

Title page

Living with breathlessness: a systematic literature review and qualitative synthesis

Ann Hutchinson, Natalie Barclay-Kling, Kathleen Galvin, Miriam J Johnson

Affiliations: AH, NBK and MJ University of Hull
KG University of Brighton

Corresponding author

Ann Hutchinson

3rd Floor
Allam Medical Building
HYMS
University of Hull
Cottingham Rd
HULL
HU6 7RX

hyah6@hyms.ac.uk

Take home message

Breathing Space: A conceptual framework for patients' coping, help-seeking and clinicians' response to breathlessness

Short title: Breathing Space: a qualitative synthesis

Abstract

Question: What is the experience of people living with breathlessness due to medical conditions, those caring for and those treating them, with regard to quality of life and the nature of clinical interactions?

Methods: Electronic databases (Ovid MEDLINE, Embase, CINAHL Plus, PsycINFO) were searched (1987 to October 2017; English language), for qualitative studies exploring the experience of chronic breathlessness (patients, carers, clinicians). Two independent reviewers screened titles, abstracts and papers retrieved against inclusion criteria. Disagreements were resolved with a third reviewer. Primary qualitative data were extracted and synthesised using thematic synthesis.

Results: Inclusion and synthesis of 101/2,303 international papers produced four descriptive themes: 1) widespread effects of breathlessness, 2) coping, 3) help-seeking behaviour, and 4) clinicians' responsiveness to the symptom of breathlessness. The themes were combined to form the concept of "Breathing Space", to show how engaged coping and appropriate help-seeking (patient) and attention to symptom (clinician) helps maximise the patient's quality of living with breathlessness.

Answers: Breathlessness has widespread impact on patient and carer and affects Breathing Space. The degree of Breathing Space is influenced by interaction between the patient's coping style, their help-seeking behaviour and their clinician's responsiveness to breathlessness itself in addition to managing the underlying disease.

Introduction

Breathlessness is a common and distressing symptom of many long-term cardiorespiratory conditions and cancers (1-3) which are prevalent globally.(4) A body of qualitative work describes its serious and widespread impact on the lives of patients and their families, and the challenges for their clinicians.(5-11) Despite optimal treatment for the underlying condition, breathlessness often persists and results in disability – recently described as chronic breathlessness syndrome. (12) Such breathlessness requires management, yet remains largely invisible to both the public and clinicians who may feel that nothing further can be done. This is partly due to its slow onset in many conditions so breathlessness is seen as “normal”; intentional “hiding” of the symptom; a stoical response to breathlessness by patients, and a lack of symptom attention from clinicians. (13)

An understanding of patient and family experience, and clinicians’ response to this symptom, is important to inform relevant clinical practice. Although qualitative studies are by nature small and not intended to be generalisable, a systematic review and synthesis of primary qualitative studies can create a body of evidence helpful to develop theory and inform practice.(14)

Other than one published in 2007 (8) which included 22 studies, qualitative systematic reviews (5-7, 9-11) focus on a single medical condition and are primarily from the patient’s perspective. The aim of this systematic review and qualitative synthesis is to explore the now large body of qualitative research on the experience of and response to breathlessness due to a variety of medical conditions, by those living with it, those who care for them and clinicians who treat them, with regard to informing directions for practice for maximising quality of life and optimising clinical interactions.

Methods

Design

A systematic search of qualitative studies was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) principles.(15)

Search strategy

The search strategy (Table 1) was guided by search terms, derivatives and related Medical Subject Headings (MeSH) terms for breathlessness (exposure); patient, carer and clinician (population); and experience, interaction, help-seeking, coping and beliefs (outcomes) combined with a validated filter for qualitative research (design).(16)

Table 1: Search strategy (Medline example)

<u>Design</u>	
1	interview*
2	qualitative
3	finding*
<u>Exposure</u>	
4	breathless*
5	dyspn* MeSH Dyspnea exp
6	(short* adj 3 breath)
<u>Population</u>	
7	patient* MeSH patient-physician relations
8	carer* MeSH caregivers
9	health* adj2 profession*
10	health personnel MeSH exp.health personnel
<u>Outcome</u>	
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

Medline, PsycINFO, Embase and CINAHL databases were searched between January 1987 and October 2017 (English language). Reference lists of reviews were hand searched and experts contacted. Titles, abstracts and retrieved papers were independently reviewed by AH, NBK against stated eligibility criteria. Any disagreements were resolved in discussion with MJ.

Studies were included if they reported on the experience of breathlessness due to an underlying medical condition from the perspective of patients, carers or clinicians and presented primary empirical qualitative data. Studies were excluded if the breathlessness was due to asthma, obesity, or in a restricted population e.g. post-transplant.

Quality appraisal

The quality of included studies was assessed using the Qualitative Assessment and Review Instrument (QARI) Critical appraisal checklist for Interpretive and Critical research; all were assessed by AH and a random five paper sample by NBK.(17)

Data extraction

A data extraction tool was developed to extract contextual information about each study and all primary data (direct participants' quotations). Data were extracted from all papers by AH, with independent data extraction from a random five paper sample by NBK.

Analysis

The synthesis was reported in accordance with the Enhancing Transparency in Reporting the synthesis of Qualitative research (ENTREQ) guidance.(18)

Data were synthesised using Thematic synthesis (19) and the principles of thematic analysis(20) whereby the context of each study is taken into account, whilst aiming to produce a generalisable synthesis.(21) The included studies were heterogeneous in terms of their research aims and populations studied, so only primary quotes from participants were extracted and coded.

The synthesis was performed in three stages: the first stage was line-by-line coding of the primary research findings of each study on the experience of breathlessness by AH. These codes were then refined, and through an inductive reasoning process organised into themes that described experience (descriptive themes). (19) The analytical theme that describes the concept of Breathing Space emerged following a process of phenomenologically orientated reflection on the descriptive themes (22)involving discussion and interpretation between AH, MJ and KG to provide a broad understanding of the experience of breathlessness and interaction with clinicians. AH has a non-clinical psychology background, NBK is a medical student, MJ is a professor of palliative care and KG is a nursing academic and qualitative researcher. All will have brought their previous experiences to bear in interpretation, but transparency of the method, independent selection of and extraction from primary studies and group discussion provides rigour to the review and synthesis process. The data were managed using NVivo 2012, 10, Victoria.

Results

Selected studies

The database searches identified 2,303 papers, with an additional 50 papers identified through other sources. These papers were independently screened and after discussion between AH, NBK and MJ, 101 full papers were included (Table 2).

<<Insert figure 1 PRISMA flow diagram here please>>

Participants were patients in 68 studies, clinicians in 5 studies and family carers in 10 studies. Additionally there were 18 studies with a mix of patients, carers and

clinicians. The conditions explored in the 101 studies were as follows: COPD (76), IPF (3), Heart failure (5), cancer (7), chronic bronchitis (1) and mixed causes (9). In keeping with the qualitative methods used, the average sample size was 20 (range 4 to 60). Included studies were from a variety of cultural settings, spread across four continents, including both low and high income countries.

Table 2: Characteristics of included studies

Author	Year	Setting	Participants	Theoretical Approach
Aasbo	2016 (23)	Norway	Carers of patients with COPD (4m, 6f)	Thematic analysis
Aasbo	2017 (24)	Norway	Carers of patients with COPD (4m, 6f)	Thematic analysis
Adams	2006 (25)	Denmark, The Netherlands and UK	COPD Patients (16m, 7f)	Grounded Theory
Ahmadi	2014 (26)	Sweden	COPD, CHF, Aortic Stenosis, Anxiety and Asthma Patients – 7m, 9f (disease split unspecified)	Unspecified
Apps	2014 (27)	UK	COPD Patients (6m, 9f)	Unspecified
Arnold	2006 (28)	UK	COPD Patients (9m, 11f)	Unspecified
Avsar	2010 (29)	Turkey	COPD Patients (11m, 3f)	Phenomenological
Bailey	2001 (30)	Canada	COPD 'family nurse units' (Patient, 2 family members, 1 nurse) 10 family nurse units	Narrative Analysis
Bailey	2004 (31)	Canada	Clinicians (10, gender unspecified)	Ethnographic Narrative
Bailey	2004 (32)	Canada	COPD 'family nurse units' (Patient, 2 family members, 1 nurse)	Narrative Analysis

			10 family nurse units	
Bajwah	2013 (33)	UK	Progressive idiopathic fibrotic interstitial lung disease patients (5m 3f) and 4 spouses (3f, 1m)	Unspecified
Barnett	2005 (34)	UK	COPD Patients (10, gender unspecified)	Phenomenological
Bergs	2002 (35)	Iceland	Carers of patients with COPD (0m, 6f)	Phenomenological
Booth	2003 (36)	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 (37)	UK	COPD, Heart Failure, Cancer (1 colon, 1 myelofibrosis), Other (interstitial lung disease) – 10 patients (4m, 6f) and 10 Carers (gender unspecified)	Unspecified
Bove	2016 (38)	Denmark	Carers of patients with COPD (9m, 13f)	Framework method
Boyle	2009 (39)	USA	Carers of patients with COPD (0m, 10f)	Phenomenological-Hermeneutic
Brandt	2013 (40)	USA	COPD Patients (19m, 9f)	Naturalistic method
Caress	2010 (41)	UK	COPD Patients (8m, 6f) Carers (9f, 3m)	Unspecified
Chang	2016 (42)	Taiwan	COPD patients (12m, 2f)	Phenomenological

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Cicutto	2004 (43)	Canada	COPD Patients (23m, 19f)	Unspecified
Clancy	2009 (44)	UK	COPD Patients (6m, 4f) Carers (2m, 5f)	Longitudinal Heideggerian
Cooney	2013 (45)	Ireland	COPD Patients (15m, 11f)	Straussian grounded theory
Dickenson	2009 (46)	UK	COPD Patients (12, gender unspecified)	Framework approach
Duck	2015 (47)	UK	IPF patients (7m, 10f) and their carers (2m, 4f)	Framework analysis
Dunger	2015 (48)	Germany	COPD patients (4m, 6f) and Lung cancer patients (5m, 3f)	Framework analysis
Edmonds	2005 (49)	UK	Heart Failure Patients (20m, 7f)	Unspecified
Ek	2008 (50)	Sweden	COPD Patients (3m, 5f)	Phenomenological
Ek	2010 (51)	Sweden	COPD Patients (1m, 3f)	Phenomenological- Hermeneutic
Ek	2011 (52)	Sweden	COPD patients and carers (4 couples)	Phenomenological- Hermeneutic
Elkington	2004 (53)	UK	Carers of patients with COPD (7m, 18f)	Unspecified

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Elofsson	2004 (54)	Sweden	COPD Patients (4m, 2f)	Phenomenological-Hermeneutic
Figueiredo	2016 (55)	Portugal	Carers of patients with COPD (12m)	Thematic analysis
Fotokian	2017 (56)	Iran	COPD patients (15) , their carers (4) and clinicians (5) (Gender unspecified)	Grounded Theory
Fraser	2006 (57)	USA	COPD Patients (5m, 5f)	Phenomenological-Hermeneutic
Gabriel	2014 (58)	Portugal	COPD patients (16m, 4f) and their carers (2m, 18f)	Thematic analysis
Gardiner	2009 (59)	UK	COPD patients (13m, 8f)	Thematic analysis
Genoe	2017 (60)	Canada	COPD patients (6m, 2f)	Interpretive Phenomenological Analysis
Goldman	2016 (61)	USA	COPD patients (16m, 23f)	Iterative immersion/crystallization qualitative analysis process
Gott	2009 (62)	UK	39 clinicians working with COPD patients	Unspecified
Guthrie	2001 (63)	UK	COPD Patients (8m, 12f)	Unspecified

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Gysels	2008 (64)	UK	COPD Patients (7m, 11f)	Grounded Theory
Gysels	2009 (65)	UK	Carers (all female n=15) Various conditions - 1xLung cancer, 2xCOPD, 3xHeart Failure, 8xMND, 1xPalliative Care (unspecified)	Grounded Theory
Gysels	2009 (66)	UK	COPD Patients (7m, 11f)	Grounded Theory
Gysels	2010 (67)	UK	COPD Patients (7m, 11f)	Unspecified
Gysels	2011 (68)	UK	Patients – various conditions Cancer – unspecified (5m, 5f), COPD (5m, 9f), Heart Failure (7m, 3f), MND (9m, 1f)	Unspecified
Habraken	2008 (69)	The Netherlands	COPD Patients (8m, 3f)	Unspecified
Hallas	2012 (70)	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 (71)	UK	COPD Patients (12m, 4f)	Interpretive Phenomenological

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Hasson	2008 (72)	Northern Ireland	COPD Patients (10m, 3f)	Unspecified
Henoch	2008 (73)	Sweden	Lung Cancer Patients (11m, 9f)	Unspecified
Jeng	2002 (74)	Taiwan	COPD Patients (7m, 2f)	Constant comparison and content analysis
Jones	2004 (75)	UK	COPD Patients (8m, 8f)	Unspecified
Kanervisto	2007 (76)	Finland	COPD Patients (5, gender unspecified) and spouses (4, gender unspecified)	Content Analysis
Kerr	2010 (77)	UK	COPD Patients (6m, 3f)	Grounded Theory
Korpershoek	2016 (78)	The Netherlands	COPD Patients (8m, 7f)	Grounded Theory
Lai	2007 (79)	China	Lung Cancer Patients (11, gender unspecified)	Content Analysis
Leidy	1999 (80)	USA	COPD Patients (6m, 6f)	Phenomenological
Lewis	2014 (81)	UK	COPD patients (25, gender unspecified)	Phenomenological
Lowey	2013 (82)	USA	COPD and Heart Failure patients – proportion unspecified (9m, 11f)	Unspecified

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Maguire	2014 (83)	UK	Lung cancer patients (4m, 6f)	Interpretive Phenomenological Analysis
Marx	2016 (84)	Germany	COPD patients (10m, 7f)	Grounded theory
Mosher	2015 (85)	USA	21 Lung cancer patients (10m, 11f) and 21 carers (6m, 15f)	Thematic analysis
Nicholls	2003 (86)	New Zealand	COPD Patients (5m, 5f)	Phenomenological
Nicolson	2000 (87)	UK	Chronic Bronchitis Patients (10m, 10f)	Unspecified
Nicolson	2003 (88)	UK	COPD Patients (10m, 10f)	Symbolic interactionist theoretical framework
O'Driscoll	1999 (89)	UK	Lung Cancer Patients (30m, 22f) 32 non-small cell, 13 small cell, 4 mesothelioma, 3 suspected	Content Analysis
Oliver	2001 (90)	UK	COPD Patients (16 – gender unspecified)	Phenomenological
O'Neill	2002 (91)	USA	COPD Patients (0m, 21f)	Common Sense Concept
Overgaard	2016 (92)	Denmark	IPF patients (15m, 10f) and their carers (24)	Framework method
Paap	2014	The Netherlands	COPD patients (13m, 8f)	Grounded Theory

	(93)			
Pinnock	2011 (94)	UK	COPD Patients (14m, 7f) Carers (13 informal, 18 professional)	Unspecified
Roberts	1993 (95)	Canada	Cancer patients (4m, 6f), Clinicians (12 – all nurses, gender unspecified) Cancers – Lung (4), Breast (2), Throat (1), Stomach (1), Prostate (1) Kidney (1)	Unspecified
Robinson	2005 (96)	UK	COPD Patients (6m, 4f)	Qualitative Phenomenological
Ryan	2009 (97)	Ireland	Heart Failure Patients (6m, 3f)	Phenomenological
Seamark	2004 (98)	UK	COPD patients and carers (Patients 9m, 1f and 8 carers)	IPA
Shipman	2009 (99)	UK	COPD Patients (9m, 7f)	Unspecified
Simon	2016 (100)	Germany	CHF patients, COPD patients, lung cancer patients and MND patients (51 in total: 30m, 21f)	Framework analysis
Simpson	2010 (101)	Canada	Carers of patients with COPD (3m, 11f)	Attride-Stirling Thematic Network
Small	2012 (102)	UK	COPD Patients (8 Devon, 13 Barnsley – gender unspecified) Clinicians (19 Devon, 20 Barnsley – gender unspecified)	Unspecified
Spence	2008 (103)	Ireland	Clinicians (7m 16f)	Unspecified

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Spence	2008 (104)	Ireland	Carers of patients with COPD (1m, 6f)	Thematic analysis
Strang	2014 (105)	Sweden	COPD patients (15m, 16f)	Manifest and latent content analysis
Stridsman	2015 (106)	Sweden	COPD patients (5m, 5f)	Latent qualitative content analysis
Stull	1999 (107)	USA	Heart Failure Patients (17m, 4f)	Grounded Theory
Taylor	2017 (108)	UK	Heart failure patients (11m, 5f)	Framework Method
Wainwright	2017 (109)	Uruguay	COPD patients (23m, 14f)	Sensorial medical anthropology
Walthall	2017 (110)	UK	Heart failure patients (15m 10f)	Thematic analysis
Walters	2008 (111)	Australia	COPD Patients (5m, 9f) Clinicians (19 GPs – gender unspecified)	Unspecified
Willgoss	2012 (112)	UK	COPD Patients (5m, 9f)	Thematic Network Analysis
Williams, S	1993 (113)	UK	COPD Patients (24 – gender unspecified) and their families	Sociological Approach
Williams, V	2007	UK	COPD Patients (4m, 2f)	Unspecified

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	(114)			
Williams, V	2010 (115)	UK	COPD Patients (6m, 3f)	Grounded Theory
Williams, V	2011 (116)	UK	COPD Patients (12m, 6f)	Grounded Theory
Wilson	2007 (117)	Ireland	COPD Patients (25m, 7f) Clinicians (8 – gender unspecified)	Unspecified
Wong	2014 (118)	Malaysia	COPD patients (18m) and their doctors (5m, 13f)	Thematic analysis
Wood	2013 (119)	UK	Lung Cancer Patients (7m, 2f)	Unspecified
Wortz	2012 (120)	USA	COPD Patients (25m, 22f)	Unspecified
Young	2012 (121)	Canada	Clinicians, caring for patients with COPD (10 family physicians, 8 respiratory specialists – gender unspecified)	Unspecified
Yu	2007 (122)	China	COPD Patients (5m, 0f)	Thematic Network Analysis
Zakrisson	2010 (123)	Sweden	Clinicians, caring for patients with COPD (12 – gender and speciality unspecified)	Unspecified

Data extraction

No differences were found between the data extracted from the five papers by the two authors.

Quality analysis

All selected papers were judged to be of sufficient quality to be included in the review.

Thematic synthesis

Coding of the 101 studies elicited 98 codes which were condensed into four descriptive themes: 1) Widespread effects of breathlessness, 2) Coping, 3) Help-seeking behaviour and 4) Clinician responsiveness to breathlessness (Table 3). The overarching analytical theme of Breathing Space emerged from reflection and discussion of these four descriptive themes to describe coherent characteristics and features of the experience of living with breathlessness and to draw out implicit meanings.

Table 3: Codes and themes from the synthesis

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, 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 Responses 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

The theme “widespread effects of breathlessness” has been described in other work (124, 125) and is presented in the online Appendix; themes 2-4 will be presented in this paper. A brief summary of theme 1 will be presented by way of context.

Widespread effects of breathlessness

The concept of “total dyspnea” (126) was used as a theoretical framework for data analysis with respect to the widespread effects of breathlessness; physical, psychological, social and existential. This concept enables patients to be seen as complex, whole people in need of a holistic understanding of the many ways breathlessness affects their lives, on which effective management can be based.

Coping

The long-term consequences to an individual’s health and that of their carer are influenced by how well they cope with the stress caused by living with breathlessness. Tobin’s categorisation of engaged and disengaged coping (127) was used as a framework to analyse the findings with respect to coping.

There were examples of disengaged coping strategies in the face of the stress caused by breathlessness; “problem avoidance”, “wishful thinking”, “self-criticism” and “social withdrawal”.

“Problem avoidance” and “wishful thinking” risk delayed presentation, either through denying a problem, or hoping that it will just go away:

“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. So I didn’t let it bother me...I just continued to let it get worse, and ignored it.” (Patient) (57)

“Self-criticism” and self-blame led some to hide their breathlessness to avoid embarrassment. Others hid their breathlessness from others, feeling that their difficulties due to breathlessness were poorly understood and unrecognised by 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 in the family.” (Carer) (41)

The result was reduced access to social support from friends, family or other sources:

“...she wouldn’t go to a community group, she is not into that.” (Carer) (41)

Conversely, others employed engaged coping strategies such as “problem solving”, “cognitive restructuring”, “expressing emotion” and “seeking social support” in order to manage their stress effectively.

Instead of avoiding activities that cause breathlessness engaged copers used “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) (86)

Ways to keep in social contact and deal with problems were found. This included the use of various aids, (e.g. ambulatory oxygen, nebulisers or mobility aids, phones and the internet), or choosing alternative activities which they found rewarding:

“I go to friends sometimes and take my nebuliser with me. She understands and does not mind. Otherwise you could be tied in forever.” (Patient) (34)

“The relationship (with family) hasn't suffered, but it's a different kind of relationship. It's a 'telephone relationship'.” (Patient) (98)

“Cognitive restructuring” and having a ‘can do’ attitude helped some to have a less bleak outlook and to be more accepting of their limitations and prognosis:

“I am not going to live forever, but I am going to live the best I can for as long as I can.” (Patient) (91)

Active seeking of information from others helped develop an informed understanding of their situation and “expressing emotions” was helpful to some:

“One thing I found useful was the literature and advice... from the right source on the subject.” (Patient) (70)

“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) (43)

Self-compassion, instead of self-blame enabled smokers to show their younger selves compassion and recognise that at the time they started smoking the harm wasn't well understood:

"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) (34)

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

"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) (43)

Help-seeking behaviour

According to the concept analysis of help-seeking by Cornally and McCarthy (2011), for a patient to seek help, they need 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 helper.(128) In this paper the term 'helped' is used rather than 'solved', as breathlessness can be managed but rarely solved.

Recognising breathlessness as a problem to be helped

Breathlessness often develops slowly and many patients find alternative explanations for it, such as aging or smoking and thus take a long time to realise that their breathlessness is a problem to be addressed:

"There were times when I struggled but I just thought it was because of old age and just let it go."

(Patient) (44)

"I didn't go to the GP, only if I'd got something, you know, wrong with me. But I'd get a bit out of breath and as I say I just put it down to smoking like." (Patient) (113)

Deciding to take action

Once breathlessness was recognised as a problem some found it difficult to act, with many remaining passive until forced by crisis and often with action taken by family:

“My daughter asked for him. I didn’t ask for him, she sent for him.” (Patient) (90)

“It has to be really bad for me to ... see the doctor” (Patient) (25)

Patients may feel unworthy of support for a symptom they perceived to have brought on themselves:

“I resent myself for letting it get to this, for smoking. When I did know better I did nothing about it. ”
(Patient) (86)

“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) (98)

Selecting a potential helper

In the UK a patient who sees breathlessness as a problem which can be helped *and* who decides to act would usually contact their general practitioner (GP):

“I see my own doctor who understands how I feel and I get on very well with him.” (Patient) (98)

Some patients, however, once diagnosed, feel that they cannot discuss their breathlessness with their GP, but instead feel they should discuss it only with their specialist:

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) (69)

In crisis the patient may not feel able to access their GP and instead seek help from the emergency department:

"I was working and my breathing all that week had been rather haywire...I do maintenance and we were steam cleaning a patio garden—and I am afraid the steam really wound me up...So... I sat on the bed for about an hour. I couldn't breathe and I thought Jesus I've got to get to hospital! " (Patient) (49)

Disclosing the problem

Finally when the patient meets the potential helper they need to disclose the problem. However time constraints and the need to repeat information influence the detail provided:

"For the first two or three years I was seeing Dr G all the time and then, all of a sudden, 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, 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!" (Patient) (113)

The characteristics and manner of the listener also affect disclosure and judgements as to what is *medically* relevant information and therefore not mention breathlessness, or its impact:

"You can't go to the doctor and say "I can't dance." It's a strange thing to say to the doctor." (Patient) (64)

Furthermore, if a patient discloses information about breathlessness, the listener may not respond in a helpful way and then the patient makes no further disclosure:

"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) (36)

Consequences of help-seeking

For some, help-seeking led to problem resolution 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) (66)

For others the problem remained unresolved with subsequent dissatisfaction, resentment and increased helplessness. The patient may then use health services inappropriately or may give up, assuming their problem is not valid and/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) (72)

Clinician responsiveness to breathlessness

The concept of epistemic injustice (129) was used as the theoretical framework for analysis of this theme. Epistemic injustice can be subdivided into testimonial injustice (a person’s testimony is not taken into account when a decision is made by another) and hermeneutical injustice (there is no shared understanding of a phenomenon to enable full interpretation of an experience) and each can shape patient/clinician interactions.

Testimonial injustice

The theme “help seeking” illustrates that patients may select which information is included in their testimony. Additionally, reliance on medical knowledge, observable signs and symptoms, and objective performance tests by clinicians may lead them to disregard the patient’s experience of breathlessness and overall functioning:

“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.” (Patient) (44)

Patients and carers are aware of time pressures for consultations, which may not allow full disclosure. This may be conveyed overtly by the clinician by hurrying the patient, or directing the consultation to contain the content. The result is a reticence in disclosing their concerns:

“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) (90)

“... 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) (35)

Clinicians were dissatisfied with service configuration constraints and understood the importance of offering patients the opportunity to discuss what was important to them:

“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.” (Doctor) (62)

Hermeneutical injustice

Patients found it difficult to explain their symptoms to clinicians, who, in turn, appeared not to fully appreciate the effects of breathlessness on their patient:

“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.” And then I left. I thought what a silly question to ask me. “What do you do for a living?” And then afterwards I thought, he’s seen emphysema on the screen 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) (64)

This may be compounded by the patient often appearing comfortable when at rest in the consultation, or only contacting the clinician during an exacerbation. Patients described unpredictable symptoms, poorly understood by clinicians, which resulted in a lack of support and limited offers of medical help:

“People like Mr X who doesn’t really bother us that much, we really only see him when he’s not well.” (Doctor) (94)

“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) (97)

Responses to breathlessness

A response that “nothing more that could be done” left both patients and carers feeling abandoned and that breathlessness was now a normal part of life:

“But then when you leave hospital he knew that there was nothing after that. Nothing there was just me and him.” (Carer) (53)

“Getting breathless has become normal for me, I don’t even notice it.” (Patient) (71)

Poor communication and a lack of information contributed to limited access to breathlessness-specific interventions or other services such as palliative care:

“I’ve heard of it [palliative care] but to be honest I never understood what the word meant.” (Patient) (104)

“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’ve never been aware that there were things that he could have done to help him.”(Carer) (41)

Some clinicians recognised the impact of breathlessness, but felt ill-equipped and under-resourced to manage it:

“... 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” (Doctor) (121)

A lack of explicit discussion of breathlessness and its management left patients unsure what to do if it worsened. Some 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) (97)

“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) (51)

Conversely, knowing that a clinician was available and responsive to breathlessness provided 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.” (Carer) (104)

When the impact of breathlessness was recognised by the clinician, patients had it managed *alongside* disease-directed treatments, using a palliative approach even if they were not deemed to be at the “end-of-life”. This often allowed the opportunity to talk about future care and enabled better coping:

“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.” (Doctor) (62)

“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) (96)

In addition, clinicians seemed to find satisfaction and a less nihilistic attitude to management:

“I still think we can make a major difference to their quality of life through various interventions aimed at symptoms, so certainly the feedback that one gets from patients is that they feel they’ve gone from being hopeless and just through the implementation of some very simple symptom based remedies one can make a big difference to how they feel.” (Doctor) (33)

Breathing Space: a concept to describe living with breathlessness

The overarching analytical theme, ‘Breathing Space’, represents the integration of the four descriptive themes. The phrase “breathing space” dates back to the 1600s (130) (131) and includes the meaning of a “period of rest that allows you to get your energy back or try a different solution” (132), “sufficient space in which to move and work” (133) and an opportunity to find out what is important and to express oneself. (134) The concept of Breathing Space draws on previous work relating to quality of life defined as “The degree to which a person enjoys the important possibilities of his or her life” (135) and also on the work of the phenomenological philosophers Heidegger and Merleau-Ponty applied by Carel to the experience of illness.(136) Carel argues that as our body is the basis of our interaction with the world, being able to or being unable to carry out our activities affects both our view of ourselves and our quality of life greatly.

Here we use Breathing Space as a metaphor for the experience of living with breathlessness: rest from the constraints imposed by breathlessness; space and time to recoup strength and then plan further action and also the circumstances under which one can find one's priorities and then fulfil them.

The degree of Breathing Space achieved results from a complex interaction between the patient's coping style, their help-seeking behaviour and their clinician's responsiveness to breathlessness. It is a continuum with some patients having restricted Breathing Space, whilst others are able to achieve more Breathing Space. Restricted Breathing Space is characterised by avoidance, resignation and stagnation; summarised by the phrase "Life stops":

"It just stops your life, stops you from living." (Patient) (41)

"You fall into a huge hole, then the world gets so tiny, it all gets so narrow that it is almost unbearable." (Carer) (38)

"I tell you, my house is my prison." (Carer) (58)

In this case patients and carers may feel they have no control:

"I have no activities, it controls me...it controls my life." (Patient) (79)

"I feel like Sleeping Beauty. The hawthorn hedge has closed around me and I cannot do anything about it." (Carer) (38)

Restricted Breathing Space may result from a combination of a disengaged coping style, delayed or crisis help-seeking behaviour and a lack of responsiveness to breathlessness by the patient's clinicians.

Conversely, greater Breathing Space may result from a combination of engaged coping strategies, timely help-seeking and responsiveness to breathlessness by their clinician. A greater degree of Breathing Space is characterised by acceptance, adaptation and participation and can be summarised 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) (86)

"I changed as a person. The disease makes me feel more mature, more prepared and responsible for other people." (Carer) (58)

<< *Insert Figure 2: Breathing Space here*>>

Discussion

The concept of Breathing Space describes the whole experience of living with breathlessness, going beyond its widespread effects to encompass how the patient (and family) copes with breathlessness, how they seek help for it and also how their clinicians respond to it. This interaction influences whether a patient achieves maximum Breathing Space within the limitations of their disease, or whether their life becomes increasingly restrictive.

Family carers also experience the widespread effects of breathlessness on their physical and mental health, as well as social and existential effects on their lives. The way that the person they care for copes and seeks help can put extra burden onto the carer. Additionally carers also experience the responsiveness, or lack, of clinicians and may feel isolated and helpless.

This review also draws on the perspectives of clinicians who care for breathless patients, showing how their response to breathlessness shapes patients' help-seeking and coping strategies. Clinicians may be unaware of breathlessness-directed treatments, but those that are aware find satisfaction when their management has helped patients to have better quality of life.

This theoretical analysis provides significant new insights from patient, carer and clinician perspectives, which have been systematically drawn into a collective whole to provide direction for clinical practice.

The widespread effects of breathlessness are consistent with previous reports (5-11); illustrating the common experience of breathlessness irrespective of medical condition. The physical, psychological, social and existential effects of breathlessness are characteristic of the effects of chronic illness in general as described by Charmaz.(137) The burden on family and friends and their need for information and support is also observed in other work.(125, 138, 139) The concept of Breathing Space extends and adds to “total dyspnea”, (126) by describing how the interaction between the patient’s coping and help-seeking behaviour and clinicians’ responsiveness to breathlessness determine the overall experience of both patients and carers living with breathlessness. There is overlap between the Breathing Space concept and that of the “Shifting perspectives model of chronic illness” (140).The opposite ends of the continuum of Breathing Space are illustrated in recent papers, however each of these papers tend to focus only on one (56, 60, 106) or other end (42, 84) rather than bringing them together as a more integrative concept.

New existential perspectives of well-being within illness support these ideas (141) Well-being is usually described in relation to its absence and as a resource within the experience of breathlessness, rather than relying on the complete eradication of the breathlessness. ‘Breathing Space’ opens up the possibility of being able to carry on with this breathlessness and a settling or ‘letting be’ that can potentially offer pathways to coping.

Breathing Space also resonates with the Breathing, Thinking, and Functioning clinical model; (142) a framework to help clinicians support patients with breathlessness to break the vicious cycles of physical, cognitive/emotional and functional deterioration experienced by many.

Breathing Space may be a useful concept with which to understand other work. The HELP-COPD study (143) found that patients had very few felt needs and did not take up offers of help. Disengaged coping behaviour developing over time coupled with a lack of responsiveness to breathlessness by their clinicians might lead to restricted Breathing Space and lowered expectations with consequent unrecognised need.

Clinicians could use the Breathing Space concept to explore how the patient is coping and seeking help as well as previous experience of clinical attention to breathlessness. This approach is seen in the London Respiratory Network's Breathing SPACE framework(144) which encourages engaged coping strategies such as exercising, smoking cessation and seeking peer support and addresses mental health issues demonstrating responsiveness to symptoms in addition to disease processes.

Strengths and limitations of this study

This large systematic literature review and synthesis followed the PRISMA process (15) to ensure rigour and minimise selection and reporting bias. The qualitative synthesis was conducted using recognised methodology. (19) Synthesis used direct quotes to keep close to the primary data.

Limitations include language restrictions; only papers in English were included. However the selected studies are drawn from a wide range of countries, each with their different cultural contexts. Only published primary quotes were extracted and it is acknowledged that there would have been more primary data than was published to which we have no access. However, qualitative methods mandate that representative quotes are used, and thus we believe, given the number of papers in this synthesis, that our findings are representative.

Implications for society, clinical practice, service providers and policy makers

Society

Greater understanding of the widespread effects of breathlessness is needed in order to overcome any epistemic injustice(129). Public recognition of chronic breathlessness may help patients bring their symptom into the “open” and legitimise requests for clinical help before a crisis, rather than assuming this is something they and their carer have to live with.

Clinicians

The Breathing Space concept could be used by clinicians as a way to systematically assess breathlessness and its impact on the patient and carer, their current access to and uptake of evidence-based management strategies and support from other relevant clinicians and their pattern of emergency services use. This would allow the clinician to give advice on how to cope in a more engaged style, how and when to seek help appropriately and to decide what further evidence-based breathlessness management to offer. Additionally the knowledge and information needs of patients and carers should be explored and met, especially with respect to diagnosis and prognosis.

Education and training for clinicians in primary and secondary care in the assessment of Breathing Space and the management of breathlessness, such as that provided around the Breathing, Thinking Functioning model,(142) could improve patients’ access to breathlessness-targeted treatments delivered by the multi-disciplinary team including support for carers. Inclusion of qualitative research as part of critical appraisal in the education of medical trainees would enable them to develop an appreciation of patient and carer voice.

This review suggests that clinicians who are responsive to breathlessness and offer evidence-based breathlessness management find satisfaction in their work and have an improved sense of achievement rather than the sense of therapeutic nihilism experienced by others.

Service providers and policy makers

Adequate provision of services which support patients and carers to achieve a greater degree of Breathing Space is called for.

Future research

Future work should include ways to address the lack of public understanding of chronic breathlessness.

The usefulness of the Breathing Space concept in assessment by clinicians should be evaluated.

The degree to which Breathing Space can be achieved by the use of engaged coping strategies, appropriate help-seeking behaviour and responsiveness to breathlessness by clinicians should be tested.

The effectiveness of education programmes for clinicians should be evaluated with regard to interactions with patients and families and the use of tailored approaches to breathlessness management.

The extent to which the Breathing Space concept could be used as an explanatory concept in other chronic conditions should be investigated.

Whilst most included studies are in people with COPD, people with a wide range of other causes for their breathlessness are represented in this qualitative synthesis. However, other research questions may arise in relation to less studied disease groups for which a qualitative approach would be the appropriate study design.

Conclusion

The Breathing Space concept could help clinicians understand how patients and their families experience, and respond to, the widespread effects of breathlessness and thereby increase or reduce their limitations. The degree of Breathing Space achieved is influenced by interaction between the patient's coping style, their help-

seeking behaviour and the responsiveness of their clinician to breathlessness itself, in addition to managing the underlying disease.

Acknowledgements

The authors thank the Hull York Medical School librarian (Catriona Kemp) for her assistance in developing the search strategy.

This study was partly funded by a grant from NHS Hull Clinical Commissioning Group. AH's PhD studentship is funded by the University of Hull.

(Online supplement mentioned on p19)

Widespread effects of breathlessness

The concept of “total dyspnea” (126) was used as a theoretical framework with which to analyse the data with respect to the widespread effects of breathlessness. It is important to realise that each of these realms affects the other, for example not being able to do physical activities can lead to changes in roles and social isolation can result in depression. Thus the concept of “total dyspnea” enables patients to be seen as complex, whole people in need of a holistic understanding of the many ways breathlessness affects their lives, on which effective management can be based.

Physical effects

Chronic breathlessness exacts a heavy physical toll, 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 and shopping 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) (41)

“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) (88)

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) (29)

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) (35)

Psychological effects

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

“Then I'd be fine but I am all the time worried—worried when this breathing will attack me again” (Patient) (97)

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, they get emotional, they're frightened.” (Carer) (70)

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 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) (117)

The strain of looking after someone who is depressed can exact a toll on those who care for them and lead them to feel depression too:

“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) (33)

“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) (35)

Understanding the psychological difficulties that are faced by breathless patients and their carers is the key to help 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) (43)

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 culminates 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, because I want to get up and I can't and it upsets us." (Patient) (27)

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) (66)

"We often feel lonely and on the edge of things." (Patient) (63)

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) (35)

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 to press him ... and this is something one cannot talk so easily about ... I am afraid he could sense it as an accusation."
(Carer) (35)

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 that 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) (36)

“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) (65)

“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) (89)

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

“It’s a hard time I tell you and it gets you down. When you think what the nurses 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.” (Carer) (98)

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:

“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) (101)

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 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—it 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."

(Patient) (97)

Patients' difficulties in determining how best to use their remaining lifetime arise from a number of issues, involving both diagnosis and prognosis with respect to their underlying condition. 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) (67)

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) (67)

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) (67)

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) (67)

Many people 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) (34):

“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) (89)

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 suffocation that is regularly experienced with increased breathlessness and fear this greatly:

“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) (120)

“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) (113)

“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) (33)

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) (89)

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