carers were found to have a considerable supporting role in the everyday life of breathless patients, including providing social support, encouragement, support with managing breathlessness and liaising with healthcare professionals.

Carers also become vigilant and monitor the state of the breathless patient and are often involved in the decision to present to the ED. These findings are corroborated by those of Hynes et al. (177) who found that carers tried hard to remain calm and support the patient, however they often felt anxiety and that their lives were much changed by living with a breathless person in much the same way as is encapsulated in the Breathing Space concept. Hynes et al. also report that carers develop great expertise and understanding of the breathless

patient and yet this expertise is not always acknowledged by healthcare professionals.

6.6.2.2 The importance of fresh air and mobility

Taking in fresh air and getting out and about were seen as positive ways of coping with breathlessness, with mobility aids being highly valued. These findings mirror those of Williams et al. (178) who suggest that stagnation is a common problem in breathless patients and that to combat it movement of both the air around them and of the patient themselves is necessary.

6.6.2.3 Knowledge, information and communication

Alongside poor knowledge with respect to diagnosis and prognosis patients often have poor knowledge about the use of inhalers; a key form of medication for breathlessness. Poor knowledge of inhaler technique was found in between 4% and 94% of patients in a recent systematic review (179). Much information is needed by patients, however the communication between patient and healthcare professional can mean this information is not gained. In part this is to do with the structure of the consultation and time pressures felt which can result in epistemic injustice (98) as previously discussed in Chapter Four.

This may also be to do with the way the consultation is held; shared decision making is commonly used in consultations these days, however patients in this study seemed not to understand that it was being used by the healthcare professional, instead expecting a more paternalistic approach whereby the healthcare professional would tell the patient what to do. Charles et al. (180) point out that in shared decision making that both the patient and the healthcare professional must realise they are taking part in that process and both must take steps to be part of the process. It would seem from the interview findings that there may be a lack of clarity over how the consultation is being run and that this gives rise to patients feeling that they aren't being told what to do by an expert as they expect and so not understanding why they are being asked what their wishes are.

More clarity and greater support for patients is needed to combat this breakdown in communication and to provide relevant information to the patient and their carer. To this end Koh et al. (181) have proposed a “Health Literate Care Model” as an appropriate method to care for people with chronic conditions. In this model support is given for self-management, access to community resources and for shared decision making, with the basic working assumption of the model being that patients are at risk of not understanding their condition or how to deal with it.

6.6.2.4 System and service issues

Timely access to their GP or one of the doctors in their GP practice was considered important by many interview patients as this enabled continuity of care. Continuity of care is considered an important aspect of primary care by the Royal College of General Practitioners, as it is associated with better health outcomes, more satisfied patients and also cost control (182). Continuity of care allows the patient to feel understood and to have trust in their GP’s advice and it has been shown to be associated with a reduction in ED presentations (183).

Conversely lack of continuity of care involves the need to re-explain their condition every time they see a new GP and an inability to relate to the GP and may result in a perceived lack of support by primary care. Barriers to timely access were lack of appointments, the need to phone early in the morning to get an emergency appointment that day and difficulty getting past the receptionists. Also access to a patient’s own GP is only available in working hours, with emergency services being available at all times. Timely access to diagnostic tests and specialist opinion was felt to be a concern to the healthcare professionals interviewed; the lack of timely access resulting in the healthcare professional deciding to refer the patient to the ED.

6.6.2.5 Decision to present to the ED

In our sample the decision to present to the ED was usually triggered by a severe worsening of the patient’s breathlessness which resulted in a

breathlessness crisis and lead to help-seeking behaviour. This is in accordance with the findings of Gysels and Higginson (39) who found that typically help for breathlessness is sought at a time of crisis rather than seeing their everyday breathlessness as something to seek help for.

The ATS define 'dyspnea crisis' (170) (also called breathlessness crisis (184)) as "sustained and severe resting breathing discomfort that occurs in patients with advanced, often life-limiting illness and overwhelms the patient and caregivers' ability to achieve symptom relief." This was indeed the case for the participants who no longer felt able to control the situation and needed to be rescued. A recent qualitative synthesis of literature on the experience of exacerbations described how patients feel they are "consumed by breathing" when a breathlessness crisis occurs (43) and that this crisis involves intense emotions, heightened bodily awareness and the need to be saved.

How the interview patients and their carers reacted to the breathlessness crisis varied, with some seeking help in primary care initially before presenting to the ED and some immediately seeking help by calling 999 and travelling by ambulance to the ED. Those that sought help in primary care were either directed to present to the ED by their healthcare professional for tests, treatment and specialist opinion only available in a timely fashion in hospital or were unable to contact their healthcare professional due to lack of provision of primary care services outside working hours and therefore they then presented to the ED.

There were other patients who did not feel well supported by primary healthcare professionals and so in their crisis they sought help immediately at the ED. Theoretically all people in the UK have access to a GP and through the GP can be referred to specialists and to a range of services available to help them manage their breathlessness. However their GP may not be responsive to breathlessness and additionally in practice access to particular GPs or other primary healthcare professionals can be difficult resulting in lack of continuity of care, which in turn may lead to problems such as lack of trust and low motivation to contact a GP, instead going straight to the emergency department.

The decision to present to the ED was not taken lightly by the interview participants who displayed considerable attendance tension, not knowing

whether they were bad enough to warrant going to the ED, wanting to be able to stay in their home environment and manage their breathlessness themselves and also being torn between the need to be rescued/be in a safe place and their previous experience of the ED which had commonly involved much waiting, frustration and a lack of communication. Some patients who had been taken directly into resuscitation spoke highly of their experience there and did feel safe, so for some the ED is a safe place, whereas for others it is an unsupportive environment. Most patients who presented to the ED perceived the wards that they would be transferred to if admitted as safe and felt that they had no choice but to present to the ED in order to get into hospital.

These findings resonate with those of Green et al. (172) in which the reasons for presentation to the ED amongst patients with palliative care needs including COPD and cancer patients were examined. Green et al. found that the context of the decision involved severe limitations to their activities of daily living and dependence on carers, as well as reliance on others (both carers and healthcare professionals) to make the decision about when to present to the ED as they felt too unwell to make the decision. Some had a positive experience of the ED whilst others experienced it as chaotic and involving long anxiety provoking waits.

6.6.2.6 What clinical pathways are followed by patients who present to the ED due to acute-on-chronic breathlessness?

The clinical pathways followed by patients are varied with some seeking help in primary care for both their breathlessness and for breathing crises and being managed successfully to a great extent, but due to service issues such as timely access to tests and specialist opinion or lack of out of hours provision of primary healthcare this then results in their eventual presentation to the ED. Alternatively there are patients who feel unsupported in primary care and whose breathlessness is not being effectively managed, who in times of crisis choose the ED as the source of potential help.

6.6.2.7 How do coping with and experience of help-seeking in the community influence their decisions to present to the ED?

The decision to present to the ED is made within a context of the daily experience that the patient and their carer has of living with breathlessness. This can be summarised by the Breathing Space concept in which coping style, help-seeking pattern and responsiveness of the healthcare professional to breathlessness all interact to determine the quality of life the patient and their carer has and how they will react when there is a breathing crisis.

6.6.2.8 What is the experience of patients and their carers when presenting with acute-on-chronic breathlessness to the ED?

The experience of breathless patients presenting to the ED is varied with some experiencing it as a safe place where their needs are dealt with immediately and they are rescued from their crisis and others experiencing it as an unsafe, chaotic environment in which they have to wait for long periods. Similarly the quality of communication with healthcare professionals is either thought to be excellent or extremely poor depending on whether they are seen to in resus or left to wait in the main area of Majors. Presenting to the ED is seen by patients as part of the process of getting the help they need, whether it be rescue when in crisis or treatment in hospital.

6.7 Implications for clinical practice

Greater understanding by all healthcare professionals of the widespread effects of breathlessness is needed in order to tailor the management of breathlessness to the patient's needs and those of their carer. The coping style and help-seeking pattern of the patient should be assessed and advice given on how to cope in a more engaged style and on how and when to seek help appropriately.

Patients' knowledge and information needs should be met so as help them understand the implications of their condition and manage their symptoms. Communication between healthcare professional and patient needs to be

clearer, with awareness that the patient may have some difficulty understanding the treatments and services being offered.

Greater continuity of care with improved access to GPs and other primary healthcare professionals outside of usual working hours may help patients cope better with their everyday breathlessness and in crisis. Quicker access to diagnostic tests and specialist advice would be helpful to primary healthcare professionals so that they could avoid directing their patient to the ED for such tests and advice.

6.8 Strengths and limitations of this study

The interviews were in-depth and allowed detailed answers from the participants. The sampling strategy was a particular strength, drawn from a pool of 150 survey patients who agreed to be contacted for an interview, enabled a wide variety of patients and healthcare professional to be purposively included. Although the sample size is not large to generalise from there are transferable findings which allow greater understanding of the context of ED presentation and many findings are similar to the systematic review, which synthesises qualitative data from around the world, from many different settings.

This sample included no non-English speakers due to lack of translation resources and so the views and experience of some patients may not be represented.

6.9 Summary

This sixth chapter described the methods of and the results from the patient, carer and healthcare professional interviews, describing patient pathways to the ED, how coping, help-seeking and interaction with healthcare professionals influences presentation to the ED and experience of being in the ED. The seventh chapter will integrate and discuss the findings from the previous three chapters.

Chapter Seven: Synthesis and discussion

7.1 Introduction

The aim of this thesis is to explore the experience of people with chronic breathlessness and to examine the factors which influence their decision to present with breathlessness to the emergency department (ED), with a view to identifying those which could be targets for interventions to reduce presentations which do not benefit the patient. This overarching question was addressed by means of a series of more specific questions:

- 1 What is the prevalence of presentations to the ED at Hull Royal Infirmary (HRI) that are due to acute-on-chronic breathlessness?
- 2 What clinical pathways are followed by patients who present to the ED due to acute-on-chronic breathlessness?
- 3 What predicts hospital admission (ED departure status) in people presenting to the ED with acute-on-chronic breathlessness?
- 4 What is the experience of people living with daily breathlessness due to chronic medical conditions and those caring for or treating them with regard to their coping with and help-seeking for their breathlessness, particularly with regard to their interaction with healthcare services?
- 5 How do coping with and experience of help-seeking in the community influence their decisions to present to the ED?
- 6 What is the experience of patients and their carers when presenting with acute-on-chronic breathlessness to the ED?

Between the different methods employed for this thesis, each specific question has been addressed and the key findings summarised in Table 10. In this chapter the findings from the methodological approaches will be synthesised and the extent to which the overarching question posed by this thesis has been answered will be discussed.

Table 10 Research questions and key findings from each research methodology

Research questions	Systematic literature review (Chapter Four)	Survey and Case note review (Chapter Five)	Patient, carer and healthcare professional interviews (Chapter Six)	Integrated analysis (Chapter Seven)
<p>1</p> <p>What is the prevalence of presentations to the ED at Hull Royal Infirmary (HRI) that are due to acute-on-chronic breathlessness?</p>	<ul style="list-style-type: none"> • Presentation to the ED may happen as a result of crisis 	<ul style="list-style-type: none"> • Presentations due to breathlessness to whole ED=5.2% To Majors=20.2% • Most of the presentations were by people with non-malignant conditions: <ul style="list-style-type: none"> ○ 26% COPD; 42% heart condition; 9% cancer ○ Non-malignant conditions over-represented in the ED compared to the prevalence of these conditions in the community 	<ul style="list-style-type: none"> • Presentation to the ED in crisis was described by all patients 	<ul style="list-style-type: none"> • Acute-on-chronic breathlessness is a common reason for presentation to the ED • Most presentations by people with non-malignant conditions who are over-represented in this setting compared with the community
<p>2</p> <p>What clinical pathways are followed by patients who present to the ED due to acute-on-chronic breathlessness?</p>	<ul style="list-style-type: none"> • Breathlessness not seen as a solvable problem by some patients - reluctance to present to the doctor with it unless really bad • Presentation to the ED may happen as a result of crisis • Breathing Space describes the 	<ul style="list-style-type: none"> • 77% of breathlessness presentations by people with mMRC 3-4 (significant impact on function) • Most talk to their GP (73%) about their breathlessness; other healthcare professionals 	<ul style="list-style-type: none"> • Some patients think nothing can be done for their breathlessness in general so only seek help in crisis • In crisis some seek help in primary care and are either directed to the ED by their healthcare professional for 	<ul style="list-style-type: none"> • Many patients have significant burden due to their severe breathlessness over an extensive period of time, but it remains largely invisible • Most see their GP about their chronic breathlessness but receive variable response to

	<p>context of living with chronic breathlessness</p> <ul style="list-style-type: none"> • Ability of patients to talk to their primary healthcare professional about their breathlessness varies • If discussed, the primary care consultation may cause limitations • Some feel their problems have been addressed, others get the impression that there is nothing more that can be done 	<p>rarely mentioned</p> <ul style="list-style-type: none"> • 26% talk to their family or friends; 14% talk to no one about their breathlessness • 46% presentations made by people with >2 years' chronic breathlessness • 68% of presentations occurred out of GP working hours • Half were re-attenders with at least 1 previous presentation in the past 12 months • 32% primary presenting complaint of breathing difficulties noted by ED triage nurses; 63% breathing difficulties documented by ED doctor • Cause of presentation: exacerbation of COPD/chest infection in 27%; heart condition in 34% • Oxygen saturations measured 100%; chest X-rays 75%; ECGs 73%, blood tests 77%; ABG done 32%. 	<p>tests/treatment, or find/know that their healthcare professional is not available and then present to the ED</p> <ul style="list-style-type: none"> • Others feel unsupported in the community and who present directly to the ED • Some have learned from previous encounters with healthcare professionals to go straight to the ED instead of seeking help in primary care first • Community LTCN nurses perceived as not meeting needs; poorly responsive and not holistic • Some healthcare professionals unresponsive to breathlessness, and did not refer to services directed at improving symptoms and function • Some healthcare professionals were responsive to breathlessness and offered appropriate management, but were unavailable at the time of the decision to present or directed the patient to the ED • ED is part of a solution to a breathlessness crisis. It is a means to an end of reaching safety, whether that be from a paramedic, in the ED (particularly in the resuscitation area) or in a ward 	<p>and help for their breathlessness.</p> <ul style="list-style-type: none"> • In crisis, some seek help from primary care, whilst others present directly to the ED (some having learnt to do this from previous experience), especially if their GP is not available. • Half had previous ED presentations in the past 12 months, but they were reluctant to go, leaving until there was an urgent need for safety and rescue.
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<p>3</p> <p>What predicts hospital admission (ED departure status) in people presenting to the ED with acute-on-chronic breathlessness?</p>	<ul style="list-style-type: none"> • Patients have difficulties knowing when and from whom to seek help for their breathlessness 	<ul style="list-style-type: none"> • Acute-on-chronic breathlessness contributes to 7.6% of all admissions from the ED • 69% of breathlessness presentations admitted to hospital; 31% discharged home) Whereas 34% of presentations for any reason resulted in admission to a ward • Predictors of admission: <ul style="list-style-type: none"> • Older age • Decreased oxygen saturation • Having talked to a specialist doctor about their breathlessness • cardiac condition 	<ul style="list-style-type: none"> • Some patients aware of their reluctance to present to their GP when their breathlessness had worsened and therefore that they had precipitated their ED presentation by leaving it too late • Patients need advice on when and from whom to seek help • Some patients sought the safety of a ward and had to present to the ED to get it, but once the need for safety and rescue had been fulfilled they were anxious to return to the comfort of their own home surroundings 	<ul style="list-style-type: none"> • People presenting with breathlessness are likely to be admitted, and breathlessness contributes to a third of all admissions to hospital from the ED. • Patients find difficulty in knowing when and from whom to seek help. Therefore, in conjunction with a reluctance to present to the ED, they present in crisis. • Admission is associated with decreased oxygen saturation, older age, having talked to a specialist doctor about their breathlessness and having a known history of a cardiac condition
<p>4</p> <p>What is the experience of people living with daily breathlessness due to chronic medical conditions and those caring for or treating them with regard to their coping with and help-seeking for their breathlessness, particularly with regard to their interaction with healthcare services?</p>	<ul style="list-style-type: none"> • Breathing Space describes the context of living with chronic breathlessness: <ul style="list-style-type: none"> • Widespread effects of breathlessness • Coping • Help-seeking • Healthcare professional responsiveness to breathlessness 	<ul style="list-style-type: none"> • Most talk to their GP (73%) about their breathlessness; other healthcare professionals rarely mentioned • 26% talk to their family or friends; 14% talk to no one about their breathlessness • 46% presentations made by people with >2 years' chronic breathlessness • Those involved in the decision to present to the ED <ul style="list-style-type: none"> • 37% themselves • 40% family or friends • 19% GP • 18% paramedic 	<ul style="list-style-type: none"> • Findings confirmatory of the Breathing Space concept and additional findings on: <ul style="list-style-type: none"> • Carer's role • Examples of good practice of healthcare professionals • Examples of patients achieving Breathing Space 	<ul style="list-style-type: none"> • The Breathing Space concept describes the experience of living with breathlessness. It forms the context for presentation to the ED in crisis when the invisibility contributed to by epistemic injustice becomes visible to clinicians and others. • Carers have an important supportive role in everyday life and play an important role in the decision to attend the ED.

<p>5</p> <p>How do coping with and experience of help-seeking in the community influence their decisions to present to the ED?</p>	<ul style="list-style-type: none"> • The Breathing Space concept describes the context within which the decision to present to the ED is made when there is a crisis • Presentation to the ED may happen as a result of crisis • Carers are sometimes involved in the decision to present 	<ul style="list-style-type: none"> • The median level of breathlessness severity at time of decision was “severe”, contrasting with “mild” whilst at rest in the ED • Those involved in the decision to present to the ED <ul style="list-style-type: none"> • 37% themselves • 40% family or friends • 19% GP • 18% paramedic • 68% of presentations occurred out of GP working hours 	<ul style="list-style-type: none"> • The Breathing Space concept describes the context within which the decision to present to the ED is made when there is a crisis • Others are often involved in the decision to present • In crisis some seek help in primary care and are either directed to the ED by their healthcare professional for tests/treatment or find/know that their healthcare professional is not available and then present to the ED • Alternatively there are those who feel unsupported in the community and who present directly to the ED • The decision to present is not taken lightly and there is much attendance tension 	<ul style="list-style-type: none"> • The Breathing Space concept describes the context within which the decision to present to the ED is made when there is a crisis • Patients find difficulty in knowing when and from whom to seek help. Others are often involved in the decision to attend the ED. Therefore, in conjunction with a reluctance to present to the ED, they present in crisis when a place of safety is urgently needed. Once safe, the severity abates and settles in the ED to “mild”. • Help from primary care is variable. Some receive good support, but others learn to present directly to the ED for a variety of reasons, including lack of GP availability out of hours.
<p>6</p> <p>What is the experience of patients and their carers when presenting with acute-on-chronic breathlessness to the ED?</p>	<ul style="list-style-type: none"> • No findings of relevance to this research question 	<ul style="list-style-type: none"> • No findings of relevance to this research question 	<ul style="list-style-type: none"> • The experience is varied with some (generally those taken direct to the resuscitation area) experiencing it as safe, whilst others find it chaotic and unsupportive. • Previous ambulance, ED and ward experience affect the decision to present to the ED again 	<ul style="list-style-type: none"> • Patients with breathlessness severe enough to warrant immediate management quickly obtained their desired of safety. However, others felt abandoned in a chaotic and frightening environment. Previous experience of paramedics, ED and ward staff was important in the decision to present.

7.2 The context to breathlessness crisis

The daily experience of those living with chronic breathlessness and of their carers forms the context within which the decision to present to the ED is made. This context can be described by the Breathing Space concept (see Chapter Four). Chronic breathlessness causes widespread effects on the lives of those living with it and their carers which can be described with reference to the concept of “total dyspnea” (3) which involves the physical, psychological, social and existential effects of breathlessness. The manner in which patients cope with these widespread effects by employing either an engaged or a disengaged coping style, their help-seeking pattern and the responsiveness/lack of responsiveness to breathlessness of the healthcare professionals they seek help from all interact to describe the quality of life they and their carers have; their Breathing Space. These aspects can be seen incorporated into the “breathing, thinking, functioning” therapeutic model used in the Cambridge Breathlessness Intervention Service (185). In this model, interventions are targeted at the cycle of events resulting from the symptom of breathlessness and its accompanying fear, social restriction and helplessness with the aim of maximising the life possibilities (and Breathing Space) for people with chronic breathlessness.

The Breathing Space achieved by some patients and their carer in the interview study was limited, whilst others achieved considerable Breathing Space. It appears many patients lessen their breathlessness by adopting disengaged coping strategies such as avoidance and social withdrawal, becoming dependent on others and this results in limited Breathing Space. However in a study involving a holistic needs assessment after discharge from hospital (186) it was found that some patients seem content with that situation as they gradually decrease their expectations for what life holds for them and therefore do not feel that they have many needs that could be fulfilled. Thus, when these patients were offered referral to other services or help of other forms there was little uptake. With reference to the Breathing Space concept possibly this is because their breathlessness had gone on for a very long time, giving ample opportunity to adapt so as to reduce its effects, and possibly their breathlessness had not been responded to sensitively by their healthcare professional, so the patient may have ceased seeking help for their symptom

and consequently readjusted their expectations. If breathless patients were offered help at an earlier stage maybe they would learn more engaged coping patterns and take more of the help offered and thereby increase their Breathing Space. This situation illustrates well the previously described taxonomy of need (187), where normative need (that identified by e.g. clinicians) is not seen by the patient as a “felt need” as they have adapted to their restricted life. Thus it is only when crisis supervenes, that patients perceive an “expressed need” and seek help.

In several of the interviews the carer was sensitive to the patient’s breathlessness, monitoring their overall condition carefully and taking on a supportive and vigilant role, playing a key role in the decision to attend the ED. This support could become all consuming. Their role was recognised and addressed by some healthcare professionals, but not by others. This burden on carers has been described recently (188) highlighting that carers should be supported in their role, with their needs being formally assessed and managed. The South Australian Health Omnibus (189), a population household survey, showed that carers of patients with respiratory illness had many unmet needs, including support and informational needs. Similarly Farquhar et al. (190) found that more than half of the carers of COPD patients in their study had informational needs, including who to seek help from as well as emotional needs and that they felt unprepared for their role as a carer. The findings by Hynes et al. (177) were similar to the interview findings in this thesis, with both reporting the extensive burden of caring and also the supportive role carers take on. Hynes et al. recommend that the carer’s expertise be recognised and tapped into by healthcare professionals. Similarly in a validation study of a needs assessment tool for patients with interstitial lung disease (ILD) and their carer (191), carers felt considerable burden and yet felt that two aspects were ignored by healthcare professionals: i) their expert knowledge of the patient’s condition was not recognised, and ii) their own needs were rarely considered.

Chronic breathlessness often remains invisible to others (160), as a result of both testimonial and hermeneutical injustice (98) (99) which would lead to restricted Breathing Space as patients and their carers may not know there is anything to be done to address their breathlessness and so they do not seek

help or employ engaged coping strategies. Additionally their primary healthcare professionals may be unaware of or unresponsive to the effects of breathlessness on their lives, offering little in the way of management for the symptom itself and so the patient's further help-seeking may be left till they have reached the point at which they can no longer manage and they suffer a breathlessness crisis (184) which leads to presentation to the ED for rescue. Patients in our interview study sought the safety of a ward and had to present to the ED to get it, but once the need for safety and rescue had been fulfilled they were anxious to return to the comfort of their own home surroundings. Seeking safety by presenting to the ED may be an attempt by the patient to achieve Breathing Space by bringing their now clearly troublesome and therefore legitimate symptom of breathlessness to the attention of healthcare professionals and get some respite from it. However this help-seeking in crisis provides only temporary respite and in order to achieve Breathing Space more has to be done by the patient, carer and healthcare professional to attend to and manage the breathlessness on a day to day basis.

Whilst there were patients who fitted the above description, it was also clear from the interview findings that there were also patients who achieved Breathing Space by employing engaged coping strategies and seeking help for their breathlessness appropriately from primary healthcare professionals who were responsive to the symptom. There was evidence of good practice with respect to chronic breathlessness amongst these healthcare professionals, who were both aware of the widespread effects of breathlessness and of ways of managing the symptom, over and above treating the underlying condition causing it. However, even when this was the case these patients reached a crisis point, which due to various factors described in the next section, resulted in the decision to present to the ED.

7.3 Clinical pathways

Taken together the answers to research questions 1, 2, 3, 5 and 6 shed light on the clinical pathways patients take that result in their presentation to the ED and consequent discharge home or admission to hospital. From the survey findings it is clear that presentation to the ED due to acute-on-chronic breathlessness is

common; estimated to be at least 1 in 20 presentations to the entire ED and a fifth of presentations to Majors. This is higher than previous estimates (23) and it represents both a high burden on the resource intensive Majors area and on ambulance services and a considerable burden on the patients and their carers who present to the ED.

7.3.1 Presentation in crisis

Presentation to the ED in crisis was described in the findings of both the qualitative synthesis and the interviews. Although it is apparent from the survey findings that presentation to the ED is common, it is clear from the interview data that patients feel considerable tension over the decision to present to the ED, not knowing how bad it has to be to warrant presentation or wishing to avoid the experience of the ED by staying in their own homes, but yet also wishing for safety and rescue. At decision to present the median level of severity of breathlessness was severe, whereas when waiting in the ED it was mild; these survey findings corroborating that the decision to present is at a time of crisis and that presentation results in a decrease in the severity of their breathlessness possibly as a result of feeling safer.

Most presentations were made by patients with non-malignant conditions and these presentations are higher than would be expected from local community prevalence data (see Chapter Five). In line with this finding only a small number of the participants who gave consent to be contacted for interview had cancer and it was only possible to interview three such patients.

A possible explanation for this is that, despite multi-disciplinary, cross-setting care being a key part of current policy and guidelines in the UK for chronic conditions, implementation is variable. Compared with cancer care which has had a well-resourced multi-disciplinary team approach since the NHS Cancer Plan of 2000 (192), care for non-cancer chronic conditions remains fragmented, under-resourced and overstretched in many areas of the UK. The higher than average prevalence of respiratory disease in Hull, coupled with strained primary care services is likely to have contributed as, although services improvements are underway, this remains a concern. Additionally there is often little discussion

of prognosis, anticipatory care planning or management of breathlessness with non-cancer conditions (193) and as such patients may feel that they should only seek help when in crisis, rather than seeking palliative care and greater guidance on management of their breathlessness, as well as how and when to seek help for people with non-malignant conditions may benefit them. Patient education is a keystone of rehabilitation programmes, but these are poorly implemented. (194) (195) (196) This lack of attention to the burden of the symptoms that patients with non-malignant conditions experience, combined with the absence of a holistic approach to managing breathlessness, leads to restricted Breathing Space for these patients and thereby accounts for the large proportion of presentations to the ED being made by patients with non-malignant conditions.

Also patients with COPD may find a lack of response from health professionals, including lack of treatment offered after diagnosis, little discussion of prognosis and stigma attached to their illness (55, 160). A similar lack of recognition of the palliative care needs of patients with heart failure (also a non-malignant condition) as compared with cancer patients was seen from an analysis of primary care data which showed that only 7% of people dying from heart failure had been identified as having palliative care needs compared with 48% of those dying from cancer (197).

Despite COPD patients having equally burdensome symptoms and being in equal need of palliative care as lung cancer patients (198) they are less likely to i) have support from district nurses and palliative care nurses; ii) be told that their condition is life-limiting; iii) die at home; iv) have physical or psychosocial needs addressed than people with lung cancer (11). Patients with COPD were often admitted to hospital only 24 hours before death and were unaccompanied by their relatives when they did die (11).

In Hull 69% of patients with respiratory illnesses and 63% of patients with cardiovascular disease died in hospital rather than at home, in a care home or a hospice, whereas only 55% of cancer patients died in hospital (20). This is an indication that there may be differences in the care patients with malignant and those with non-malignant conditions are being offered and that this may be affecting the Breathing Space they can achieve and consequently leading to

their presentation at emergency departments, rather than being cared for in the community.

Patients with breathlessness due to non-cancer causes may have no crisis plan available, at least in part because they may not have been offered palliative care in the same way as cancer patients would have been. Similarities with the experience of COPD patients have been described in people with heart failure: lack of understanding of information on their diagnosis and problems getting to consultations and finding that once in a consultation forgetting what they needed to ask (199). They sometimes had little discussion of their prognosis and some didn't really know what they could do to improve their life whilst living with their condition.

From survey data (see Chapter Five) it was clear that most patients had significant functional limitations due to breathlessness experienced over a considerable length of time. Many of these patients discuss their breathlessness with their GP, but some healthcare professionals are responsive to breathlessness whilst others are not; giving the impression that nothing more can be done. Additionally patients are limited by the set-up of consultations and may not be able to explain the full burden from breathlessness that they are experiencing and therefore not receive help for their symptom, limiting the possibility that they can achieve Breathing Space.

From survey data it is clear that not many patients discuss their breathlessness with healthcare professionals other than their GP, with a sizeable proportion (14%) reporting that they talk to no one about it. These findings are in line with previous work on the invisibility of breathlessness (160). Some interview participants describe a lack of responsiveness to breathlessness from long term conditions nurses and that their needs went unmet. Therefore it seems that apart from seeing GPs only a small proportion seem to be having their needs met by other healthcare professionals in the community. From the qualitative synthesis it is clear that patients have difficulty in knowing when and from whom they should seek help.

7.3.2 The decision to present to the ED

When describing their decision to present to the ED patients in the interview sample fell into three categories: i) those who presented to their primary healthcare professional with worsened breathlessness and who were then directed to present to the ED for tests and treatment there; ii) those who would wish to present to their primary healthcare professional but due to service provision found that they were unavailable at the time of crisis and so presented to the ED and finally iii) those who felt unsupported in the community and having no trusted primary healthcare professional to turn to in crisis presented to the ED.

From survey and case note data it was found that 68% of presentations due to breathlessness occurred outside GP working hours and therefore these may include patients from category ii) above. Given that a majority of the presentations happen at night or on weekends better advance planning for how to cope in a crisis may help avoid some of these presentations, as might extended working hours (200). The need for crisis planning for breathlessness has been highlighted by the ATS working party (170).

From interview data it was clear that there were examples of good practice in which healthcare professionals were responsive to breathlessness and offered appropriate management for it, however they sometimes felt the need to direct their patient to the ED for tests, treatment and access to specialists (category i) above) or were unavailable (category ii) above). Equally there were healthcare professionals who were unaware of the extent of the effects of breathlessness on their patient's lives and were not offering appropriate management and also patients who were unable to nominate a supportive healthcare professional for interview who felt unsupported in the community and in these cases these patients had restricted Breathing Space and a crisis resulted in their presenting to the ED directly (category iii) above.)

Survey and case note review data shows that half of presentations were made by re-attenders, these people having had the chance to experience the ED previously (and also possibly have experience of a ward if they were admitted). Previous experience of the ED had an effect on their decision to re-present to

the ED. Some felt the ED to be a safe place, whilst others found it to be an unsupportive environment. For those with previous experience of the ED it seems that presentation to the ED was seen as part of the solution to a breathlessness crisis and as a means to an end of reaching safety, whether it be from a paramedic team, in the ED (particularly if they had experienced the resuscitation area) or in a ward.

Survey data shows that although the decision to present to the ED was sometimes made by the patient, it was often made by others including carers, paramedics and GPs. This was also apparent from interview data. The role of carers in a crisis is also very important and carers should be supported more in their difficult role (188). To this end the ATS have produced a guidance leaflet for carers on how to best handle a breathlessness crisis (184). The ATS guidance on what to do in such crises suggests that a stepwise approach to managing the crisis should be taken, with carers being encouraged to support the patient through these steps before seeking help from healthcare providers. Once help is sought it should be provided by a multi-disciplinary team taking an individualised palliative care approach (170).

When in crisis many patients rely on paramedics to make a decision on whether or not to present to the ED and there may be alternative ways of working which could involve communication between the paramedics and a patient's GP before making the decision to present that might result in a reduction of presentations and also better management of breathlessness in the community thereafter. Furthermore the important role of paramedics in modelling how to calm a patient may help carers manage in future crises, thereby avoiding a re-attendance. The importance of showing carers how to manage breathlessness was identified early in the work of Booth et al. who encouraged carers to be present during exercise tests, and inclusion of carers has formed an integral part of the Cambridge Breathlessness Intervention Service (201) (139).

Additionally if healthcare professionals such as the Macmillan nurses and respiratory physiotherapists interviewed could be better resourced and work in shift patterns that enabled access out of hours then ED presentations may be avoided, since they could help calm the patient and suggest appropriate management of the crisis. In many areas of the UK there is now provision of

palliative care nurse specialists 7 days per week, but this rarely extends to overnight.

7.3.3 In the ED and post ED destination

When assessed in the ED only 32% were noted to have a primary presenting complaint of breathing difficulties by triage nurses and in 63% of presentations due to breathlessness did the doctor document breathing difficulties; suggesting that although breathlessness was a reason for presentation by patient self-report that it remained unobserved by many ED clinicians, or its significance unrecognised.

Observations of oxygen saturation were made for all patients, chest X-rays were performed in 75% of the presentations, ECGs performed in 73%, blood tests done in 77% and an ABG done in 32%. From the interview data, the need for urgent investigations such as a chest X-ray was cited by a GP as a reason to attend the ED. However, in the multiple regression, having a chest X-ray did not contribute to the final predictor model for hospital admission. All predictors remaining in the final model (with decreased oxygen saturation, increased age, having talked to a specialist doctor about their breathlessness and having a known history of a cardiac condition) which could therefore help a clinician assess the need for hospital attendance can all be made in the community. Additionally, these predictors could be used in the ED for early assessment of whether to admit or not, thus allowing the process of securing a hospital bed to be started promptly thereby reducing the waiting time in a relatively unsupportive environment for those who will be admitted.

7.4 Targets for interventions to reduce presentation to the ED

7.4.1 Achieving epistemic justice and making the invisible visible

Fricker (98) maintains that epistemic injustice is “a potent, yet largely silent dimension of discrimination” and by understanding the way it arises we may be able to reduce the wrongs it causes. In this thesis it is argued that breathless

patients are vulnerable to epistemic injustice, although there are also examples of epistemic *justice* which occur when healthcare professionals do attend to their patients' testimonies with respect to breathlessness and understand the full extent of the burden that it imposes on the patient and those that care for them. Epistemic justice or injustice is important in that it determines whether or not optimal management of breathlessness will occur and suffering be alleviated or not. It is vital to understand the conditions under which epistemic injustice may occur, thereby avoiding harm to the patient and enabling the healthcare professional to fulfil their vocational aim of alleviating suffering.

There is a gap in understanding about breathlessness (found in both patients and healthcare professionals) resulting in hermeneutical injustice. To combat this injustice a greater recognition of breathlessness as a symptom with widespread effects, combined with greater knowledge of the many ways of managing breathlessness is needed (202) (203) (204) (204) (205). A greater understanding of breathlessness by the general public and by healthcare professionals could lead to patients being able to be more open about their symptom and thereby receive help for it and achieve Breathing Space.

With greater public and professional understanding of the symptom and its effects there would be a reduction in both testimonial and hermeneutical injustice and a symptom which is presently largely invisible could be made visible. To this end Johnson et al. (4) argue that breathlessness should be seen as a therapeutic target in its own right and urge routine assessment of breathlessness combined with greater understanding of ways of managing breathlessness. There are several ways in which breathlessness could be assessed including quick assessments of severity of breathlessness used by Baker et al. (36) to the use of holistic tools such as the Dyspnoea-12 developed by Yorke et al. (206). Additionally the Breathing Space concept could be used by healthcare professionals new to the patient to assess the current coping and help-seeking strategies that the patient is employing and also to assess the current level of responsiveness to breathlessness demonstrated by any healthcare professionals already involved in their care. This could give an overview of their current level of Breathing Space and give indicators of how to aid the patient in achieving greater Breathing Space.

A greater understanding and the use of these methods of assessment could then lead to earlier help-seeking amongst patients and increased responsiveness to breathlessness amongst healthcare professionals allowing patients to achieve greater Breathing Space. They could then experience what Carel (48) (p.16) calls “health within illness”, whereby their experience of coping with chronic illness can result in adaptation, creativity, reprioritising what is important to them and living a meaningful life. A more holistic approach to the management of breathlessness based on a thorough understanding of the widespread effects of breathlessness (3) may lead to a more comprehensive patient-centred approach, in which breathlessness itself is seen as the target for intervention rather than leaving it develop into a crisis which results in ED presentation. This approach is already being used in the implementation of a psychosocial care model taking into account the psychosocial needs of the patients and carers in their treatment (207) and is the cornerstone of the palliative care approach (208) and reflected in complex interventions such as the “breathing, thinking, functioning” model (209) (210) (211).

7.4.2 Breathlessness management plans

Acute-on- chronic breathlessness represents a significant burden for patients, their family carers and the emergency health services. The ED may not be the best place to coordinate the care of an important proportion for whom this could be optimised by co-ordinating breathlessness management plans from primary care after presentation to the ED. From the regression model it can be seen that younger patients, those with higher oxygen saturation and a non-cardiac underlying condition are more likely to be discharged, it may be that for these patients, post-discharge follow up resulting in a tailored breathlessness management plan (170) may increase quality of life and Breathing Space for the patient and their carer and also reduce ED re-attendance (173).

A trial on the use of a single interdisciplinary case conference in patients with advanced life-limiting illness found that it resulted in a better maintained performance status and also in a reduction of the rate of hospital admissions (212). Most of the patients in the trial by Abernethy et al. (212) were cancer patients and it is clear they benefitted from a case conference to address their

palliative care needs. Case conferences also appear to reduce hospital admission in other chronic conditions (213).

Additionally recognising the high level of anxiety and depression found in breathless patients would aid both their quality of life and the severity of their breathlessness and also decrease the costs involved in treatment. Interventions such as cognitive behavioural therapy have been found to be helpful (214) (215). Treating anxiety in patients with long-term conditions would be beneficial to the patient and also be cost-effective for the healthcare providers. Allison et al. (216) observe that readmission to hospital and mortality in patients with coronary artery disease were considerably higher in anxious or depressed patients and that the costs involved in their care were four times higher than people without psychological distress. If part of that money was instead spent on appropriate treatment of the anxiety or depression then not only would huge savings be made, but also far more effective treatment would be given to the patient. In the same way it would be reasonable to expect that by recognising depression and anxiety may be a factor in how patients react to their breathlessness more targeted and effective treatment could be given, thus both reducing medical costs and benefitting the patient. A similar approach may benefit carers, addressing their unmet needs and thereby enabling them to better support the patient and to both achieve greater Breathing Space.

7.4.3 Referral to palliative care services

Another way of tackling the issue and preventing emergency presentations is to refer people with complex and persistent problems to community-based palliative care services. An Australian retrospective cross-sectional study which found that early referral into community-based palliative care was associated with reduced presentation to the ED amongst cancer patients in the last 90 days of life (217). This reduction in use of the ED leads to less stress for the elderly patients and also decreases burden on the ED; freeing up facilities to provide care for those where ED treatments are able to reverse acute pathology. It could be argued that an approach involving early referral to community-based palliative care services can more appropriately come from primary healthcare professionals rather than waiting for a patient to present to the ED and then be

referred to palliative care services (217). However, most palliative care concerns should be within the skills of the usual care services, and referral of all patients with chronic breathlessness to specialist palliative care services would be both unnecessary and unsustainable (218).

The development of self-management strategies and advance care planning are important to prevent emergency presentations to hospital and inappropriate attempts at treatment near the end of life (219). The NHS has been very successful in treating a wide range of illnesses with the result that the life expectancy for many people has increased. The very success of the present system has led to an ageing population which now needs a different pattern of care.

An intervention to reduce emergency presentation by breathless patients involving better management of their condition in the community is warranted. The current Department of Health approach to the care of long-term conditions is to promote self-management by for example the Year of Care programme (220). This approach is also adopted by the Co-Creating Health programme (221) and is advocated by the Cochrane review on the effectiveness of self-management for COPD patients (222).

Given that breathlessness will become a more common symptom as the UK population ages, the pressure on the ED will increase if effective interventions to reduce presentation are not put in place. Also the patient may have to wait in a busy environment some time whilst being assessed which may exacerbate anxiety. Although expert medical care is available at the ED, it is an acute setting and the chronically breathless patient who does not have reversible pathology may benefit more from easy access to primary and, if necessary, planned secondary care, in addition to a self-management approach with which they can engage easily. Referral to palliative care for patients with persistent breathlessness due to malignant or non-malignant underlying conditions could be through primary care and also through the ED to help as many patients as possible be directed to appropriate care for their needs. In current practice the treatment of the underlying condition is seen as the most pressing need, rather than focusing on treating breathlessness itself (4). Although this is a vitally important basis for symptom management, once optimum treatment of the

underlying condition has been put in place, remaining symptoms must also be addressed.

7.5 Clinical and research implications

Greater understanding by the general public and by all healthcare professionals of the widespread effects of breathlessness is needed in order to overcome epistemic injustice and enable patients to bring their breathlessness out into the open, knowing that their concerns are legitimate and to allow healthcare professionals to tailor the management of breathlessness to the patient's needs and those of their carer. "This could be addressed in a variety of creative ways, for example, by having public photographic exhibitions which illustrate the widespread effects of breathlessness on the lives of those living with it, as well as showcasing the many ways breathlessness can be managed and signposting to relevant health services, charities and support groups. Routine holistic assessment of the effects of breathlessness on patients is warranted, as is routine assessment of the needs of patients and their carer.

Using the Breathing Space concept as a guide the coping style and help-seeking pattern of the patient, as well as the responsiveness to breathlessness that their present healthcare professional displays, could be assessed and advice given on how to cope in a more engaged style and on how and when to seek help appropriately. Additionally further training could be given to healthcare professionals to help them to assess and manage breathlessness more effectively.

The knowledge and information needs of patients and carers should be met, especially with respect to diagnosis and prognosis.

Healthcare professionals need to be aware of evidence based breathlessness management strategies and to refer to the relevant services consistently.

Appropriate guidance for patients and carers on when to present to the ED and how to manage breathlessness is necessary and may reduce the number of presentations.

Prior planning on what to do in a crisis and/or greater availability out of hours of primary healthcare professionals may avoid some presentations. Additionally paramedics, who are available at all times, trained in how to manage breathlessness crises may be able to reduce the need to convey the patient to the ED and may result in the patient and carer learning new ways of dealing with future crises.

Timely access to tests and specialist advice in the community may reduce the need for healthcare professionals to refer their patients to the ED.

Arranging a multidisciplinary case conference on breathlessness management, including what to do in crisis, after a paramedic callout or on discharge from the ED may reduce need for re-attendance.

Attention needs to be paid to the psychological needs of the patient and their carer and appropriate access to treatment may be of benefit.

Referral to palliative care may allow more appropriate management of breathlessness, as may taking a multidisciplinary approach in primary care, as is presently used with cancer patients, with patients with non-malignant conditions.

The factors associated with admission could be used by community healthcare professionals to better assess the need for presentation to the ED and could be used by ED staff to assess need for admission promptly to avoid lengthy waits.

Future research plans include investigating what elements would be necessary in a breathlessness management plan and conducting a feasibility study of how best to instigate a multidisciplinary case conference after presentation to the ED. Additionally investigation of the elements of a breathlessness crisis management plan to be used by paramedics and how best to conduct this intervention is planned.

7.6 Overall summary of the thesis

The overall aim of this research is to improve our understanding of the role of chronic breathlessness in emergency presentations to hospital by people with

advanced cardiorespiratory disease and to identify potential targets for interventions to prevent or avoid emergency presentations. It was found that living with chronic breathlessness involves widespread effects on the lives of both the patient and those caring for them, yet this impact may remain largely invisible to others. Quality of life with chronic breathlessness is maximised by a patient's engaged coping style and a clinician's responsiveness to breathlessness as well as to the underlying disease. This is described by the Breathing Space concept. Presentation to the ED sits within this context and occurs as a result of a breathlessness crisis. There are a proportion of patients who may have avoidable attendances and could be more optimally managed in the community. Greater public and professional understanding of the widespread effects of breathlessness, combined with appropriate assessment and management of the symptom, including planning for crisis may reduce the need to present to the ED.

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9 Appendices

Appendix 1 Search strategy for systematic literature review

Search terms (MEDLINE example)

Design

To identify qualitative research papers Flemming's 3 line qualitative filter was used:

1 interview*

2 qualitative

3 finding*

Exposure

4 breathless*

5 dyspn* MeSH Dyspnea exp

6 (short* adj 3 breath)

Population

7 patient* MeSH patient-physician relations

8 carer* MeSH caregivers

9 health* adj2 profession*

10 health personnel MeSH exp.health personnel

Outcome

11 experience

12 interaction*

13 help seeking MeSH Primary Health Care

14 coping MeSH Adaptation, Psychological

15 belief* MeSH attitude

16 psychosocial

17 psycho-social

18 1 OR 2 OR 3

19 4 OR 5 OR 6

20 7 OR 8 OR 9 OR 10

21 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17

22 18 AND 19 AND 20 AND 21

Appendix 2 Inclusion and exclusion criteria

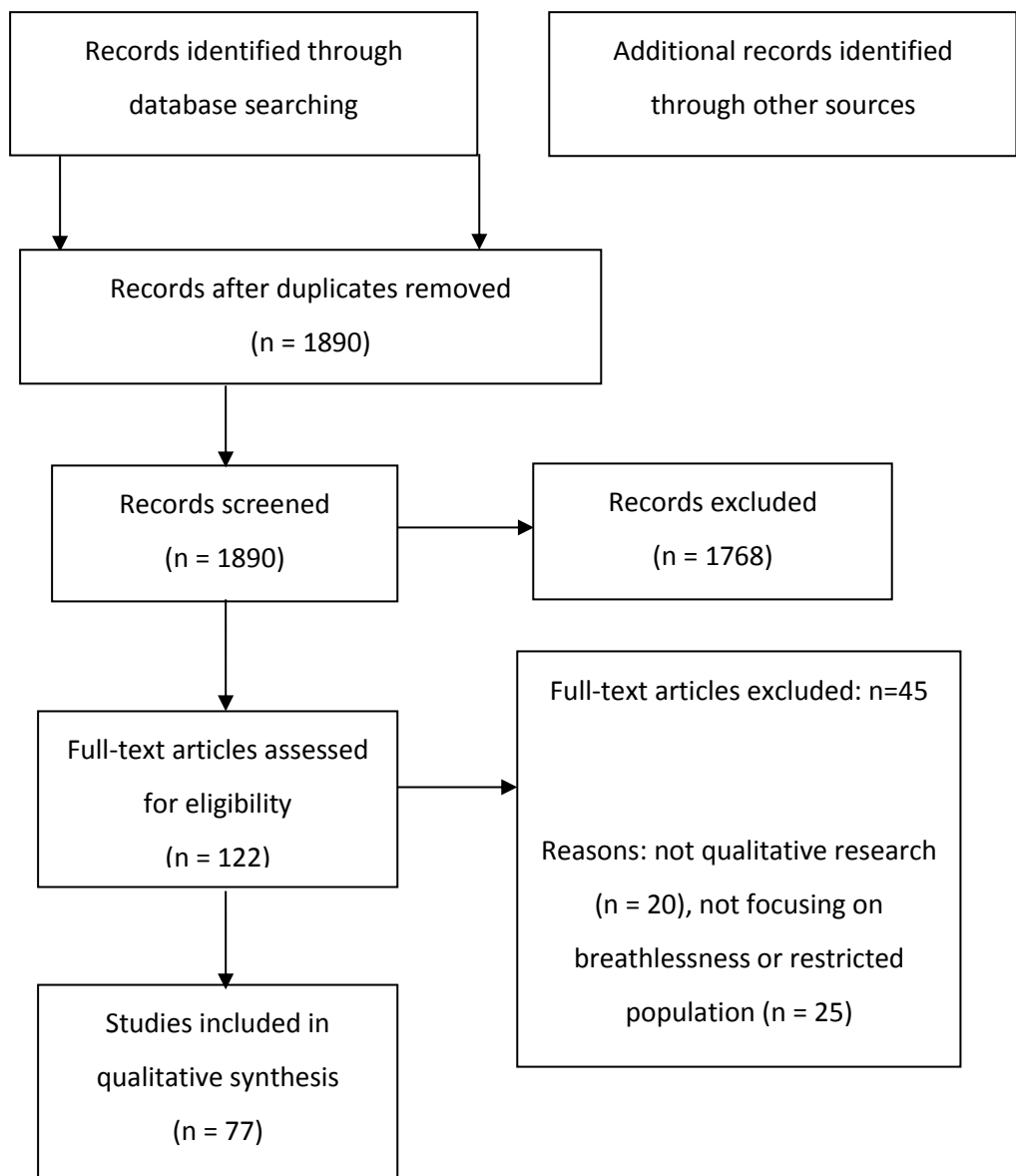
Inclusion Criteria

- English language full reports (with at least one full sentence quote)
- (published between 1987 and 2014)
- primary qualitative empirical research
- studies addressing any aspect of the experience of breathlessness from any underlying chronic condition from the perspective of patients, carers and healthcare professionals

Exclusion Criteria

- studies labelled qualitative but not using qualitative methodology (e.g. studies using qualitative categorical variables or structured interviews)
- secondary syntheses of primary qualitative empirical research
- quantitative research
- any studies relating to breathlessness caused by only obesity or asthma
- restricted populations e.g. post-transplant, ICU patients
- case reports (unless recognised qualitative methodology)
- opinion pieces

Appendix 4 PRISMA flow diagram



Appendix 5 Table 11 Characteristics of included studies

Table 11 Characteristics of included studies

Author	Year	Setting	Participants	Theoretical Approach
Adams	2006 (128)	Denmark, The Netherlands and UK	COPD Patients (16m, 7f)	Grounded Theory
Ahmadi	2014 (223)	Sweden	COPD, CHF, Aortic Stenosis, Anxiety and Asthma Patients – 7m, 9f (disease split unspecified)	Unspecified
Apps	2014 (110)	Leicester, UK	COPD Patients (6m, 9f)	Unspecified
Arnold	2006 (125)	Southampton, UK	COPD Patients (9m, 11f)	Unspecified
Avsar	2010 (102)	Turkey	COPD Patients (11m, 3f)	Phenomenological
Bailey	2001 (224)	Canada	COPD 'family nurse units' (Patient, 2 family members, 1 nurse) 10 family nurse units	Narrative Analysis
Bailey	2004 (225)	Canada	Healthcare Professionals (10, gender unspecified)	Ethnographic Narrative
Bailey	2004 (226)	Canada	COPD 'family nurse units' (Patient, 2 family members, 1 nurse) 10 family nurse units	Narrative Analysis
Bajwah	2013 (104)	London, UK	Progressive idiopathic fibrotic interstitial lung disease patients (5m 3f) and 4 spouses (3f, 1m)	Unspecified
Barnett	2005 (108)	Devon, UK	COPD Patients (10, gender unspecified)	Phenomenological
Bergs	2002 (103)	Reykjavik, Iceland	Carers of patients with COPD (0m, 6f)	Phenomenological
Booth	2003 (45)	Cambridge, UK	COPD Patients (6m, 4f) and Cancer Patients (6m, 4f) Cancers = 6 x respiratory system, 1 x breast, 2 x non-Hodgkin's lymphoma, 1 x renal cell carcinoma	Unspecified

Booth	2006 (139)	Cambridge, UK	COPD, Heart Failure, Cancer (1 colon, 1 myelofibrosis), Other (interstitial lung disease) – 10 patients (4m, 6f) and 10 Carers (gender unspecified)	Unspecified
Boyle	2009 (56)	USA	Carers of patients with COPD (0m, 10f)	Phenomenological-Hermeneutic
Brandt	2013 (227)	USA	COPD Patients (19m, 9f)	Naturalistic method
Caress	2010 (100)	Manchester, UK	COPD Patients (8m, 6f) Carers (9f, 3m)	Unspecified
Cicutto	2004 (109)	Ontario, Canada	COPD Patients (23m, 19f)	Unspecified
Clancy	2009 (127)	Manchester, UK	COPD Patients (6m, 4f) Carers (2m, 5f)	Longitudinal Heideggerian
Cooney	2013 (228)	Western seaboard, Ireland	COPD Patients (15m, 11f)	Straussian grounded theory
Dickenson	2009 (229)	Retford, UK	COPD Patients (12, gender unspecified)	Framework approach
Edmonds	2005 (46)	London, UK	Heart Failure Patients (20m, 7f)	Unspecified
Ek	2008 (117)	Sweden	COPD Patients (3m, 5f)	Phenomenological
Ek	2010 (141)	Sweden	COPD Patients (1m, 3f)	Phenomenological-Hermeneutic
Ek	2011 (140)	Sweden	COPD patients and carers (4 couples)	Phenomenological-Hermeneutic
Elkington	2004 (137)	Southampton, UK	Carers of patients with COPD (7m, 18f)	Unspecified
Elofsson	2004 (230)	Sweden	COPD Patients (4m, 2f)	Phenomenological-Hermeneutic

Fraser	2006 (116)	USA	COPD Patients (5m, 5f)	Phenomenological-Hermeneutic
Gardiner	2009 (231)	East Devon and South Yorkshire, UK	COPD patients (8 East Devon, 13 South Yorkshire – 13m, 8f region unspecified)	Thematic analysis
Gott	2009 (134)	Sheffield, UK	39 healthcare professionals working with COPD patients	Unspecified
Guthrie	2001 (112)	Leeds, UK	COPD Patients (8m, 12f)	Unspecified
Gysels	2008 (55)	London, UK	COPD Patients (7m, 11f)	Grounded Theory
Gysels	2009 (54)	London, UK	Carers (all female n=15) Various conditions - 1xLung cancer, 2xCOPD, 3xHeart Failure, 8xMND, 1xPalliative Care (unspecified)	Grounded Theory
Gysels	2009 (111)	London, UK	COPD Patients (7m, 11f)	Grounded Theory
Gysels	2010 (39)	London, UK	COPD Patients (7m, 11f)	Unspecified
Gysels	2011 (126)	London, UK	Patients – various conditions Cancer – unspecified (5m, 5f), COPD (5m, 9f), Heart Failure (7m, 3f), MND (9m, 1f)	Unspecified
Habraken	2008 (132)	The Netherlands	COPD Patients (8m, 3f)	Unspecified
Hallas	2012 (106)	London, UK	Patients with various conditions (5m, 7f) Respiratory conditions – 5x Idiopathic pulmonary fibrosis, 1x cystic fibrosis, 2x bronchiectasis, 1x COPD, 1 x primary pulmonary hypertension, 1x recurrent pneumothoraces; Heart problems – 1x Eisenmengers syndrome	Phenomenological
Harris	2008 (119)	North-east Derbyshire, UK	COPD Patients (12m, 4f)	Interpretive Phenomenological

Hasson	2008 (133)	Northern Ireland	COPD Patients (10m, 3f)	Unspecified
Henoch	2008 (120)	Sweden	Lung Cancer Patients (11m, 9f)	Unspecified
Jeng	2002 (122)	Taiwan	COPD Patients (7m, 2f)	Constant comparison and content analysis
Jones	2004 (130)	Bolton, UK	COPD Patients (8m, 8f)	Unspecified
Kanervisto	2007 (232)	Finland	COPD Patients (5, gender unspecified) and spouses (4, gender unspecified)	Content Analysis
Kerr	2010 (121)	UK (region unspecified)	COPD Patients (6m, 3f)	Grounded Theory
Lai	2007 (151)	Hong Kong, China	Lung Cancer Patients (11, gender unspecified)	Content Analysis
Leidy	1999 (233)	USA	COPD Patients (6m, 6f)	Phenomenological
Lewis	2014 (234)	Southampton, UK	COPD patients (25, gender unspecified)	Phenomenological
Lowey	2013 (63)	New York, USA	COPD and Heart Failure patients – proportion unspecified (9m, 11f)	Unspecified
Nicholls	2003 (61)	Auckland, New Zealand	COPD Patients (5m, 5f)	Phenomenological
Nicolson	2000 (136)	'Industrial Cities', UK	Chronic Bronchitis Patients (10m, 10f)	Unspecified
Nicolson	2003 (101)	UK (region unspecified)	COPD Patients (10m, 10f)	Symbolic interactionist theoretical framework
O'Driscoll	1999 (114)	Unspecified	Lung Cancer Patients (30m, 22f) 32 non-small cell, 13 small cell, 4 mesothelioma, 3 suspected	Content Analysis

Oliver	2001 (131)	UK (region unspecified)	COPD Patients (16 – gender unspecified)	Phenomenological
O'Neill	2002 (124)	USA (region unspecified)	COPD Patients (0m, 21f)	Common Sense Model
Pinnock	2011 (118)	Lothian, Tayside and Forth Valley; Scotland, UK	COPD Patients (14m, 7f) Carers (13 informal, 18 professional)	Unspecified
Roberts	1993 (152)	Canada	Cancer patients (4m, 6f), Healthcare professionals (12 – all nurses, gender unspecified) Cancers – Lung (4), Breast (2), Throat (1), Stomach (1), Prostate (1) Kidney (1)	Unspecified
Robinson	2005 (142)	Northern England, UK	COPD Patients (6m, 4f)	Qualitative Phenomenological
Ryan	2009 (62)	Ireland	Heart Failure Patients (6m, 3f)	Phenomenological
Seamark	2004 (58)	Devon, UK	COPD patients and carers (Patients 9m, 1f and 8 carers)	IPA
Shipman	2009 (129)	South-East London	COPD Patients (9m, 7f)	Unspecified
Simpson	2010 (113)	Canada	Carers of patients with COPD (3m, 11f)	Attride-Stirling Thematic Network
Small	2012 (235)	East Devon and Barnsley, UK	COPD Patients (8 Devon, 13 Barnsley – gender unspecified) Healthcare Professionals (19 Devon, 20 Barnsley – gender unspecified)	Unspecified
Spence	2008 (143)	Ireland	Healthcare Professionals (7m 16f)	Unspecified
Spence	2008 (138)	Ireland	Carers of patients with COPD (1m, 6f)	Thematic analysis
Stull	1999 (123)	Northeast Ohio, USA	Heart Failure Patients (17m, 4f)	Grounded Theory
Walters	2008 (236)	Tasmania	COPD Patients (5m, 9f) Healthcare professionals (19 GPs – gender unspecified)	Unspecified

Willgoss	2012 (53)	Northwest England, UK	COPD Patients (5m, 9f)	Thematic Network Analysis
Williams, S	1993 (41)	UK	COPD Patients (24 – gender unspecified) and their families	Sociological Approach
Williams, V	2007 (237)	South of England, UK	COPD Patients (4m, 2f)	Unspecified
Williams, V	2010 (238)	Oxford, UK	COPD Patients (6m, 3f)	Grounded Theory
Williams, V	2011 (178)	England (region unspecified), UK	COPD Patients (12m, 6f)	Grounded Theory
Wilson	2007 (107)	Ireland	COPD Patients (25m, 7f) Healthcare Professionals (8 – gender unspecified)	Unspecified
Wood	2013 (239)	Newcastle, UK	Lung Cancer Patients (7m, 2f)	Unspecified
Wortz	2012 (115)	East Texas, USA	COPD Patients (25m, 22f)	Unspecified
Young	2012 (105)	Southern New Brunswick, Canada	Healthcare professionals, caring for patients with COPD (10 family physicians, 8 respiratory specialists – gender unspecified)	Unspecified
Yu	2007 (240)	Hong Kong	COPD Patients (5m, 0f)	Thematic Network Analysis
Zakrisson	2010 (135)	Central Sweden	Healthcare professionals, caring for patients with COPD (12 – gender and speciality unspecified)	Unspecified

Appendix 6 Survey



Survey Number _____

PATIENT SURVEY

We are always looking for ways to improve our service. Filling in this survey will help us understand the problems of people who come to our emergency department.

Please could you spend a few minutes filling in this survey? It should take you about 5-10 minutes to complete. (If you have filled in this survey before please just answer up to question B5.)

You are completely free to choose to take part or not, it will not affect your care in any way. Your answers will be kept confidential and seen only by the research team. Thank you.

First, some questions about you:

A1 Date of birth ____/____/____

A2 Gender Male Female

A3 Postcode

Now a question about your breathing:

B1 Have you had shortness of breath most days for the **last month**?

Yes No

If you answered **no** you can stop now.

Thank you for your time.

If you answered YES, I do suffer from shortness of breath, please continue.

(Please note there are questions on four sides of paper in this survey.)

Now some questions about the breathing trouble you have had today:

B2 Was shortness of breath **one of** the reasons you came to hospital today?

Yes No

B3 Was shortness of breath **the main** reason you came to hospital today?

Yes No

B4 When you decided to come to hospital today, how bad was your breathlessness?

None Mild Moderate Severe

B5 How bad is your breathlessness now?

None Mild Moderate Severe

B6 On average over the **past month** how would you describe your shortness of breath? (Please tick the **one** that **best** describes your shortness of breath)

- I am not troubled by shortness of breath except on strenuous exercise
- I get short of breath when hurrying on the level or walking up a slight hill

- I walk slower than most people on the level and stop after a mile or so, or stop after 15 minutes walking at my own pace
- I stop for breath after walking about 100 yards or after a few minutes on level ground
- I am too short of breath to leave the house, or I am short of breath when undressing

B7 Who was involved in making the decision to come to hospital today?

(Please tick **all** that apply)

- Self
- Out of Hours clinic
- Heart failure nurse
- Family/Friend
- Long-term conditions nurse
- GP practice
- Paid carer
- NHS Direct
- Respiratory nurse
- Paramedic
- Macmillan nurse
- 999 operator

Now some questions about any breathing trouble you have had in the past:

C1 How long have you had shortness of breath?

- from 1 to 6 months
- between 7m and 2 yrs
- more than 2 yrs

C2 How many times have you come to the Emergency Department because you were short of breath in the last 12 months (roughly)?

- only this time
- twice
- 3 to 5 times
- more than 5 times

C3 When you feel **very** short of breath, roughly how long does your shortness of breath last?

less than 5 mins 5-10 mins 11-15 mins

16-30 mins more than half an hour not sure

C4 Who do you usually talk to about your breathing problems? (Please tick **all** that apply)

GP Practice nurse Respiratory nurse

Family/friends Breathing clinic Heart failure nurse

Specialist doctor Respiratory Support Group Macmillan nurse

Long-term conditions nurse No one Other -

And finally some more questions about you

D1 Are you: a current smoker an ex-smoker a non-smoker

D2 Do you live alone? Yes No

D3 Who filled in this survey?

- I did I had help Someone filled it in for me

D4 Do you have any of the following conditions? (Please tick **all** that apply)

COPD (also called lung disease, emphysema or chronic bronchitis)

Lung Cancer Cancer (other than lung cancer)

Problems with your heart Asthma

Is there anything else you'd like to tell us?

Thank you for filling in this survey!

We would like to look at your hospital notes to find out what treatment you had in hospital for your breathlessness.

If you agree that we can look at your notes please sign below:

Signature _____

My name is _____

Telephone

number _____

We would like to talk to some patients about their breathlessness and the effect it has on everyday life.

If you would be happy for someone to get in touch with you about this, please sign below:

Signature _____

Appendix 7 Table 12 Case note review data extraction sheet

Table 12 Case note review data extraction sheet

1	Patient identifier:	
2	Date of index presentation:	
3	Day:	
4	Time of presentation:	
5	Number of previous attendances in last 12m:	
6	Did Dr note breathlessness as a presenting symptom	Yes No
7	Diagnosis thought to be primary cause of breathlessness:	
8	Charlson comorbidity index (0-6):	
9	Treatment given in the ED:	Oxygen
		Nebuliser
		Inhaler
		Antibiotics
		Fluids
		Opioids
		Benzodiazepine
		Other
10	Assessments done in ED:	Chest x-ray
		Blood tests
		ABG
		ECG
		Oxygen Saturation
		Respiratory rate
		Other
11	Admitted to hospital:	Yes No
	<i>If not admitted go to number 18</i>	
12	Number of days in hospital (index):	
13	Number of days of each previous admission in last 12m:	
14	Treatment given once admitted (index):	
15	Assessments done once admitted:	
16	Number of days in hospital (index):	
17	Number of days of each previous admission in last 12m:	
18	Arranged an out-patient clinic if sent home without admission	Yes No
19	Referral made when discharged	Yes No

Appendix 8 Table 13 Patient characteristics

Table 13 Patient characteristics

Patient characteristics (self-report)	n=245/1,212
Age mean (SD)	65yrs (19)
Gender	117 M (48%) 128 F (52%)
Medical Research Council Dyspnea Scale Median (IQR*)	4 (3 to 5)
Length of time experiencing chronic breathlessness Median (IQR)	7m-2yr (1-6m to >2yrs)
Diagnosis	
COPD	63 (26%)
Cancer	21 (9%)
Heart conditions	104 (42%)
Asthma only	0 (0%)
Who does the patient talk to about their breathlessness?	
GP	178 (73%)
Practice nurse	14 (6%)
Respiratory nurse	34 (14%)
Breathing clinic	7 (3%)
Heart failure nurse	3 (1%)
Specialist doctor	29 (12%)
Macmillan nurse	5 (2%)
Long Term Conditions Nurse	16 (7%)
Family/friends	64 (26%)
Support group	1 (0.4%)
No one	34 (14%)
Factors relevant to ED presentation (self-report)	n=245/1,212
Breathlessness severity at decision Median (IQR; range)	Severe (Moderate to severe; Mild to severe)

Breathlessness severity at time of survey Median (IQR; range)	Mild (Mild to moderate; None to severe)
Who was involved in the decision to present?	
Self	92 (37%)
<i>People known to patient</i>	
Family/friend	98 (40%)
Paid carer	9 (4%)
GP surgery	47 (19%)
Long Term Condition Nurse	4 (2%)
Heart failure nurse	0 (0%)
Respiratory nurse	4 (2%)
Macmillan nurse	3 (1%)
<i>Emergency services</i>	
Out of hours service	7 (3%)
NHS Direct**	18 (7%)
999 (Emergency number)	14 (6%)
Paramedic	43 (18%)
Data from Case Note Review	(n=177/1,212)
Time/day of presentation	
Working hours***	56 (32%)
Out-of-hours	121 (68%)
Number of previous presentations in last 12 months	
0	83 (47%)
1 or more	94 (53%)
Median (IQR; range)	1 (0-2; 0-30)
Presenting complaint: (documented by triage nurse)	
“Breathing difficulties”	56 (32%)
“Chest pain”	41 (23%)
“Illness”	47 (27%)
Other	32 (18%)
Presentations in which breathlessness was documented by the doctor ****	112 (63%)
Presentations in which breathlessness was noted by either a triage nurse and/or a doctor	122 (69%)
Patients admitted	122 (69%)

Patient discharged	55 (31%)
No. days admitted Median (IQR; Range)	1 (0 to 5; 0 to 44)

* IQR=Interquartile range

** NHS Direct was a 24 hour a day nurse-led telephone information service, since replaced by the 111 service

*** Definition of working hours is 08.00-18.30 Monday to Friday excluding bank holidays

**** See box 1

Appendix 9 Table 14 General characteristics

Table 14 General characteristics

	Experiencing chronic breathlessness (n=424)	Presenting due to breathlessness (n=245)
General characteristics		
<i>MRC Dyspnea scale grade:</i>	4	4
Median	3 to 5	3 to 5
IQR	1 to 5	1 to 5
Range	252 (59%)	159 (65%)
No. Grade 4 or 5	300 (71%)	188 (77%)
No. Grade 3 to 5		
<i>Length of time experiencing chronic breathlessness:</i>	>2 yrs	7m-2yr
Median	1-6m to >2yrs	1-6m to >2yrs
IQR	1-6m to >2yrs	1-6m to >2yrs
Range	214 (52%)	112 (46%)
No. >2yrs		
<i>Duration of episodes of breathlessness:</i>		
Median	16-30min	16-30min
IQR	5-10min to >30min	5-10min to >30min
Range	5-10min to >30min	5-10min to >30min
<i>Smoking status:</i>		
Current smoker	120 (29%)	69 (29%)
Ex-smoker	186 (45%)	109 (45%)
Never smoker	109 (26%)	63 (26%)
<i>Living alone</i>	159 (38%)	86 (36%)
<i>Index of Multiple Deprivation:</i>		35.1 (21.6)
Mean (S.D.)		1.74-81.54
Range		
<i>Diagnosis (self-report):</i>		
COPD (prevalence; 95% CI)	121/1,212 (10%; 8-12%)	63 (26%) -
<i>Diagnosis (self-report):</i>		

Lung Cancer	10	9
<i>Diagnosis (self-report):</i>		
Other Cancer	32	12
<i>Diagnosis (self-report):</i>		
Total cancer (prevalence; 95% CI)	42/1,212 (3.5%; 2.7-4.3%)	21 (9%) -
<i>Diagnosis (self-report):</i>		
Heart conditions (prevalence; 95% CI)	165 (14%; 12-16%)	104 (42%) -
<i>Diagnosis (self-report):</i>		
Asthma mixed	108 (26%)	54
<i>Diagnosis (self-report):</i>		
Asthma only (prevalence; 95% CI)	54 (4.5%; 3.3-5.7%)	0 (0%) -
<i>Who does patient talk to about their breathlessness?</i>		
GP	282/424 (68%)	178 (73%)
Practice nurse	28 (7%)	14 (6%)
Respiratory nurse	53 (13%)	34 (14%)
Breathing clinic	15 (4%)	7 (3%)
Heart failure nurse	5 (1%)	3 (1%)
Specialist doctor	46 (11%)	29 (12%)
Macmillan nurse	10 (2%)	5 (2%)
Long Term Conditions Nurse	29 (7%)	16 (7%)
Family/friends	97 (23%)	64 (26%)
Support group	4 (1%)	1 (0.4%)
No one	77 (19%)	34 (14%)
Characteristics with respect to ED presentation		
<i>Rough estimate of number of ED visits in last 12m (self-report)</i>		
Median	1	2
IQR	0 to 2	1-3 to 5 times
Range	None to more than 5 times	Once to more than 5 times

<i>Severity of breathlessness at time of decision to present</i>		
Median	Moderate Mild to severe	Severe Moderate to severe
IQR	None to severe	Mild to severe
Range		
<i>Severity of breathlessness when waiting in the ED</i>		
Median	Mild None to moderate	Mild Mild to moderate
IQR	None to severe	None to severe
Range		
<i>Who was involved in the decision to present?</i>		
Self	146 (36%)	92 (37%)
Family/friend	149 (37%)	98 (40%)
Paid carer	24 (6%)	9 (4%)
GP surgery	75 (19%)	47 (19%)
LTCN	9 (2%)	4 (2%)
Heart failure nurse	3 (1%)	0
Respiratory nurse	8 (2%)	4 (2%)
Macmillan nurse	4 (1%)	3 (1%)
Out of hours service	11 (3%)	7 (3%)
NHS Direct (111 now)	30 (7%)	18 (7%)
999	24 (6%)	14 (6%)
Paramedic	65 (16%)	43 (18%)

Appendix 10 Table 15 Patients presenting due to breathlessness

Table 15 Patients presenting due to breathlessness

	Patients presenting due to breathlessness (n=177)
<i>Time/day of presentation</i>	
Working hours*	56 (32%)
Out-of-hours	121 (68%)
<i>No. of previous presentations in last 12 months</i>	
0	
1 or more	83 (47%)
Median	94 (53%)
IQR	1
range	0-2 0-30
<i>Admissions</i>	
No. admitted	122 (69%)
No. discharged	55 (31%)
<i>No. of days admitted to hospital for</i>	
Median	1 day
IQR	0 to 5 days
Range	0 to 44 days
<i>Presenting complaint**</i>	
Breathing difficulties	56 (32%)
Chest pain	41 (23%)
Illness	47 (27%)
Other	32 (18%)
<i>Did the Doctor note breathlessness in the notes***</i>	
Y	
N	112 (63%) 65 (37%)
<i>Number of presentations in which breathlessness was noted by either a triage nurse and/or a doctor</i>	
	122/177=69%

<i>Doctor's diagnosis of the cause of index presentation</i>	
Exacerbation of COPD/ Chest infection	
Heart conditions	48 (27%)
Other****	60 (34%)
	69 (39%)
<i>Known History</i>	
COPD	53
Lung cancer	9
Other cancer	10
Heart failure	54
Any cardiac condition	77
<i>Charlson comorbidity score</i>	
Median	1
IQR	1 to 2
Range	0 to 6
<i>Respiratory rate</i>	
Mean (SD)	20 (4)
Range	12 to 40
<i>Oxygen saturation (SpO2)</i>	
Mean (SD)	96 (3)
Range	72 to 100
<i>Treatments given</i>	
Nebuliser	40
Inhaler	1
Antibiotics	26
Opioids	16
Benzodiazepine	3
Oxygen given	53
IV Fluids given	21
<i>Tests performed</i>	
Electrocardiogram	129
Blood tests	136
Chest X-ray	132
Arterial Blood Gas	56

*(Definition of working hours is 08.00-18.30 Monday to Friday excluding bank holidays)

** (documented by triage nurse)

*** word documented in notes, meaning=unable to cope at home

Box to describe what counted as SOB: we arrived at this judgement based on very careful scouring of the notes for ANY indication that the Dr is aware that the patient has breathlessness e.g notes such as: SOB increased, dyspnea etc; also if treatments ordered included a nebuliser or an inhaler

**** e.g. anxiety, pleural effusion, collapse, constipation, confusion, cellulitis, gallstones, kidney failure

Appendix 11 Table 16 Predictors of admission

Table 16 Predictors of admission

	Admitted n=122	Discharged n=55
Continuous variables		
Age		
Mean	69.48 sd 14.356	51.45 sd 20.75
Assumptions:		
Groups size >=50		
Test used:	z test independent samples	
Test statistic z and df	z=5.843 df=78	
p value	0.000 p<0.05	
Mean diff (95% CI range)	18yrs (95% CI;12-24)	
Conclusion	There is a significant difference in the average ages of the two groups	
Respiratory rate		
Mean	20.49 sd 4.508	19.35 sd 3.375
Assumptions:		
Groups size >=50		
Test used:	z test independent samples	
Test statistic z and df	1.810 df=125	
p value	.073	
Mean diff (95% CI range)	1.139 (-0.106-2.383)	
Conclusion	There is not a significant difference in respiratory rate	

<p>SpO2 (Oxygen saturation)</p> <p>Mean</p> <p>Assumptions:</p> <p>Groups size >=50</p> <p>Test used:</p> <p>Test statistic z and df</p> <p>p value</p> <p>Mean diff (95% CI range)</p> <p>Conclusion</p>	<p>95.5 sd 3.594</p> <p>z test independent samples</p> <p>-3.592 df 141</p> <p>0.000 p<0.05</p> <p>-1.669 (-2.587- -0.750)</p> <p>There is a significant difference in the average SpO2 of the two groups</p>	<p>97.17 sd 2.38</p>
<p>IMD</p> <p>Mean</p> <p>Assumptions:</p> <p>Groups size >=50</p> <p>Test used:</p> <p>Test statistic z and df</p> <p>p value</p> <p>Mean diff (95% CI range)</p> <p>Conclusion</p>	<p>32.9 SD 20.7</p> <p>z test independent samples</p> <p>-1.773 df 92</p> <p>0.079</p> <p>-6.69 (-14.18 to 0.80)</p> <p>There is not a significant difference in IMD score of the two groups</p>	<p>39.6 SD 22.6</p>
<p>No. previous presentations</p> <p>Mean</p> <p>Assumptions:</p> <p>Groups size >=50</p>	<p>1.44 2.909 (whole numbers?)</p>	<p>1.89 4.379</p>

Test used:	z test independent samples	
Test statistic z and df	-0.693 df=76	
p value	0.490	
Mean diff (95% CI range)	-0.448 (-1.736-0.839)	
Conclusion	There is not a significant difference in No.of prev presentations in the two groups	
Categorical variables		
Gender		
Nominal data		
Number male	61	27
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	1.000	
OR and 95% CIs	1.04 (0.55-1.96)	
Conclusion	There is not a significant association between gender and admission.	
Severity of SOB at decision		
Ordinal data		
Assumption	Distribution free	
Test used:	Kendall's Tau b	
Tau-b value	0.048	
p value	0.502	
Conclusion	There is no significant correlation between severity of SOB at decision and admission	

Severity of SOB in ED Ordinal data Assumption Test used: Tau-b value p value Conclusion	Distribution free Kendall's Tau b -0.068 0.349 There is no sig correlation between severity of SOB in the ED and admission	
MRC Ordinal data Assumption Test used: Tau-b value p value Conclusion	Distribution free Kendall's Tau b 0.061 0.409 There is no significant correlation between MRC score and admission	
Decision to present (who was involved)		
Self Nominal data Number yes Assumption Test used: p value Asymp.sig. (2 sided) OR and 95% CIs Conclusion	47 None Fisher's Exact test 0.868 1.07 (0.55-2.07) There is not a significant association between decision= self and admission.	20

<p>Out of hours</p> <p>Nominal data</p> <p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p> <p>Conclusion</p>	<p>5</p> <p>None</p> <p>Fisher's Exact test</p> <p>1.000</p> <p>1.11 (0.21-5.92)</p> <p>There is not a significant association between decision= out of hours service and admission.</p>	<p>2</p>
<p>HF nurse</p> <p>Number yes</p>	<p>0</p>	<p>0</p>
<p>Family/friend</p> <p>Nominal data</p> <p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p> <p>Conclusion</p>	<p>53</p> <p>None</p> <p>Fisher's Exact test</p> <p>0.622</p> <p>1.11 (0.21-5.92)</p> <p>There is not a significant association between decision= friends/family and admission.</p>	<p>21</p>
<p>Long term conditions nurse</p> <p>Nominal data</p> <p>Number yes</p> <p>Assumption</p> <p>Test used:</p>	<p>3</p> <p>None</p> <p>Fisher's Exact test</p>	<p>1</p>

p value Asymp.sig. (2 sided)	1.000	
OR and 95% CIs	1.34 (0.14-13.16)	
Conclusion	There is not a significant association between decision= LTCN and admission.	
GP		
Nominal data		
Number yes	22	6
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	1.000	
OR and 95% CIs	1.34 (0.14-13.16)	
Conclusion	There is not a significant association between decision= GP and admission.	
Paid carer		
Nominal data		
Number yes	2	4
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.073	
OR and 95% CIs	0.21 (0.04-1.17)	
Conclusion	There is not a significant association between decision= paid carer and admission.	
NHS Direct		
Nominal data		
Number yes	7	7
Assumption	None	
Test used:	Fisher's Exact test	

p value Asymp.sig. (2 sided)	0.131	
OR and 95% CIs	0.41 (0.14-1.23)	
Conclusion	There is not a significant association between decision= NHS Direct and admission.	
Respiratory Nurse		
Nominal data		
Number yes	2	1
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	1.000	
OR and 95% CIs	0.88 (0.08-10.00)	
Conclusion	There is not a significant association between decision= Respiratory nurse and admission.	
Paramedic		
Nominal data		
Number yes	26	7
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.216	
OR and 95% CIs	1.82 (0.74-4.48)	
Conclusion	There is not a significant association between decision= paramedic and admission.	
Macmillan nurse		
Nominal data		

<p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p> <p>Conclusion</p>	<p>3</p> <p>None</p> <p>Fisher's Exact test</p> <p>0.554</p> <p>-</p> <p>There is not a significant association between decision= Macmillan nurse and admission.</p>	<p>0</p>
<p>999</p> <p>Nominal data</p> <p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p> <p>Conclusion</p>	<p>8</p> <p>None</p> <p>Fisher's Exact test</p> <p>0.279</p> <p>3.72 (0.45-30.30)</p> <p>There is not a significant association between decision= 999 and admission.</p>	<p>1</p>
<p>Duration SOB (How long had chr br)</p> <p>Ordinal data</p> <p>Assumption</p> <p>Test used:</p> <p>Tau-b value</p> <p>p value</p> <p>Conclusion</p>	<p>Distribution free</p> <p>Kendall's Tau b</p> <p>0.082</p> <p>0.259</p> <p>There is no significant correlation between duration of SOB and admission</p>	
<p>Number ED visits self-report</p> <p>Ordinal data</p>		

Assumption	Distribution free	
Test used:	Kendall's Tau b	
Tau-b value	0.170	
p value	0.016	
Conclusion	There is a significant correlation between number of previous visits to the ED and admission	
Episode length (mins)		
Ordinal data		
Assumption	Distribution free	
Test used:	Kendall's Tau b	
Tau-b value	0.004	
p value	0.963	
Conclusion	There is no significant correlation between episode length and admission	
Talk to about breathlessness		
GP		
Nominal data		
Number yes	92	39
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.463	

OR and 95% CIs	1.30 (0.64-2.67)	
Conclusion	There is not a significant association between Talk to= GP and admission.	
Practice nurse		
Nominal data		
Number yes	10	3
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.757	
OR and 95% CIs	1.56 (0.41-5.92)	
Conclusion	There is not a significant association between Talk to= practice nurse and admission.	
Respiratory nurse		
Nominal data		
Number yes	19	6
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.489	
OR and 95% CIs	1.52 (0.57-4.04)	
Conclusion	There is not a sig association between Talk to= respiratory nurse and admission.	
Family/friends		
Nominal data		
Number yes	34	14
Assumption	None	
Test used:	Fisher's Exact test	

p value Asymp.sig. (2 sided)	0.855	
OR and 95% CIs	1.14 (0.55-2.36)	
Conclusion	There is not a significant association between Talk to= family/friends and admission.	
Breathing clinic		
Nominal data		
Number yes	5	0
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.327	
OR and 95% CIs	-	
Conclusion	There is not a significant association between Talk to= breathing clinic and admission.	
HF nurse		
Nominal data		
Number yes	0	1
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.313	
OR and 95% CIs	-	
Conclusion	There is not a significant association between Talk to= HF nurse and admission.	
Specialist Doctor		
Nominal data		
Number yes	22	1

Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.002	
OR and 95% CIs	12.00 (1.57-91.48)	
Conclusion	There is a significant association between Talk to= Specialist doctor and admission.	
RSG		
Nominal data		
Number yes	0	0
Macmillan		
Nominal data		
Number yes	3	1
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	1.000	
OR and 95% CIs	1.37 (0.14-13.51)	
Conclusion	There is not a significant association between Talk to= Macmillan nurse and admission.	
Long term conditions nurse		
Nominal data		
Number yes	10	3
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.757	

OR and 95% CIs Conclusion	1.56 (0.41-5.92) There is not a significant association between Talk to= LTCN nurse and admission.	
Talk to no one Nominal data Number yes Assumption Test used: p value Asymp.sig. (2 sided) OR and 95% CIs Conclusion	14 None Fisher's Exact test 0.479 0.67 (0.27-1.66) There is not a significant association between Talk to= no one and admission.	9
Live alone Nominal data Number yes Assumption Test used: p value Asymp.sig. (2 sided) OR and 95% CIs Conclusion	47 None Fisher's Exact test 0.173 1.72 (0.85-3.45) There is not a significant association between Live alone and admission.	15

Self-report diagnosis		
<p>COPD</p> <p>Nominal data</p> <p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p> <p>Conclusion</p>	<p>34</p> <p>None</p> <p>Fisher's Exact test</p> <p>1.000</p> <p>0.95 (0.47-1.93)</p> <p>There is not a significant association between Diagnosis= COPD and admission.</p>	<p>16</p>
<p>Lung Cancer</p> <p>Nominal data</p> <p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p> <p>Conclusion</p>	<p>3</p> <p>None</p> <p>Fisher's Exact test</p> <p>0.378</p> <p>0.44 (0.09-2.26)</p> <p>There is not a significant association between Diagnosis= Lung Cancer and admission.</p>	<p>3</p>
<p>Other cancer</p> <p>Nominal data</p> <p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p>	<p>7</p> <p>None</p> <p>Fisher's Exact test</p> <p>0.628</p>	<p>2</p>

OR and 95% CIs	1.63 (0.32-8.13)	
Conclusion	There is not a sig association between Diagnosis= Other Cancer and admission.	
Heart problems		
Nominal data		
Number yes	63	16
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.005	
OR and 95% CIs	2.65 (1.34-5.24)	
Conclusion	There is a significant association between Diagnosis= heart problems and admission.	
Asthma		
Nominal data		
Number yes	23	16
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.170	
OR and 95% CIs	0.57 (0.27-1.20)	
Conclusion	There is not a significant association between Diagnosis= Asthma and admission.	
Known history COPD		
Nominal data		
Number yes	38	15
Assumption	None	
Test used:	Fisher's Exact test	

p value Asymp.sig. (2 sided)	0.723	
OR and 95% CIs	1.19 (0.59-2.42)	
Conclusion	There is not a significant association between Known History= COPD and admission.	
Known history Lung Cancer		
Nominal data		
Number yes	7	2
Assumption	No	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.723	
OR and 95% CIs	1.60 (0.32-7.94)	
Conclusion	There is not a significant association between Known History= Lung Cancer and admission.	
Known history Other Cancer		
Nominal data		
Number yes	9	1
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.146	
OR and 95% CIs	4.26 (0.53-34.48)	
Conclusion	There is not a significant association between Known History= Other Cancer and admission.	
Known history HF		
Nominal data		

Number yes Assumption Test used: p value Asymp.sig. (2 sided) OR and 95% CIs Conclusion	47 None Fisher's Exact test 0.001 4.27 (1.78-10.20) There is a sig association between Known History= Heart Failure and admission.	7
Known history cardiac cond. Nominal data Number yes Assumption Test used: p value Asymp.sig. (2 sided) OR and 95% CIs Conclusion	66 None Fisher's Exact test 0.000 p<0.05 4.69 (2.21-10) There is a significant association between Known History= Cardiac condition and admission.	11
In/out of hours <i>Time Out of hours defined as 6.30pm to 8am and 6.30pm Friday to 8am Monday and public hols (incl. Mon 26th May)</i> Nominal data Number yes Assumption Test used: p value Asymp.sig. (2 sided)	82 None Fisher's Exact test 0.728	39

OR and 95% CIs Conclusion	0.84 (0.42-1.68) There is not a significant association between Presentation In or Out of hours and admission.	
Presenting complaint Assumption At least 80% of the cells exceed 5 and all have at least 1 Test used: Test statistic and df P value Asymp.sig. (2 sided) Conclusion	Yes Pearson's Chi squared test 0.608 3df 0.899 There is not a significant association between Presenting complaint and admission.	
Breathing difficulties Number yes	39/122 (32%)	17/55 br diff (31%)
Chest pain Number yes	27 (22%)	14 (25%)
Illness Number yes	34 (28%)	13 (24%)
Other Number yes	17 (14%)	15 (27%)
Dr diagnosis of this presentation Assumption At least 80% of the cells exceed 5 and all have at least 1	Yes	

Test used:	Pearson's Chi squared test	
Test statistic and df	9.252 3df	
P value Asymp.sig. (2 sided)	0.026	
Conclusion	There is a significant association between Dr diagnosis and admission.	
Exacerbation of COPD or Chest infection	31 (25%)	17 (31%)
Heart conditions (ACS/HF etc)	38 (31%)	7 (13%)
Chest pain	12 (10%)	3 (5%)
Other	41 (33%)	28 (51%)
Dr diagnosis of this presentation (repeated with groups AP suggested: Resp/heart/other)		
Assumption	Yes	
At least 80% of the cells exceed 5 and all have at least 1		
Test used:	Pearson's Chi squared test	
Test statistic and df	12.94 2df	
P value Asymp.sig. (2 sided)	0.002	
Conclusion	There is a significant association between Dr diagnosis and admission.	
Charlson comorbidity		
Ordinal data		
Assumption	Distribution free	
Test used:	Kendall's Tau b	
Tau-b value	0.267	

p value	0.000 p<0.05	
Conclusion	There is a significant correlation between Charlson comorbidity and admission	
DidDrNoteSOB		
Nominal data		
Number yes	85	27
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.011	
OR and 95% CIs	2.38 (1.24-4.59)	
Conclusion	There is a sig association between Did the Dr note breathlessness and admission.	
Treatments given		
Nebuliser		
Nominal data		
Number yes	30	10
Assumption	None	
Test used:	Fisher's Exact test	
p value Asymp.sig. (2 sided)	0.556	
OR and 95% CIs	1.39 (0.62-3.10)	
Conclusion	There is not a sig association between Treatment given= Nebuliser and admission	
Inhaler		
Nominal data		
Number yes	1	0
Assumption	None	

<p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p> <p>Conclusion</p>	<p>Fisher's Exact test</p> <p>1.000</p> <p>-</p> <p>There is not a sig association between Treatment given= Inhaler and admission.</p>	
<p>Antibiotics</p> <p>Nominal data</p> <p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p> <p>Conclusion</p>	<p>19</p> <p>None</p> <p>Fisher's Exact test</p> <p>0.819</p> <p>1.20 (0.47-3.05)</p> <p>There is not a significant association between Treatment given= Antibiotics and admission.</p>	7
<p>Opioids</p> <p>Nominal data</p> <p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p> <p>Conclusion</p>	<p>10</p> <p>None</p> <p>Fisher's Exact test</p> <p>0.569</p> <p>0.69 (0.24-2.01)</p> <p>There is not a significant association between Treatment given= Opioids and admission.</p>	6
<p>Benzodiazepine</p> <p>Nominal data</p>		

<p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p> <p>Conclusion</p>	<p>3</p> <p>None</p> <p>Fisher's Exact test</p> <p>0.555</p> <p>-</p> <p>There is not a significant association between Treatment given= Benzodiazapine and admission.</p>	<p>0</p>
<p>None given</p> <p>Nominal data</p> <p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p> <p>Conclusion</p>	<p>68</p> <p>None</p> <p>Fisher's Exact test</p> <p>0.406</p> <p>1.39 (0.72-2.66)</p> <p>There is not a sig association between Treatment given= None and admission.</p>	<p>25</p>
<p>Chart ECG done</p> <p>Nominal data</p> <p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p> <p>Conclusion</p>	<p>91</p> <p>None</p> <p>Fisher's Exact test</p> <p>0.463</p> <p>1.36 (0.67-2.75)</p> <p>There is not a significant association between ECG done and admission.</p>	<p>38</p>

<p>O2 given</p> <p>Nominal data</p> <p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p> <p>Conclusion</p>	<p>43</p> <p>None</p> <p>Fisher's Exact test</p> <p>0.032</p> <p>2.43 (1.11-5.29)</p> <p>There is a significant association between Oxygen given and admission.</p>	<p>10</p>
<p>Fluids given</p> <p>Nominal data</p> <p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p> <p>Conclusion</p>	<p>17</p> <p>None</p> <p>Fisher's Exact test</p> <p>0.315</p> <p>2.08 (0.67-6.49)</p> <p>There is not a significant association between ECG done and admission.</p>	<p>4</p>
<p>Blood tests</p> <p>Nominal data</p> <p>Number yes</p> <p>Assumption</p> <p>Test used:</p> <p>p value Asymp.sig. (2 sided)</p> <p>OR and 95% CIs</p>	<p>109</p> <p>None</p> <p>Fisher's Exact test</p> <p>0.000 p<0.05</p> <p>8.70 (3.98-18.87)</p>	<p>27</p>

Conclusion	There is a significant association between Blood tests done and admission.	
Arterial Blood Gas Nominal data Number yes Assumption Test used: p value Asymp.sig. (2 sided) OR and 95% CIs Conclusion	47 None Fisher's Exact test 0.003 p<0.05 3.21 (1.44-7.14) There is a significant association between ABG done and admission.	9
Chest x-ray Nominal data Number yes Assumption Test used: p value Asymp.sig. (2 sided) OR and 95% CIs Conclusion	105 None Fisher's Exact test 0.000 p<0.05 6.99 (3.28-14.93) There is a significant association between Chest X-ray done and admission.	27
Binary logistic regression		
Dependent variable	Admission/discharge	
Independent variables	Age continuous	

<p>Backwards stepwise regression Variables significantly contributing to the odds of admission:</p>	<p><i>SpO2 continuous</i> <i>Talk Spec Dr</i> <i>Self-report diagnosis heart or known history heart or known history cardiac</i> <i>Charlson</i></p> <p><i>Age p=0.001</i> <i>OR 1.041 (1.016-1.066) per year of age</i> For every year of age the odds of admission are increased a little</p> <p><i>SpO2value p=0.023</i> <i>OR 0.826 (0.701-0.974)</i> For every percentage increase in SpO2 value there is a decreased likelihood of admission</p> <p><i>Talk specialist Dr p=0.044</i> <i>OR 9.262 (1.066-80.491)</i> If talk to specialist the odds of admission increase ninefold</p> <p><i>Known History of Cardiac condition</i> <i>P=0.002</i> <i>OR=4.177 (1.680-10.386)</i> If KH cardiac the odds of admission increase fourfold</p>	
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Appendix 12 Table 17 Unifactorial analysis

Unifactorial analysis of candidate predictors with respect to patient characteristics

(Only factors significantly associated with admission are included in this table.)

Table 17 Unifactorial analysis

Candidate predictor variables	Coefficient	95% confidence intervals	Unifactorial analysis (P value)
Age	Mean diff=18yrs	12-24	P<0.05
Oxygen saturation	-1.669	-2.587 to -0.750	P<0.05
Talk to specialist doctor	OR=12.00	1.57 to 91.48	0.002
Self-reported diagnosis-heart condition	OR=2.65	1.34 to 5.24	0.005
Known history cardiac condition	OR=4.69	2.21 to 10.00	P<0.05
Known history of heart failure	OR=4.27	1.78 to 10.20	0.001
Charlson comorbidity	Tau-b=0.267	-	P<0.05

Appendix 13 Table 18 Final regression model

Final regression model investigating factors associated with admission to hospital in patients presenting to the ED due to breathlessness

Table 18 Final regression model

	OR	95% CI	P
Age	1.041	1.016-1.066	0.001
Oxygen saturation	0.826	0.701-0.974	0.023
Talked to a specialist doctor	9.262	1.066-80.491	0.044
Known History of Cardiac problems	4.177	1.680-10.386	0.002

Appendix 14 Participant information sheets

Patient Information Sheet

Breathlessness and presentation to the ED study



Invitation

We would like to invite you to take part in a research project. To help you decide, the following leaflet sets out what research is being done and how you can help.

If you are interested in taking part you will have the opportunity to discuss this further and ask about anything which is not clear. If you would like to ask any questions please contact the researcher, Ann Hutchinson (contact details at the end of this leaflet). Thank you for taking the time to read this leaflet.

What is the purpose of the study?

The aim of the study is to understand more about how breathlessness affects the daily lives of patients and the friends/relatives who care for them. In particular, we know that patients can experience episodes of worse breathlessness that may lead to visits to the emergency department at the hospital. We want to get a better understanding of those episodes and the experience at the emergency department. This will help us provide better care for breathless patients in the future.

Why have I been invited?

You have been invited because you are living with breathlessness and you recently attended the emergency department at Hull Royal Infirmary and kindly filled in one of our surveys.

Do I have to take part?

No. It is up to you to decide if you want to take part and your decision will not affect the standard of care you receive. Once we explain the study and answer any questions, if you do decide to participate you will be asked to indicate this by signing a consent form.

It is important to note that **you are free to leave the study at any time**, even after it has started, without giving a reason, and without affecting your future care.

What will happen to me if I take part?

If you agree to take part I will interview you about your breathlessness for about 1 hour. If you have a friend/relative who helps care for you and he/she is willing to participate as well, I would like to interview him/her with you at the same time at a time and place that is convenient to you both. However, if that is not possible for any reason and you or they would prefer to be interviewed alone, then that can be arranged. The interview will be audio recorded.

Expenses and payments

There is no payment for taking part in the study. We are able to reimburse travel expenses, so that you do not incur additional costs by helping us.

What are the possible disadvantages and risks of taking part

It is possible that the interview with the researcher may raise issues which make you feel uncomfortable, or which you do not wish to discuss. I will do my best to avoid this, but if it does occur you do not have to talk about these issues and can stop the interview at any time.

The discussion may make you think about the future, or about care needs which had not been talked about before. If this is the case and you wish to discuss them further, outside of the study, we will help you to do this by putting you in touch with your usual care team.

What are the possible benefits of taking part?

You will be helping to improve our knowledge of the conditions we are studying and the services available in future to others, but there are no direct health benefits for you in taking part.

Will my taking part in the study be kept confidential?

All the information you give is strictly confidential. We will not share your personal information with anybody outside of the study group, including your carer or relative if you wish to be interviewed alone.

All medical staff must practice within the law and General Medical Council (GMC) guidelines. In the very unlikely event that you disclose information that we believe places you or others at risk, we have a professional and legal duty to share this with the relevant agencies, such as the Safeguarding Adults Team. This is the only circumstance in which confidentiality would be broken.

What will happen if I do not want to carry on with the study?

If you wish to leave the study, you can do so at any time and this will not affect any future treatments. At interview you will be asked to give your written consent to participation. You can decide not to continue at any point.

What will happen to the results of the research study?

The results of the study will be published in medical journals and sent to relevant patient support organisations. If you wish we will send you a summary of the findings at the end of the study.

What if there is a problem?

If you have a concern about any aspect of this study, you may wish to speak to Professor Miriam Johnson, who is leading this project and who will do her best to answer your questions (contact number: 01482 463482).

If you remain unhappy and wish to complain formally, you may do this through the normal National Health Service complaints procedure which you can access via the practice manager at your GP practice.

In the unlikely event something should go wrong and you are harmed due to someone's negligence, then you may have grounds for a legal action for compensation against the University of Hull, but you may have to pay your legal costs.

Who is organising the research?

The study has been organised and is being conducted by Hull York Medical School. The members of the research team are: Professor Miriam Johnson, Dr Alastair Pickering, Dr Julie

Seymour and Ann Hutchinson. The University of Hull has funded the study. Approval has been given by the NHS Ethical committee and NHS Research and Development departments.

Thank you for taking the time to read this information sheet. We are very grateful to you for considering participation in this study.

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Carer Information Sheet

Breathlessness and presentation to the ED study



Invitation

We would like to invite you to take part in a research project. To help you decide, the following leaflet sets out what research is being done and how you can help.

If you are interested in taking part you will have the opportunity to discuss this further and ask about anything which is not clear. If you would like to ask any questions please contact the researcher, Ann Hutchinson (contact details at the end of this leaflet). Thank you for taking the time to read this leaflet.

What is the purpose of the study?

The aim of the study is to understand more about how breathlessness affects the daily lives of patients and the friends/relatives who care for them. In particular, we know that patients can experience episodes of worse breathlessness that may lead to visits to the emergency department at the hospital. We want to get a better understanding of those episodes and the experience at the emergency department. This will help us provide better care for breathless patients in the future.

Why have I been invited?

You have been invited because you are caring for someone living with breathlessness who recently attended the emergency department at Hull Royal Infirmary and kindly filled in one of our surveys.

Do I have to take part?

No. It is up to you to decide if you want to take part and your decision will not affect the standard of care your friend/relative receives, or their ability to participate in the study if they choose. Once we explain the study and answer any questions, if you do decide to participate you will be asked to indicate this by signing a consent form.

It is important to note that **you are free to leave the study at any time**, even after it has started, without giving a reason, and without affecting your future care.

What will happen to me if I take part?

If you agree to take part I will interview you and the person you care for about their breathlessness and their recent visit to the emergency department for about 1 hour. I would like to interview you both at the same time if you agree and I would like to make an audio recording of the interview at a time and place that is convenient to you both. However, if that is not possible for any reason and you would prefer to be interviewed alone, then that can be arranged.

Expenses and payments

There is no payment for taking part in the study. We are able to reimburse travel expenses, so that you do not incur additional costs by helping us.

What are the possible disadvantages and risks of taking part

It is possible that the interview with the researcher may raise issues which make you feel uncomfortable, or which you do not wish to discuss. I will do my best to avoid this, but if it does occur you do not have to talk about these issues and can stop the interview at any time.

The discussion may make you think about the future, or about care needs which you have not talked about before. If this is the case and you wish to discuss them further, outside of the study, we will help you to do this through available support services.

What are the possible benefits of taking part?

You will be helping to improve our knowledge of the conditions we are studying and the services available in future to others, but there are no direct health benefits for you (or the person you care for) in taking part.

Will my taking part in the study be kept confidential?

All the information you give is strictly confidential. We will not share your personal information with anybody outside of the study group.

All medical staff must practice within the law and General Medical Council (GMC) guidelines. In the very unlikely event that you disclose information that we believe places you or others at risk, we have a professional and legal duty to share this with the relevant agencies, such as the Safeguarding Adults Team. This is the only circumstance in which confidentiality would be broken.

What will happen if I do not want to carry on with the study?

If you wish to leave the study, you can do so at any time and this will not affect any future treatments for your friend/relative or yourself. At interview you will be asked to give your written consent to participation. You can decide not to continue at any point.

What will happen to the results of the research study?

The results of the study will be published in medical journals and sent to relevant patient support organisations. If you wish we will send you a summary of the findings at the end of the study.

What if there is a problem?

If you have a concern about any aspect of this study, you may wish to speak to Professor Miriam Johnson, who is leading this project and who will do her best to answer your questions (contact number: 01482 463482).

If you remain unhappy and wish to complain formally, you may do this through the normal National Health Service complaints procedure which you can access via the practice manager at your GP practice.

In the unlikely event something should go wrong and you are harmed due to someone's negligence, then you may have grounds for a legal action for compensation against the University of Hull, but you may have to pay your legal costs.

Who is organising the research?

The study has been organised and is being conducted by Hull York Medical School. The members of the research team are: Professor Miriam Johnson, Dr Alastair Pickering, Dr Julie Seymour and Ann Hutchinson. The University of Hull has funded the study. Approval has been given by the NHS Ethical committee and NHS Research and Development departments.

Thank you for taking the time to read this information sheet. We are very grateful to you for considering participation in this study.

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HCP Information Sheet

Breathlessness and presentation to the ED study



Invitation

We would like to invite you to take part in a research project. To help you decide, the following leaflet sets out what research is being done and how you can help.

If you are interested in taking part you will have the opportunity to discuss this further and ask about anything which is not clear. If you would like to ask any questions please contact the researcher, Ann Hutchinson (contact details at the end of this leaflet). Thank you for taking the time to read this leaflet.

What is the purpose of the study?

The aim of the study is to understand more about how breathlessness affects the daily lives of patients and the friends/relatives who care for them. In particular, we know that patients can experience episodes of worse breathlessness that may lead to visits to the emergency department at the hospital. We want to get a better understanding of those episodes and the experience at the emergency department. This will help us provide better care for breathless patients in the future.

Why have I been invited?

You have been invited because you have been nominated by your patient as a key person in their care. Your patient is living with breathlessness and recently attended the emergency department at Hull Royal Infirmary. He/she filled in one of our

surveys and also agreed to be interviewed. I would like to obtain further information from your perspective about the patient and the effect breathlessness has on their life.

Do I have to take part?

No. It is up to you to decide if you want to take part. Once we explain the study and answer any questions, if you do decide to participate you will be asked to indicate this by signing a consent form.

It is important to note that **you are free to leave the study at any time**, even after it has started, without giving a reason.

What will happen to me if I take part?

If you agree to take part I will interview you about your patient's breathlessness for no longer than 1 hour at a time and place that is convenient to you. The interview will be audio recorded.

Expenses and payments

Healthcare professionals will be given a £25 Waterstones voucher by way of thanks for their participation.

What are the possible disadvantages and risks of taking part

We do not anticipate any risk to the health care professional.

It is possible that the interview with the patient may raise issues which may make them feel uncomfortable, or do not wish to discuss. We have reassured them that they do not have to talk about these, and can stop the discussion at any time.

The discussion may also make them think about their future, or about care needs which had not been talked about before. Patient participants will be aware that they can discuss these issues further outside the study with you and your team.

What are the possible benefits of taking part?

You will be helping to improve our knowledge of the conditions we are studying and the services available in future to others.

Will my taking part in the study be kept confidential?

All the information you give is strictly confidential. Your personal details will not appear anywhere.

What will happen if I do not want to carry on with the study?

If you wish to leave the study, you can do so at any time. You do not have to give a reason for doing so.

What will happen to the results of the research study?

The results of the study will be published in medical journals and sent to breathlessness patient organisations. If you wish we will send you a summary of the findings at the end of the study.

What if there is a problem?

If you have a concern about any aspect of this study, you may wish to speak to Professor Miriam Johnson, who is leading this project and who will do her best to answer your questions (contact number: 01482 463482).

If you remain unhappy and wish to complain formally, you may do this through the normal National Health Service complaints procedure which you can access via the practice manager at your GP practice.

In the unlikely event something should go wrong and you are harmed due to someone's negligence, then you may have grounds for a legal action for compensation against the University of Hull, but you may have to pay your legal costs.

Who is organising the research?

The study has been organised and is being conducted by Hull York Medical School. The members of the research team are: Professor Miriam Johnson, Dr Alastair Pickering, Dr Julie Seymour and Ann Hutchinson. The University of Hull has funded the study. Approval has been given by the NHS Ethical committee and NHS Research and Development departments.

Thank you for taking the time to read this information sheet. We are very grateful to you for considering participation in this study.

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Appendix 15 Participant consent form

CONSENT FORM

Breathlessness and presentation to the ED study



Patient Identification Number for this study:

Title of Project: **Breathlessness and presentation to the ED** Name of lead researcher:
Ann Hutchinson

Please
initial all boxes

1. I confirm that I have read and understand the information sheet dated 24/8/13 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily and I agree to participate in the study.	<input type="checkbox"/>
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	<input type="checkbox"/>
3. I agree to the interview being audio recorded.	<input type="checkbox"/>
4. I agree that direct quotes from my interview may be published, provided I cannot be identified.	<input type="checkbox"/>
5. I understand that relevant sections of my medical notes and data collected during this study may be looked at by responsible individuals from the research team, from regulatory authorities or from the NHS trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	<input type="checkbox"/>
6. I agree that you may notify my GP that I am taking part in this study.	<input type="checkbox"/>
7. I would like a copy of the summary results of the study.	<input type="checkbox"/>

Name of participant Date Signature

OR

Name of witness to verbal consent Date Signature

AND

Name of person taking consent Date Signature

Appendix 16 Topic guides

Semi-structured interview-Patient

Introduction to researcher and project

- University of Hull/HYMS, independent of ED and HRI
- Information sheets for both patient
- Consent forms to sign
- Turn recorder on!

First I'd like to ask you a little about your health

1 Please can you tell me a little about your health and how it affects your life?

- *(No right or wrong answers, I want to hear your story...)*

2 How has breathlessness changed you and your life?

- positive/negative-*health within illness*
- Social/ relationships/ identity/ finances/ work
- physical/ psychological/ social/ spiritual
- coping strategies
- What brings on your breathlessness?

3 When you become breathless what goes through your mind?

- worried, panicky, depressed, impending death
- Frustration at limitations and loss of previous function
- How do you deal with these thoughts/feelings?

3a Can you describe what it feels like when you are very breathless?

4 What do you think people can do to help with their breathlessness?

- behaviour change
- coping mechanisms
- causes of condition [general]/personal

5 What do you do to help with your breathlessness?

- what helps/usual day to day
- bad attack? what do? How feel after that? How manage to avoid going to hospital?
- avoidance
- medication any good or not?
- lifestyle – smoker/ ex-smoker?/ exercise/
- breathing techniques/position/pacing
- Do you feel your strategies are working?

5a When you see an HCP do talk about your breathlessness? What kinds of things do you discuss? TI?

And now I'd like to ask you about your recent hospital visit

6 Please tell me about your recent visit to the emergency department:

- How did you come to be there?
- How was your experience from start to finish?
- Good/ bad aspects / hopes / expectations
- Staff attitude to need for visit? stigma?/ listened to? EI? low grade insults? involved in treatment decisions
- decision to go/pattern in preceding days
- how long did you feel as bad as you did when you decided to come?
- looking back how do you feel about your visit- worth it? do it again?

(Q7 is for some patients only, identified from survey)

7 I understand you've been to the emergency department before when your breathlessness has been bad:

- How was your experience from start to finish?
- Good/bad aspects /hopes /how feel-worth it? /staff attitude-stigma/
- How did you come to be there? decision to go - how made/ who with?
- pattern in preceding days

8 Have you ever decided *not* to go to hospital when you were very breathless?

Can you tell me a bit about that time?

- How did it go?
- How come to decision?
- Right decision or not?
- If things could be different what would help you not to go?

9 From your recent hospital visit can you suggest how they could improve the care of breathless people?

Thank you, now let's think about your health in the future a little

10 How do you see the next few weeks/months going?

- Anything you are feeling worried about?
- Plans/ negative/ positive/ authentic Heidegger?
- Idea of prognosis?
- Anything you are hoping for?
- Have you made plans for your funeral?
- Who do you discuss your health and future with?
- Would you like to discuss your worries with anyone?
- Who helps you with your condition?
- How do they help you?
- Is there one healthcare worker you find most helpful and ***in what way?***
- Would you be happy for me to contact them to talk about your care with them please?

(Obtain details.)

and is there anything you wouldn't be happy for me to share with your HCP?

11 What services would you like to see for breathless people?

12 And finally is there anything else about your experience you'd like to share with me?

Thank you for taking part!

- Thank you for helping us understand more about your situation and how to improve the services offered
- Will send you a summary of the results (if requested on consent form)
- Need GP's name and address

- Remember I will be telling your GP you have been interviewed (if consented to) and if you are upset/need advice/need to talk more, then your GP/specialist nurse will be able to discuss it further...

GP Name

GP address

Semi-structured interview-Patient and Carer

Introduction to researcher and project

- University of Hull/HYMS, independent of ED and HRI
- Information sheets for both patient and carer
- Consent forms to sign
- Turn recorder on

First I'd like to ask you a little about your health

1 Please can you tell me a little about your health and how it affects your life/lives?

- *(No right or wrong answers, I want to hear your story...)*

2 How has breathlessness changed you and your life/lives?

- positive/negative-*health within illness*
- Social/ relationships/ identity/ finances/ work
- physical/ psychological/ social/ spiritual
- coping strategies
- What brings on your breathlessness?
- Carer's perspective

3 When you become breathless what goes through your mind?

- worried, panicky, depressed, impending death
- Frustration at limitations and loss of previous function
- How do you deal with these thoughts/feelings?
- Carer perception-how affecting carer and how does that affect patient?

3a Can you describe what it feels like when you are very breathless?

4 What do you think people can do to help with their breathlessness?

- behaviour change
- coping mechanisms
- causes of condition [general]/personal

- Carer's opinion?

5 What do you do to help with your breathlessness?

- what helps/usual day to day
- bad attack? what do? How feel after that? How manage to avoid going to hospital?
- avoidance
- medication any good or not?
- lifestyle – smoke/exercise
- breathing techniques/position/pacing
- Do you feel your strategies are working?
- carer's opinion

5a When you see an HCP do talk about your breathlessness? What kinds of things do you discuss? TI?

And now I'd like to ask you about your recent hospital visit

6 Please tell me about your recent visit to the emergency department:

- How did you come to be there?
- How was your experience from start to finish?
- Good/ bad aspects / hopes / expectations
- Staff attitude to need for visit? stigma?/ listened to? EI? low grade insults? involved in treatment decisions
- decision to go/pattern in preceding days
- how long did you feel as bad as you did when you decided to come?
- looking back how do you feel about your visit- worth it? do it again?

(Q7 is for some patients only, identified from survey)

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- How was your experience from start to finish?
- Good/bad aspects /hopes /how feel-worth it? /staff attitude-stigma/
- How did you come to be there? decision to go - how made/ who with?
- pattern in preceding days

8 Have you ever decided *not* to go to hospital when you were very breathless?

Can you tell me a bit about that time?

- How did it go?
- How come to decision?
- Right decision or not?
- If things could be different what would help you not to go?

9 From your recent hospital visit can you suggest how they could improve the care of breathless people?

Thank you, now let's think about your health in the future a little

10 How do you see the next few weeks/months going?

- Anything you are feeling worried about?
- Plans/ negative/ positive/ authentic Heidegger?
- Idea of prognosis?
- Anything you are hoping for?
- Who helps you with your condition?
- How do they help you?
- Who do you discuss your health and future with?
- Would you like to discuss your worries with anyone?
- Is there one healthcare worker you find most helpful and ***in what way?***
- Would you be happy for me to contact them to talk about your care with them please

(Obtain details.)

and is there anything you wouldn't be happy for me to share with your HCP?

11 What services would you like to see for breathless people?

12 And finally is there anything else about your experience you'd like to share with me?

Thank you for taking part!

- Thank you for helping us understand more about your situation and how to improve the services offered

- Will send you a summary of the results (if requested on consent form)
- Need GP's name and address
- Remember I will be telling your GP you have been interviewed (if consented to) and if you are upset/need advice/need to talk more, then your GP/specialist nurse will be able to discuss it further...

GP Name

GP address

Semi-structured interview with healthcare professional

- Introduction to researcher and project
- Information sheets for HCP-any Qs? (Sent with introductory letter/email)
- Consent form to sign

Opening Qs

1 Can you tell me a bit about your patient [name] and his/her use of healthcare services?

- consults regularly or not
- attitude to their illnesses
- expectations
- how do you feel about treating him/her?

2 How do you think breathlessness has affected their lives?

- difficulties
- positive changes
- coping strategies
- social life
- roles
- relationships
- roles, identity
- finances
- personal plans
- work
- effect on carer

Thinking about breathlessness

3 What do you think people should do to manage their breathlessness?

- changing behaviour
- reducing risk
- coping mechanisms

3a How do you think breathlessness can be treated?

4 What strategies do you think [name] uses to manage his/her breathlessness?

- what helps?
- bad attacks?
- day to day?
- any situations they avoid?
- adhere to medication
- continue to exercise
- stop smoking

5 How do you feel [name] is coping?

- in general
- during bad attacks
- Does [name] become worried, panicky or depressed when they become breathless?

6 How do you feel their carer [name] copes with [name] being breathless?

- in general
- during bad attacks
- contribution of their anxiety/panic/depression
- Does [name] become worried, panicky or depressed when [name] becomes breathless?

ED Visit

7 As you may know your patient [name] recently attended the ED on [date]

How did you find out?

- From ED
- From patient/carer
- my letter

8 What do you know about the days building up to their attendance?

- Did they use primary care? If so how?
- Was it a sudden decision or was there a long build up?
- what do you think about their attendance? avoidable/appropriate

9 How do you think [name] came to the decision to go to the ED?

- Who was involved in the decision?
- HCP, patient, carer, others?

(Q10 for some only, identified from survey)

10 I understand [name] has been to the ED before when he/she was breathless:

What do you know about the days building up to their attendance?

- Who was involved in the decision at that time(s)?
- Did they use primary care? If so how?
- Was it a sudden decision or was there a long build up?
- what do you think about their attendance? avoidable/appropriate

10a What has happened since their ED pres and my interview with them on....?

11 Are you aware of any times when [name] felt very breathless but decided not to go to the hospital?

- Why do you think they didn't go that time?
- What was different on that occasion?
- what do you think about their non-attendance? avoidable/appropriate

12 If things could be different what would help [name] not go to the ED?

- What care do you think should be available for [name]?
- How could [name] do things differently?

12a How have changes to how GPs worked affected your care of breathless patients?

13 What 3 services/improvements in present services would you like to see for people with breathlessness in this area?

Thoughts for the future

14 How do you see the next few weeks / months going for [name]?

15 As far as you know, who does [name] discuss things that really matter to them about their health and future with?

- yourself
- health professionals
- family, friends
- spiritual leader
- no one

16 What discussion have you had with [name] about their condition?

- Management: medication, rehabilitation...
- Psychological aspects: management?
- Prognosis
- Palliative care
- Advance Care Planning
- How do you feel about treating [name] and his/her breathlessness?

Finishing off

17 Is there anything else you'd like to tell me about [name] and their breathlessness?

Thank you for taking part!

- Thank you for helping us understand more about your patient
- Will send you a summary of the results (if requested on consent form)
- payment form