BMJ Open

Patients and informal caregivers' experiences of burden of treatment in lung cancer and chronic obstructive pulmonary disease (COPD): a systematic review and synthesis of qualitative research

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To cite: Lippiett KA, Richardson A, Myall M, *et al*. Patients and informal caregivers' experiences of burden of treatment in lung cancer and chronic obstructive pulmonary disease (COPD): a systematic review and synthesis of qualitative research. *BMJ Open* 2019;**9**:e020515. doi:10.1136/bmjopen-2017-020515

► Prepublication history and additional material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2017-020515).

Received 4 December 2017
Revised 15 November 2018
Accepted 28 November 2018

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ABSTRACT

Objective To identify, characterise and explain common and specific features of the experience of treatment burden in relation to patients living with lung cancer or chronic obstructive pulmonary disease (COPD) and their informal caregivers.

Design Systematic review and interpretative synthesis of primary qualitative studies. Papers were analysed using constant comparison and directed qualitative content analysis.

Data sources CINAHL, EMBASE, MEDLINE, PsychINFO, Scopus and Web of Science searched from January 2006 to December 2015.

Eligibility criteria for selecting studies Primary qualitative studies in English where participants were patients with lung cancer or COPD and/or their informal caregivers, aged >18 years that contain descriptions of experiences of interacting with health or social care in Europe, North America and Australia.

Results We identified 127 articles with 1769 patients and 491 informal caregivers. Patients, informal caregivers and healthcare professionals (HCPs) acknowledged lung cancer's existential threat. Managing treatment workload was a priority in this condition, characterised by a short illness trajectory. Treatment workload was generally well supported by an immediacy of access to healthcare systems and a clear treatment pathway. Conversely, patients, informal caregivers and HCPs typically did not recognise or understand COPD. Treatment workload was balanced with the demands of everyday life throughout a characteristically long illness trajectory. Consequently, treatment workload was complicated by difficulties of access to, and navigation of, healthcare systems, and a fragmented treatment pathway. In both conditions, patients' capacity to manage workload was enhanced by the support of family and friends, peers and HCPs and diminished by illness/smoking-related stigma and social isolation.

Conclusion This interpretative synthesis has affirmed significant differences in treatment workload between lung cancer and COPD. It has demonstrated the importance of the capacity patients have to manage their workload in both conditions. This suggests a workload which exceeds capacity may be a primary driver of treatment burden.

Strengths and limitations of this study

- To the best of our knowledge, this is the first systematic review and synthesis that compares treatment burden in malignant and non-malignant disease.
- The review synthesises patient and informal caregiver experience of treatment burden across a wide range of healthcare settings and systems.
- The heterogeneity of studies included means uniformities highlighted should facilitate the development of an explanatory model of burden of treatment.
- The data analysed, while ostensibly from primary sources, are seen through the multiplicity of theoretical lenses chosen by the studies' authors and their varying epistemological and ontological stances and, indeed, the authors' own which may be a limitation of the study.

PROSPERO registration number CRD42016048191.

INTRODUCTION

Burden of treatment (BoT) is not simply the unavoidable workload that illness inevitably confers on patients and their informal caregivers but is a potentially *modifiable* workload which treatment for the illness may create.[1]This workload consists of affective, cognitive, informational, material, physical and relational tasks delegated to patients and/or their informal caregivers by healthcare professionals (HCPs).[1 2] The literature on BoT discusses the concept of 'capacity' and defines this as the resources (which may be affective, cognitive, informational, material, physical and relational) and limitations that affect patients' capability to carry out the work of chronic illness.[1 3 4] Capacity may be viewed at an individual (ie, the patient) or collective level (ie, the patients' social network).[5] Capacity may be affected by a range of variables, from socioeconomic factors such as ethnicity and poverty, to the social skill necessary to engage and mobilise stakeholders.[1–4 6–12] A workload that exceeds capacity might, in some cases, be a primary driver of BoT for patients.[1 4] Neither workload nor capacity is static. They may fluctuate over time as illness progresses, functional capacity declines and patients' social networks change[1 3 4] or, indeed, as the patient is able to accept, adapt and normalise their condition into their daily life.[2 9 12 13]

The literature[1 7 11 14 15] emphasises the importance of adequately equipping clinicians with tools to detect BoT and training in interventions that might ameliorate burden in order to provide 'minimally disruptive medicine'.[15] This is an approach to healthcare that takes into account patient priorities, multimorbidity and seeks to reduce the BoT on the patient and informal caregiver.[15]

Chronic obstructive pulmonary disease (COPD) and lung cancer are the most common causes of respiratory-related mortality in the UK, excluding pneumonia.[16] Tobacco smoking is the main risk factor for both diseases, linked to an estimated 86% of lung cancer and 90% of COPD cases in the UK.[17 18] Thus, both may carry the stigma of a 'self-inflicted' disease.[19 20]

Tobacco is a legal drug, used commonly, and has been previously socially acceptable. More recently, recognition of the significant risks of tobacco smoking and public health strategies to 'denormalise' tobacco has contributed to a social transformation that actively stigmatises smokers.[21]

COPD generally has a protracted trajectory of increasing respiratory limitation, punctuated by recurrent episodes of worsening termed 'exacerbations'. Globally, COPD is a major cause of chronic morbidity and mortality; prognosis is uncertain but many people die prematurely because of the disease or its complications (such as pneumonia).[22] Conversely, lung cancer typically has a rapid trajectory involving steady progression with a clear terminal phase.[23] The prognosis for lung cancer is poor; only 1 in 10 patients in the UK live for more than 5 years after diagnosis. Lung cancer treatments in England are predominantly hospital based: outpatient chemotherapy or systemic anticancer treatment or inpatient surgical treatment.[24] In contrast, treatment for COPD generally involves self-management (management of treatment regimens by patients and informal caregivers in the home).[25] BoT may, therefore, be experienced very differently by patients living with these two common respiratory conditions.

Aim of the review

We aimed to undertake a comprehensive search of the literature to identify, characterise and explain common and specific features in the experiences of treatment burden in relation to patients living with either lung cancer or COPD.

Research question

What is BoT in lung cancer and COPD, and how is it experienced by patients and their informal caregivers?

METHODS

Identifying relevant studies

This review forms part of a larger body of work which we are undertaking in order to identify, characterise and explain the intricate interpersonal and institutional processes that mediate patient and informal caregiver experiences of their interactions with healthcare. Thus, for this study we replicated and extended a previously developed search strategy which was built around three search concepts[26] :

1. Index conditions (heart failure, chronic kidney disease and COPD).
2. Qualitative research methodology terms.
3. Patient/informal caregiver experience.

We initially ran the search based on the above index conditions. We subsequently ran a separate search with lung cancer as the index condition. The full search strategy as performed in MEDLINE is available in online supplementary appendix 1. The search was piloted in MEDLINE and then adapted for other electronic databases used (CINAHL, Embase, Scopus, Web of Science, PsycInfo). We looked at primary qualitative studies examining patients with COPD or lung cancer and their informal caregivers' interactions with health and social care, rather than studies which explicitly examine treatment burden in COPD or lung cancer as there are so few. Searches were limited to countries with advanced healthcare systems comparable to the UK as the synthesis is intended to inform a future research project that will take place in the National Health Service in England. We limited our search to publications from the year 2006 onwards. This is because, like Gallacher *et al*,[7] we wanted to locate patient/informal caregiver experiences of BoT in current rather than historical health and social care practices. After retrieving and screening full-text articles, we decided not to use the mixed methods studies identified, as the majority of these studies screened suggested the qualitative components of the studies addressed a very specific research question, meaning that there was little data relevant to our research question. This is a potential limitation of the systematic review as there is a possibility that we have missed some pertinent studies. Table 1 details inclusion/exclusion criteria.

Study selection

KAL, MM, AC and CRM individually screened batches of citations and abstracts to assess eligibility against the inclusion/exclusion criteria. A further reviewer (Jonathan Harvey, see Acknowledgements) resolved eligibility disagreements at this stage. We obtained studies in full text where it was not immediately possible to determine eligibility against inclusion/exclusion criteria. KAL, MM and Jonathan Harvey independently double screened all

Table 1 Inclusion/exclusion criteria for systematic review

Inclusion criteria	Exclusion criteria
Participants: aged >18 years, diagnosed with lung cancer or COPD, or their informal caregivers	Reports of treatment effectiveness, for example, RCTs; reports of healthcare provision which are not focused on patients' or informal caregivers' experiences; qualitative studies which focus only on professional experience, or report secondary analyses, or review or synthesise data; editorials, notes, letters and case reports; protocols of qualitative studies
Reports: results of primary qualitative studies of patients' or informal caregivers' experiences of interactions with health and social care services published in peer-reviewed journals	Insufficient data to answer research question
Settings: healthcare systems in Europe (excluding Turkey), North America and Australia	
Date of publication: between 1 January 2006 and 31 December 2015	
Language: English	

COPD, chronic obstructive pulmonary disease; RCT, randomised controlled trial.

full-text COPD articles for eligibility; KAL screened all full-text lung cancer articles for eligibility with 10% of the full-text papers screened by CRM. A further reviewer (Katherine Hunt, see Acknowledgements) resolved eligibility disputes at this stage.

Quality assessment

MM, AC, Jonathan Harvey and KAL undertook quality assessment of included papers using a modified version of the qualitative appraisal tool: RATS (Relevance, Appropriateness, Transparency, Soundness) guidelines[27] (see online supplementary appendix 2). We took a conservative approach to assessment, primarily undertaking it to ensure transparency of study design, aims and the sampled population. Thus, we excluded only five of the lung cancer studies that had not appeared to seek ethical permissions.

Data extraction and analysis

We extracted data from the findings/results, discussion and conclusion sections of each paper. Extracted data included verbatim quotes from patients and caregivers and authors' interpretations.[2] As the aim of the review was to identify and characterise patient and informal caregiver experience, we omitted results relating to HCPs in the analysis (n=12 studies included HCPs). CRM, AR, KAL, MM, AC and Jonathan Harvey developed a coding framework, underpinned by robust, empirically derived, middle-range theories: BoT theory (described above)[1] and status passage theory.[28] Middle-range theories are applicable to discrete conceptual ranges, sitting between frequently generated minor working hypotheses and all-encompassing efforts to explain systematically the observed uniformities of society. They may be particularly helpful, therefore, in generalising learning in health services improvement so that interventions can be replicated in different contexts.[29] Status passage theory describes people as constantly in passage between temporally limited and societally ascribed statuses (eg, from being unmarried to married). Status passages may (or may not) be desirable, inevitable, reversible, repeatable or voluntarily undertaken. They may vary in their importance to the person undergoing the passage. Passages may have to be legitimised by authorised agents. Status passage theory is a particularly useful tool when considering illness, which is an undesirable, involuntary and often irreversible passage, legitimised by HCPs as authorised agents.[28]

In keeping with the principles of directed qualitative content analysis which seeks to extend conceptually an existing theory, we identified key concepts of BoT and status passage theories as coding categories and determined operational definitions for these creating a coding framework.[30] KAL, MM, AC and Jonathan Harvey then independently used the coding framework to code a selected group of data and compared results. Once intercoder reliability had been established, KAL downloaded full-text articles into the qualitative data analysis software Nvivo 11, used to organise and manage data. KAL read the full-text versions of identified papers to enable immersion in the data to understand their scope and context[31] and coded data using the coding framework described above. KAL, supported by CRM and AR, analysed data using directed qualitative content analysis[30] and constant comparison.[32] We grouped related codes into sets for each condition and compared sets within and between conditions. We used Shippee *et al*'s[4] proposition that a workload that exceeds capacity might be the primary driver of BoT and thus grouped coded data into sets of **workload** (the affective, cognitive, informational, material and relational tasks delegated to patients/caregivers) and **capacity** (the affective, cognitive, informational, material and relational resources available to be mobilised by patients/caregivers). We then formulated simple explanatory propositions with which to characterise differences and similarities in treatment burden between conditions. These propositions, with coded data as supporting evidence, were used to develop a taxonomy which identifies and characterises primary and secondary constructs of BoT in lung cancer and COPD (table 2).

Reflexivity

As this was an interpretative synthesis, it was important to ensure that reflexivity was ongoing throughout the study. We did this first through discussions and reflections on the theoretical coding framework. Second, in discussions and reflections on extracted and coded data. Third, in reflections and discussions on the development of the simple explanatory propositions, supporting evidence for these and the development of the taxonomy.

Patient and public involvement

Our wider National Institute for Health Research (NIHR) funded programme of research on complexity, patient experience and organisational behaviour has been developed in engagement with three groups in which more than 40 patients and caregivers have played a substantial role. In this particular study, we worked closely with the late Mark Stafford-Watson (see Acknowledgements). He played a valuable role in the development of the research question. Emerging results from this systematic review have been discussed with members of a local Breathe Easy (British Lung Foundation patient support group), and these discussions have informed the development of empirical research following the review.

RESULTS

Characteristics of studies

Figures 1 and 2 show each stage of the review process. We identified 127 articles: 85 COPD and 42 lung cancer. The papers included 1233 patients with COPD, 251 informal caregivers of patients with COPD; 536 patients with lung cancer and 240 informal caregivers of patients with lung cancer. The majority of the papers were set in the UK, USA, Canada and Sweden. Ninety-nine papers used qualitative interviews, 14 used interviews alongside either participant observation or focus groups. Eleven studies employed focus groups, two studies used case study and one study used serial dialogue. Further characteristics of studies are available in online supplementary appendix 3 .

For ease of reference, we include a table with primary and secondary constructs (table 3).

Workload (primary construct)

Diagnosis (secondary construct)

For the majority of patients with COPD, the experience of receiving a diagnosis of COPD was not a memorable event[33–46]; ‘a story without a beginning’.[43] Often, patients had never received a formal diagnosis or were not informed of their diagnosis for many years. One study described how its participants questioned why they were recruited, unaware that they had been diagnosed with COPD.[42] Even when given a diagnosis, many patients often did not understand the term ‘COPD’: ‘… as I say, I wasn’t even sure, it had never been put to me, formally put to me that I’d got this obstructive pulmonary or whatever they call it’[35] (p.706).

In contrast, patients with lung cancer almost universally described the moment of diagnosis as a ‘shock’,[47–53] an unexpected and undesirable ‘crisis’ which ‘flooded’ patients’ lives.[28] Patients felt overwhelmed by the existential threat of cancer that took away their ability to plan for or even imagine a future.[48 54 55]

Illness identity (secondary construct)

Several studies demonstrated a lack of public understanding of COPD.[33–35 37 39 42 43 45 56–59] Thus, patients and their informal caregivers often had not heard of COPD prior to diagnosis and therefore had no expectations of the disease and its likely trajectory: ‘When cancer was excluded all worries about the future or fear of death fell away’[34] (p.558). Conversely, cancer has a recognisable public narrative, replacing tuberculosis as the disease the public most fears.[60–63] In several of the studies, the patient’s experience reflected this narrative shift[50 53 64]: ‘Patients acknowledged despair … and some hoped for an alternative diagnosis: ‘It doesn’t have to be lung cancer … it doesn’t have to be the worst’[64] (p.1207).

Attitude towards treatment (secondary construct)

Consequently, treatment for the illness—often became the over-riding priority in life for patients with lung cancer,[64–67] suspending the demands of everyday life: ‘Life is immediately put on hold … so a normal everyday life didn’t concern me because everything revolved around treatment and only completion of the treatment was important so everything else didn’t matter’[66] (p.5). Conversely, patients often saw COPD as a ‘way of life’[43] not an illness. The management and treatment of ‘stable’ COPD symptoms was seen as something that had to be integrated into everyday life rather than being a priority.[35 43 57 59 68–73] Many patients with COPD, even with advanced illness, did not regard themselves as unwell.[43 59 70 71 73] Patients reported exacerbations of COPD as ‘proper’ illnesses but saw the often debilitating symptoms of ‘stable’ COPD as a normal part of life, something to be accepted and coped with.[70]

In the papers included, patients often described COPD as a ‘planning’ disease, balancing the work of everyday life with the material demands of managing their treatment workload.[42 72 74–79] This was complicated by the uncertainty of the illness trajectory making disease fluctuations difficult to anticipate and, consequently, to manage.[33 37 39 70 80–84] Less commonly, patients with lung cancer also described the importance of planning and managing their own treatment workload.[47 66 67 85–87] More commonly, patients with lung cancer were overwhelmed by the debilitating pathophysiological side effects of their treatment such as breathlessness, fatigue, nausea

Table 2 Taxonomy of treatment burden in lung cancer and COPD

Primary construct	Secondary construct	Lung cancer	References	COPD	References
Workload (the affective, cognitive, informational, material and relational tasks delegated to patients/caregivers)	**Diagnosis /illness identity**	Diagnosis as shock	47–55	Diagnosis imperceptible	33–46
		Obvious illness identity with sociocultural resonance (therefore understood by patient/informal caregiver/HCP)	50 53 64	Unclear illness identity, without sociocultural resonance (therefore, poorly understood by patient/informal caregiver/HCP)	33–35 37 39 42 43 45 56–59
		Short disease trajectory (clear to patient and informal caregiver)	50 53 64	Long and uncertain disease trajectory (unclear to patient and informal caregiver)	33–35 37 39 42 43 45 56–59
	Attitude towards treatment	Demands of treatment workload as over-riding life priority (for both patient and informal caregiver)	64–67	Demands of treatment workload balanced with domestic/professional/sentimental demands of everyday life (for both patient and informal caregiver)	35 43 57 59 68–73
		Practical demands of treatment workload as a relief from the existential threat of cancer	51 53 86 93	Practical demands of treatment workload as hard work	33 37 39 42 70 72 74–84
		Treatment as hope	49 51 64 86 87 91 94 95	Institutionalised care as respite from unrelenting demands of self-management	57 58 84 104 109–119
		Sense of ‘limbo’ once treatment completed	48 66 96–98		
		Reluctance to stop treatment despite debilitating pathophysiological side effects	86		
		Treatment for family rather than for patient	67 87 99		
	Treatment options	Lack of options: treatment or death	67 91 93 97 121	Lack of treatment options (lack of information or feeling that ‘nothing can be done’ from HCPs)	35 57 70 113 123
		Decision to cede control over choice of treatment options to trusted HCPs	86 93 97 99 121 122		
	Access to/ navigation of healthcare system/institutions	Immediacy of access to healthcare	49 67 85 121 131 132	Difficulties with access to healthcare	44 45 58 78 109 112 113 116 124 126 129
		Specialist HCPs with specific knowledge of lung cancer	49 67 85 121 131 132	Generalist HCPs who lack specific knowledge of COPD	44 45 58 78 109 112 113 116 124 126 129
		Structured treatment pathway	49 53 66 67 85 121 131 132	Fragmented treatment pathway	34 37 42 44 58 73 74 76 103 108 109 116 120 126 127 129
	Practical workload of treatment	Specialist treatment workload in secondary care with debilitating pathophysiological side effects	52 91 134	Multiple appointments for treatment in primary, secondary care and in the community	73 101 108 120 123 125 133 135
		Limited delegated tasks from HCPs	48 50 52 53 65–67 86 89 91 93 97–99 121 131 146	Significant workload of delegated treatment tasks at home from HCPs	33 35 37 42 45 58 59 68 69 72–76 79 80 83 103 106 108 109 114 126 127 129 130 133 136–145
	Informational workload of treatment	Generally high-quality information provided in written form and from specialist HCPs	64 67 85 93 97–99 121 132 147 148 151	Patients typically poorly informed about condition from diagnosis to death adding to treatment workload	33–46 74 76 78 81 108 123 127 130 133 137 154
		Lack of information as a deliberate choice on the part of patients—a tactic for maintaining hope in the face of a poor prognosis	48 51 64 66 97 99 121 122 152 153	Conflicting/contradictory information adds to patient/informal caregiver distress	36 44 56 79 109 110
		Conflicting/contradictory information adds to patient/informal caregiver distress	89 96–98 122		

Continued

Table 2 Continued

Primary construct	Secondary construct	Lung cancer	References	COPD	References
Capacity (the affective, cognitive, informational, material and relational resources available to be mobilised by patients/caregivers) - **Enhanced by diagnosis**	**Family and friends**	Family and friends are seen as the main source of support post diagnosis (but fear of being a 'burden' on family)	49 55 66 67 87 132 147 **'Burden'**49 52 54 85 86 91 95 96 99 132 147:	Family and friends are seen as the main source of support post diagnosis	37 58 73 74 76 79 80 108 125 130
		Family and friends are able to prioritise supporting the patient through their treatment workload owing to the short disease trajectory and the recognition of the patient's likely imminent death	54	Family and friends have to balance the demands of the treatment workload with the demands of everyday life owing to the long and uncertain disease trajectory	36 74 76 130 133 136
		Support for the patient's treatment workload seen as an affirmation of the strength of the patient/family member relationship in the face of imminent death	55 66 132 151	Support for the patient's treatment workload may be seen as an affirmation of the strength of the patient/family member relationship	36 58 73 74 79 80 130
				Caregivers feel compelled to take on a care-giving role over the long duration of the disease trajectory	36 37 74 76 80 130 133 136
	HCPs	Importance of support from empathetic, trusted HCPs in whom patients have faith	49 53 66 85–87 93 97 121 122 131 132	Importance of support from trusted HCPs, especially those with specialist knowledge of COPD	57 78 80 103 106 109 120 125 127 129
		Less commonly, loss of faith in HCPs	(85 122)	Importance of relational continuity with HCPs making access to and navigation of the healthcare system and its institutions easier	80 81 109 111 125 129
				Loss of faith in HCPs	35 38 41 44 45 73–76 109 113 123 126
	Peer support	Little peer support available for patients with lung cancer. What is available appears impromptu and transitory	91 97 156	Peer support is an important resource and is generally accessed through PR	40 68 82 108 **PR:** 56 57 100–105 107 115 135 155
				Shared experiences with peers reduces isolation	56 100–102 104 105 107 115 135
				Peer support is used as a resource for information sharing	(56 57)
	Disease trajectory	Short disease trajectory: ill equipped to self-manage symptoms at home	92	Long disease trajectory: get to know their bodies and symptoms, through trial and error	35 37 42 68 73 103 114 150

Continued

Table 2 Continued

Primary construct	Secondary construct	Lung cancer	References	COPD	References
Capacity (the affective, cognitive, informational, material and relational resources available to be mobilised by patients/caregivers) - **Diminished by diagnosis**	**Stigma**	Patients are considered culpable for their illness and stigmatised by society	(151 158)	Patients are considered culpable for their illness and stigmatised by society	38 40 75 113 126
		Patients consider themselves culpable for their illness: a 'self-inflicted' disease	85 159 160	Patients consider themselves culpable for their illness: a 'self-inflicted' disease	33 35 44 75 77 79 101 161
		Patients experience 'felt' stigma of blame, guilt and shame	49 85 152 158 159	Patients experience 'felt' stigma of blame, guilt and shame	38 40 44 75 79 101 145
		Patients attempt to conceal their condition owing to fear of 'enacted' stigma leading to social isolation	(49 152)	Patients attempt to conceal their condition owing to fear of 'enacted' stigma leading to social isolation	(38 40)
		Patients feel 'marked' by visible treatment leading to social isolation	(87 91)	Patients feel 'marked' by visible treatment leading to social isolation	42 126 137 143
				Patients internalise stigma, considering themselves undeserving of treatment	(41 101)
				Patients experience 'enacted' stigma from HCPs, making access to treatment challenging	36 38–40 44 71 74 75 118 126–128
	Social isolation (self-imposed)	Embarrassment about symptoms, medications and treatment technologies which mark the patient as ill leading to fear of 'enacted' stigma	87 90 91	Embarrassment about symptoms, medications and treatment technologies which mark the patient as ill leading to fear of 'enacted' stigma	42 77 137 142 143
				Exacerbation triggers—leads to avoidance of social situations	(76 111)
	Social isolation (involuntary)	Illness as contagious: social networks contract as friends withdraw	50 53 156	Illness as contagious: social networks contract as friends withdraw. Isolation worsens with disease progression and deterioration of physical function	82 101 136 143 **Deterioration:** 37 74 80 82 127 139 161 162
		Psychological comorbidities lead to avoidance of social situations	(53 156)	Logistical difficulties of treatment workload limit patient to home	38 42 58 59 69 73 79 108 111 126 137 139–141 143
				Social isolation extends beyond patient to affect informal caregiver	36 37 74 76 80 133 136
				Psychological comorbidities lead to avoidance of social situations	78 79 82 101 102

COPD, chronic obstructive pulmonary disease; HCPs, healthcare professionals; PR, pulmonary rehabilitation.

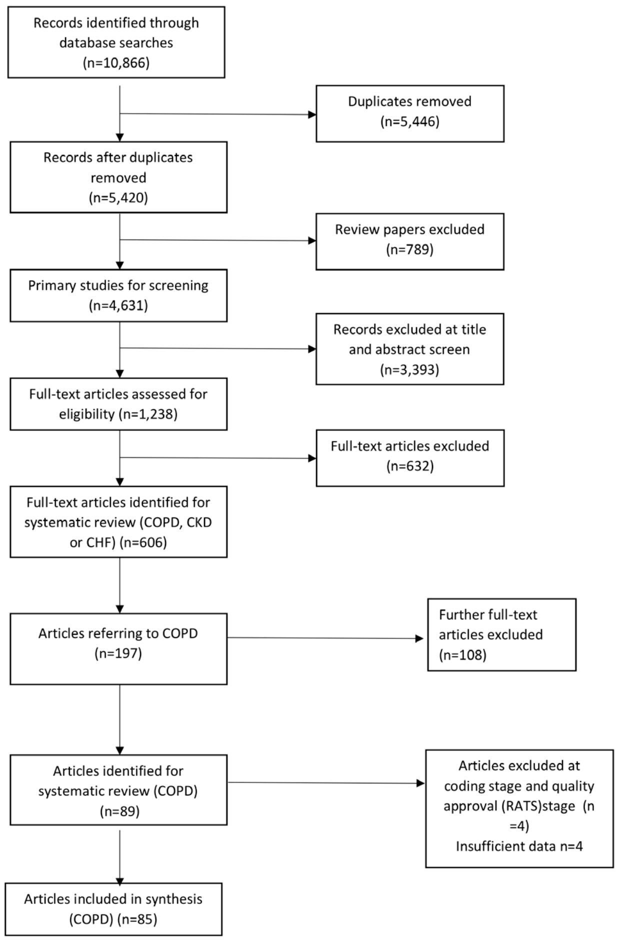

Figure 1 PRISMA flowchart for COPD articles. CHF, congestive heart failure; CKD, chronic kidney disease; COPD, chronic obstructive pulmonary disease; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses; RATS, Relevance, Appropriateness, Transparency, Soundness.

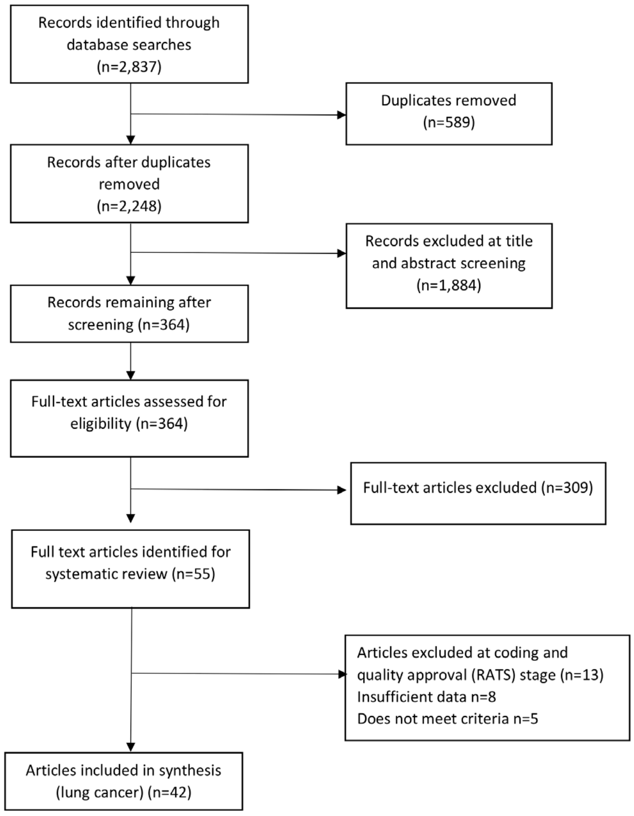

Figure 2 PRISMA flowchart for lung cancer articles. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses; RATS, Relevance, Appropriateness, Transparency, Soundness.

and vomiting and were unable to focus on anything apart from treatment completion.[48 55 65–67 86 88–92] Nonetheless, patients with lung cancer often experienced the practical demands of treatment—the treatment workload—as a relief, despite these potentially incapacitating pathophysiological side effects.[51 53 86 93] Patients repeatedly used the metaphor of treatment as 'hope', a lifebelt in the existential flood caused by the diagnosis of lung cancer.[49 51 64 86 87 91 94 95] Indeed, some patients reported a sense of 'limbo' once the practical workload of treatment had finished.[48 66 96–98] This 'limbo' was both existential[66 98]: 'Now I have lived for something, to complete and survive the treatment and suddenly the priority of life is gone'[66] (p.5) or structural, where patients felt in transition between healthcare institutions.[48 96 97] Thus, paradoxically, patients with lung cancer could report a reluctance to stop treatment, despite its unpleasant pathophysiological side effects: 'I'll keep taking chemo as long as you'll give it to me'[86] (p.105). Some patients with lung cancer also described continuing with treatment because they believed it was what their family wanted, rather than consulting their own preferences.[67 87 99]

Patients with COPD reported how elements of treatment that supported self-management (eg, educational sessions at pulmonary rehabilitation (PR)) provided a much needed sense of control over their condition.[35 72 78 100–107] Yet, it was evident how fragile this sense of control might be, easily undermined by structural disadvantages such as transitions between healthcare institutions and lack of communication from and between HCPs[33 37 41 58 73 108 109]:

> I said, put them bloody tablets back [after one of usual medications stopped in hospital, followed by him feeling unwell]. Don't take stuff off me without telling me. And I swore at him, [hospital doctor] I did, I was blazing. For giving me a dodgy thing again. But that's what you've got to put up with you see.[41] (p.269)

This suggests unsupported and undermined self-management may be an exhausting and frightening, rather than empowering experience for the patient and their informal caregiver. Indeed, in the studies included, patients with COPD repeatedly describe the relief of respite from the demands of self-management that institutionally provided treatment (specifically

Table 3 Primary/secondary constructs

Primary construct	Secondary construct
Workload (the affective, cognitive, informational, material and relational tasks delegated to patients/caregivers)	Diagnosis/illness identity
	Attitude towards treatment
	Treatment options
	Access to/navigation of healthcare system/institutions
	Practical workload of treatment
	Informational workload of treatment
Capacity (the affective, cognitive, informational, material and relational resources available to be mobilised by patients/caregivers) - **Enhanced by diagnosis**	Family and friends
	Healthcare professionals
	Peer support
	Disease trajectory
Capacity (the affective, cognitive, informational, material and relational resources available to be mobilised by patients/caregivers) - **Diminished by diagnosis**	Stigma
	Social isolation (self-imposed)
	Social isolation (involuntary)

hospitalisation, PR, day hospice and specialist outpatient care) brings[57,58,84,104,109–119]:

> 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.[111] (p.1485)

However, particularly in the case of hospitalisation, institutionally provided treatment might also significantly add to the workload of patients with COPD. Patients reported a hospital stay as a chaotic, confusing and disruptive experience. They felt they were seen as 'low priority' by the healthcare provider and frequently moved from ward to ward.[41,79,116,120] Thus, some patients might try to avoid hospitalisation.[37,41,120]

Identifying and accessing treatment options (secondary construct)

In the papers included, patients with lung cancer reported frequently having to make decisions about whether or not to have treatment, which they repeatedly phrased as a lack of choice: a choice between death or treatment.[67,91,93,97,121] While ostensibly involved in the treatment decision-making process, some patients described having little real control over treatment options, believing they lacked the cognitive ability and specialist knowledge required to make informed treatment decisions.[93,97,99] Indeed, frequently patients reported choosing to cede the cognitive burden of decision-making over treatment options to a trusted HCP.[86,93,97,99,121,122]

For patients with COPD, identification of treatment options could, itself, be problematic.[35,57,70,113,123] Patients described being repeatedly told that 'nothing could be done for them' by HCPs in both primary and secondary care.[35,57,70,113,123] Thus, papers reported patients identifying treatment options from other sources of information such as the experience of peers or through their own research.[56,57,68,108,113] Once treatment options were identified, patients could experience difficulty in accessing them.[34,35,39,40,42,44–46,58,70,73,74,76,103,108,109,116,120,124–130]

Access to and navigation of healthcare institutions/systems (secondary construct)

After diagnosis, patients with lung cancer frequently reported rapid access to healthcare institutions and specialist HCPs who recognised and understood lung cancer and were able to coordinate its treatment workload.[49,67,85,121,131,132] Furthermore, patients with lung cancer appeared to follow a relatively structured treatment pathway.[49,53,66,67,85,121,131,132] In contrast, patients with COPD described encounters with gatekeeping generalist HCPs who did not recognise or understand their disease[44,45,58,78,109,112,113,116,124,126,129] and, consequently, significant delays in accessing specialist care. Patients with COPD reported the hard work of accessing healthcare, having to navigate between primary and secondary care, in a fragmented system, lacking a clear COPD treatment pathway.[34,37,42,44,45,58,73,74,76,103,108,109,116,120,126,127,129] Furthermore, patients described being expected to act as custodians of their own medical history, having to update HCPs with changes to their treatment.[109,133]

Practical workload of treatment (secondary construct)

Once treatment options were identified and accessed, patients with both conditions reported experiencing a significant practical workload, with multiple appointments for treatment, most commonly in hospitals for cancer[52,91,134] and occurring in a variety of settings for COPD.[73,101,108,120,123,125,133,135] Patients with both conditions described structural disadvantages such as the availability and cost of transportation and parking, physical restrictions in accessing healthcare (such as stairs), waiting for appointments and restricted time for appointments with HCPs that make their workload more onerous.[34,39,42,52,58,73,91,101,108,109,120,123,125,126,129,134,135]

Patients with COPD and their informal caregivers reported being delegated a wide range of material treatment tasks by HCPs to self-manage at home. These included the management of complex medication regimens,[33 35 42 72 74–76 80 109 129 130 136] the operation of technologies such as oxygen,[42 45 58 59 73 79 83 106 108 109 126 127 136–143] nebulisers[33 68 80 126 127 140] and non-invasive ventilation.[69 144] These also included self-management of the illness itself: avoiding exacerbation triggers, monitoring physical symptoms and help-seeking when appropriate.[35 37 68 72–74 76 80 103 114 130 133 145] In contrast, patients with lung cancer described receiving highly specialised, predominantly hospital-based therapies with little delegation of material treatment tasks.[48 50 52 53 65–67 86 89 91 93 97–99 121 131 146] The exception was a study interviewing patients receiving oral targeted therapies who described the rigorous process they underwent when securing and taking medication.[87] This paper highlighted the priority patients with lung cancer gave to their treatment because of the recognition of lung cancer's immediate threat to life as they rigidly adhered to their delegated task.[87]

Informational workload of treatment (secondary construct)

Patients with both conditions described being required to comprehend a large amount of information about their treatment.[35 37 51 56 64 66–68 73 83 85 88 89 94 96 97 99 103 108 121 130 132 133 136 141 147–150] Commonly, patients with lung cancer felt that high-quality information about their treatment was available to them when they required it.[64 67 85 93 97–99 121 132 147 148 151] Nonetheless, the 'shock' of diagnosis meant some patients struggled to retain or process information about treatment and therefore felt that further information was required once they began to assimilate their diagnosis.[53]

Some patients with lung cancer wanted to be fully informed about their condition and treatment by their HCP, including prognosis, however bleak this was.[67 85 98 121 132 147 148] In contrast, other patients found being fully informed overwhelming and frightening, particularly when given comprehensive written materials.[53 97 147] They wanted limited information from HCPs, appearing to use this as a coping strategy to maintain hope for as long as possible,[48 51 64 66 97 99 121 122 152 153] preferring not to be 'frightened with too much … knowledge'[97] (p.969).

In a minority of cases, patients with lung cancer described information as not forthcoming when they wanted it and, as a consequence, felt ill-informed.[94 99 122 147] This was more frequently the case in patients with COPD. Patients often felt poorly informed about their condition and treatment at diagnosis and this continued throughout their disease trajectory.[33–46 74 76 78 81 108 123 127 130 133 137 154] This could be as fundamental as being given an inhaler without instructions on how to use it.[42 45]

Information could become a source of anxiety in both COPD and lung cancer when it was inconsistent or contradictory.[36 44 56 79 89 96–98 109 110 122] Patients with lung cancer found the side effects of treatment about which they had not been informed, significantly more distressing than those symptoms about which they had been warned and therefore anticipated.[88 89]

Capacity (primary construct)

We found, in both conditions, capacity could be enhanced and/or, paradoxically, diminished following diagnosis.

Capacity enhanced following diagnosis

Family and friends (secondary construct)

Patients with lung cancer and COPD repeatedly described family and friends as the main source of support for their treatment workload.[37 49 55 58 66 67 73 74 76 79 80 87 108 125 130 132 147] Informal caregivers, like patients with lung cancer, prioritised the demands of treatment workload over the demands of everyday life and thus put their own life on hold:

> Participants and carers described their … life as inextricably tied to and affected by treatment patterns, appointments, complications and side effects. Additionally, the impact of various test results created a 'scan by scan', 'treatment cycle by cycle' or 'suspended' approach to life, which had an impact not only for the patient but also carers and family.[67] (p.24)

There could be an explicit recognition that this was possible owing to the short disease trajectory in lung cancer.[54]

Informal caregivers' participation in the treatment workload, while practically onerous, was often seen as an affirmation of the strength of their relationship with the patient.[55 66 132 151] This was echoed in many of the COPD studies.[36 73 79 80 130] Indeed, there was a suggestion from some informal caregivers that the demands of the caring role deepened and enhanced their relationship with the patient over the protracted COPD disease trajectory.[58 74] Yet, still more studies demonstrate that informal caregivers felt 'compelled' to take on a caring role rather than this being a conscious choice. Their identity imperceptibly and inexorably shifted from family member to caregiver.[36 37 74 76 80 130 133 136] The length of the disease trajectory in COPD meant that the informal caregiver, like the patient, had to balance the demands of treatment workload with the demands of everyday life.[36 74 76 130 133 136] The studies included repeatedly show that informal caregivers might find this practically limiting and affectively and cognitively demanding.[36 37 69 74 76 80 83 130 133 136 137 145]

Interestingly, despite the evidence of significant workload encountered by informal caregivers in COPD, it was patients with lung cancer who consistently described their fear of being a 'burden' on their caregivers.[49 52 54 85 86 91 95 96 99 132 147] This was less common in the COPD studies,[42 75 101 127] perhaps because the gradual development of the caring role over the long disease trajectory meant that the tasks the caregiver took on were not always obvious to the patient.

HCPs (secondary construct)

Patients with lung cancer frequently reported the importance of support from empathetic, trusted specialist HCPs in whom they had faith.[49,53,66,85–87,93,97,121,122,131,132] Patients with COPD also described positive experiences of interactions with HCPs,[125,129] particularly those with a specialist interest in COPD[57,78,80,103,106,109,120,127] or those with whom they had relational continuity.[80,109,125,129] Patients with COPD described lack of relational continuity with HCPs as making access to, and navigation of, the healthcare system more challenging.[81,109,111,129] In a small minority of lung cancer cases, patients had lost confidence in their HCPs.[85,122] This loss of confidence in HCPs appeared more common in COPD.[35,38,41,44,45,73–76,109,113,123,126]

Peer support (secondary construct)

Patients with COPD appeared to benefit hugely from peer support,[40,68,82,108] which they generally accessed through PR.[56,57,100–105,107,115,135,155] Peer support had both psychosocial benefits as patients felt less isolated[56,100–102,104,105,107,115,135] and practical benefits as a means of information sharing about treatment options.[56,57] In contrast, there appeared to be little formal peer support accessed by patients with lung cancer. Interactions with other patients tended to be impromptu and often transitory[91,97,156] perhaps because of the typically short disease trajectory of lung cancer.

Disease trajectory (secondary construct)

Patients with COPD described a process of getting to know their bodies and symptoms over their long disease trajectory and, through a process of trial and error, being able to adapt and normalise treatments into their daily life.[35,37,42,68,73,103,114,150] Patients attending PR reported the importance of support to self-manage, and education and information about their condition from specialist HCPs.[78,101–106,115] In contrast, patients with lung cancer described feeling ill-equipped to self-manage symptoms such as breathlessness at home, particularly in the earlier stages of treatment.[92] This may be because the short disease trajectory of lung cancer does not allow patients to develop adequate self-management techniques and/or because patients/informal caregivers do not see self-management as appropriate or possible.

Capacity diminished following diagnosis

Stigma (secondary construct)

Stigma occurs when society labels someone 'tainted' or 'spoiled' on the basis of an attribute that signals their difference to a societally perceived norm.[157] Scambler[62] usefully distinguishes between 'enacted' and 'felt' stigma.[62] 'Enacted' stigma is actual discrimination by society against people with stigmatising conditions. 'Felt' stigma is internalised stigma by people with stigmatising conditions, manifesting itself as shame, guilt or blame or as fear of 'enacted' stigma.

In the papers included, patients with lung cancer and COPD frequently reported being considered culpable for their illness through smoking and consequently stigmatised by society.[38,40,75,113,126,151,158] Patients with both conditions clearly internalised this stigma, repeatedly describing their diseases as 'self-inflicted'.[33,35,44,75,77,79,85,101,158–160] They experienced 'felt' stigma of self-blame, guilt and shame.[38,40,44,49,75,79,85,101,145,152,158,159] Some patients with COPD described how this internalised stigma led them to believe they do not deserve treatment[40,101]: 'I refused to go to the doctor. I thought it [COPD] was self-inflicted. If it's self-inflicted, why bother anyone?'[101] (p.314). Conversely, in the papers included, patients with lung cancer did not describe themselves as undeserving of treatment. Only one patient in one lung cancer study reported having to 'endure' the unpleasant side effects of treatment because of his smoking history.[147]

Both COPD and lung cancer are not immediately visible to others. Patients reported how fear of 'enacted' stigma led them to conceal their illness identity.[38,40,49,152] Thus, patients with both conditions attempted to impose a 'closed awareness context',[28] concealing their illness from all but a select few. Patients with both conditions also experienced the fear of 'enacted' stigma when 'marked' as unwell by their treatment.[42,87,91,137,143] Hair loss caused by the side effects of lung cancer treatment is a clear signal of illness as is the ambulatory oxygen carried by some patients with COPD. In both conditions, therefore, the visible side effects of treatment or technologies may disrupt the 'closed awareness context'[28]patients have carefully maintained around their illness identity, leading to patients avoiding social situations and, consequently, social isolation[42,126]

Patients with COPD often described feeling stigmatised by their HCPs.[39,40,44,71,74,75,118,126–128] Patients with COPD and their informal caregivers felt that HCPs believed that patients who had smoked were not entitled to treatment or gave substandard treatment to (ex) smokers[39,75,126,128]:

> Well, the care from Father's doctors was extremely basic and, I felt, on the most part extremely uncaring …. The doctors really had an attitude of 'You were a smoker, you're dying of lung disease, and what do you want us to do about it[36] (p.161).

Consequently, patients were reluctant to access treatment for fear of such enacted stigma.[38,40] Several papers reported the difficulties of accessing treatment for patients who had smoked.[36,75,126,128] One study described an extreme example of HCP stigma where the authors argue that patients receiving non-invasive ventilation, an unpleasant treatment for exacerbations of COPD, experienced this as a 'punishment' for their 'self-inflicted' disease.[118]

In contrast, in the studies included, patients with lung cancer did not describe encountering stigmatising attitudes from HCPs. Only one patient in one study was concerned that their care would be affected because of the links the disease had to smoking.[158]

Social isolation (secondary construct)

Self-imposed social isolation

Frequently, patients with lung cancer and COPD experienced social isolation because of their illness.[36,37,42,53,66,74,76–80,82,96,101,102,111,114,126,127,133,136,139,143,145,156,161,162] This might be self-imposed because of embarrassment about visible symptoms (such as breathlessness and cough), medications (such as inhalers) or health technologies (such as oxygen) that mark patients as ill and therefore expose them to the threat of enacted stigma.[42,77,87,90,91,137,142,143] Additionally, in COPD, self-imposed isolation was also used as a self-management technique to avoid exacerbation triggers (such as the risk of infection from crowds).[76,111]

Involuntary social isolation

Social isolation might likewise be involuntary in both lung cancer and COPD as friends withdrew and social networks contracted.[50,53,82,101,136,143,156] Patients reported feeling 'contagious' (p.734)[50], (p.145).[136]. In both conditions, social isolation was also a result of common psychological comorbidities such as depression, low mood and anxiety following diagnosis leading to avoidance of social situations.[53,78,79,82,101,102,156]

Patients with COPD reported that the practical and logistical challenges of the treatment workload itself (eg, the weight of portable oxygen cylinders, the fear of running out of oxygen while waiting for appointments, having complex technologies such as non-invasive ventilation at home) further added to involuntary social isolation.[38,42,58,59,69,73,79,108,111,126,137,139–141,143] In COPD, involuntary social isolation also appeared to worsen with disease progression and the consequent relentless deterioration of physical function.[37,74,80,82,127,139,161,162] This clearly extended beyond the patient to affect the informal caregiver as their responsibilities increased with the pathophysiological decline of the patient.[36,37,74,76,80,133,136] In the papers included, there were fewer accounts of this from patients with lung cancer, perhaps because of the typically short disease trajectory.[96]

DISCUSSION

Illness as agent; patient as agent

The over-riding discourse evident throughout the lung cancer studies is that of 'illness as agent'. Patients with lung cancer, informal caregivers and HCPs immediately recognise lung cancer as an existential threat. In order to stave off death, the significant demands of treatment workload become the over-riding life priority in what is typically a short illness trajectory. Patients with lung cancer have to undergo a gruelling treatment workload in secondary care, with potentially debilitating pathophysiological side effects but limited delegated tasks from HCPs. This workload is generally well supported by an immediacy of access to healthcare institutions and specialist HCPs and a typically clear and structured treatment pathway. Patients with lung cancer often regard the practicalities of the treatment workload as a relief from the cognitive burden the existential threat of their illness identity has imposed. Patients and informal caregivers use the simile of 'treatment as hope' and may be reluctant to stop treatment, despite potentially devastating side effects.

Conversely, the recurrent theme throughout the COPD studies is that of 'patient as agent'. Patients do not recognise or understand their illness and therefore do not consider it a terminal disease. Consequently, the demands of treatment workload are balanced with the domestic, professional and sentimental demands of the workload of everyday life throughout the typically long illness trajectory. Patients with COPD are delegated a wide range of highly complex treatment tasks by HCPs to self-manage at home. This workload may be made more onerous by difficulties of access to, and navigation of, primary and secondary healthcare systems, generalist professional gatekeepers who lack understanding of COPD and a fragmented treatment pathway that does not meet the needs of home-based self-management. Synthesis of patient and informal caregiver accounts demonstrates that poorly supported self-management is hard, unrelenting work for patients with COPD and their informal caregivers. Patients and their informal caregivers can build up strategies over time to self-manage their condition more effectively, particularly when supported by healthcare provision such as PR. Nonetheless, pathophysiological deterioration and increasingly complex management and treatment regimens mean that the demands of the treatment workload over the long disease trajectory accumulate. Thus, institutionalised care that temporarily relieves patients and informal caregivers of the practical, affective and cognitive workload of self-management may be seen as a welcome respite from self-management. Yet patients with COPD often lack access to such specialist, institutionalised care, especially at the end of life.[112,163]

Social skill, capital and structural resilience

Patients with lung cancer and COPD are typically able to draw on the support of family and friends which enhances their social skill (the extent to which they are able to secure the cooperation and coordination of others) and social capital (their ability to access informational and material resources), bolstering their structural resilience (their potential to absorb adversity).[1] Like patients themselves, informal caregivers of patients with lung cancer recognise cancer's existential threat and prioritise supporting the treatment workload over the demands of everyday life. This support can be a cathartic and life-enhancing process for patients and informal caregivers alike. While this can also apply in COPD, informal caregivers often lack choice in taking on the caregiving role, describing an inexorable process of accumulating responsibility over the long disease trajectory as patients' functional performance deteriorates. In lung cancer, informal caregivers may also lack choice in taking on the caregiving role but the disease trajectory (and thus the caring trajectory) is shorter.

The 'weaker ties'[164] of peer support are extremely important in enhancing the social skill and capital of patients with COPD and bolstering structural resilience. In lung cancer, because of its high mortality and short disease trajectory, patients are less likely to need peer support, or indeed, be able to access it as their peers die around them.

Illness-related and especially smoking-related 'felt' and 'enacted' stigma degrade the social skill and capital of patients with both conditions. The invisibility of both conditions, unless 'marked' by treatment means that patients may attempt to conceal their condition, leading to social isolation. Social isolation is increased by the psychosocial impact of diagnosis and pathophysiological deterioration caused by both illness and the side effects of treatments. Stigma and social isolation and the consequent loss of opportunities to use social skill and access capital reduces the structural resilience of patients with both conditions.

Strengths and limitations

This systematic review and qualitative synthesis differs from previous reviews on BoT. BoT has been examined generally across many conditions,[2 12] with capacity considered specifically.[3] Other systematic reviews are condition specific: heart failure[8 10] and stroke.[9] Yet more consider treatment burden in multiple chronic conditions: diabetes, chronic kidney disease and heart failure[6] and chronic kidney disease, heart failure and COPD.[165] This review, like May *et al*,[165] considers patient and caregiver interactions with healthcare services in order to characterise treatment burden but identifies primary qualitative papers rather than systematic reviews and meta-syntheses.

To the best of our knowledge, this review is the first to explicitly compare BoT in malignant and non-malignant disease. As such, it offers a novel review which synthesises patient and informal caregiver perspectives on BoT in malignant and non-malignant disease across a range of healthcare systems and settings. It identifies and characterises BoT in lung cancer and COPD through the development of a taxonomy (table 2). This has important implications both for researchers seeking to understand BoT and for clinicians, as they seek to ameliorate the impact of treatment on respiratory patients and their informal caregivers. We have made recommendations for clinical practice which can be found in box 1.

Box 1 Recommendations for clinical practice

- Patients living with respiratory disease and their informal caregivers may experience treatment as hard work. Equally, patients and caregivers may see treatment as 'hope' and therefore be reluctant to stop.
- Patients' capacity to undertake the treatment workload may be enhanced and/or diminished by diagnosis. Consideration should be given to the volume of treatment workload delegated to the patient/informal caregiver and their capacity undertake this workload. Clinicians could use the taxonomy (table 2) to aid and support consideration and discussion of workload and capacity.

The heterogeneity of the papers included is both a strength and limitation of this synthesis. The heterogeneity of papers means uniformities identified through the taxonomy should facilitate the development of an explanatory model of BoT.[166] However, the taxonomy has been developed from descriptions of patient experience taken *out of context*. It describes the generalities of patient experience across multiple healthcare systems and settings, rather than considering factors such as socioeconomic status and the attributes of healthcare systems that have been shown to be important in the consideration of BoT.[1] Furthermore, qualitative research is, necessarily, interpretative and therefore the data analysed, while ostensibly from primary sources, are seen through the multiplicity of theoretical lenses chosen by the studies' authors and their varying epistemological and ontological stances. Finally, this paper itself uses an interpretative framework for synthesis and therefore results are refracted through the authors' own lenses.

We limited our search to publications between January 2006 and December 2015 as we intended to identify BoT in COPD and lung cancer with the aim of informing *current* healthcare practice and policy. In their discussion of the methodological challenges of reviewing patient experience of treatment burden in stroke, Gallacher *et al*[7] highlight how the management of chronic disease has changed dramatically in recent years. We believed it was important, therefore, that pertinent (and thus more recent) literature was identified and reviewed to ensure that patient experience of treatment burden was based on current rather than historical healthcare practices. The systematic review took some time to undertake and write up, hence publications after December 2015 are not included which is a limitation.

We excluded studies that were not in peer-reviewed journals (ie, grey literature) and studies that are not in the English language because of resource constraints which could be regarded as a limitation.

What is not in the literature?

The studies identified focus almost exclusively on the index conditions of lung cancer and COPD. Studies focus on lung cancer or COPD, whereas many patients may have both lung cancer and COPD.[167]They do not discuss the issue of multimorbidity which is common in both conditions[168 169] and is likely to have a significant impact on BoT.[4]

CONCLUSIONS

This interpretative synthesis of qualitative literature on patient/informal caregiver interactions with healthcare in lung cancer and COPD demonstrates that the workload of treatment may be very different in each condition. The sociocultural status of cancer as one of the most feared of all diseases[60 61] means that 'illness is agent'. Thus, lung cancer patients are required to subordinate the demands of everyday life to the demands of the treatment workload. Patients have little choice but to follow a structured treatment pathway, in healthcare systems that generally meet the needs of their typically short diseases trajectory. Conversely, in COPD, patients are expected to exert agency over their own condition, 'empowered' to self-manage, integrating the demands of the treatment workload into their everyday life. Patients have to identify their own treatment pathway, navigating between institutions, in healthcare systems that are not set up to meet the needs of their uncertain and often lengthy disease trajectory. The differences in the treatment workload of lung cancer and COPD identified by this synthesis resonate with other qualitative studies comparing cancer with other chronic conditions (predominantly heart failure but also COPD and motor neuron disease).[61 170 171]

Despite the differences of the treatment workload between conditions, this interpretative synthesis has demonstrated the importance of the personal and collective capacity available to patients and their informal caregivers in both conditions, suggesting that a workload which exceeds capacity is likely to be a primary driver of treatment burden.

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Acknowledgements The authors thank Dr Jonathan Harvey for his assistance with the literature searches, screening and development of coding framework; Dr Katherine Hunt for acting as impartial arbiter in cases of disagreement about inclusion in this review and Martin Simpson-Scott for his assistance with data preparation. We also gratefully acknowledge the support and advice of the late Mark Stafford-Watson, patient advisor to NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Wessex.

Contributors KAL drafted this paper. KAL, AR and CRM developed the conceptual framework informing this study. KAL designed the review with assistance from CRM and AR. KAL and CRM assisted by AC and MM undertook literature searches. KAL assisted by AC, MM and CRM screened titles, abstracts and full papers. KAL, CRM, MM and AC developed the BoT/status passage coding framework. KAL performed first-line content analysis and constant comparison. CRM and AR critically reviewed the manuscript for important intellectual content; all authors approved the final version of the paper. KAL is guarantor.

Funding This work was supported financially by the Health Foundation and non-financially by the NIHR CLAHRC Wessex which is a partnership between Wessex NHS organisations and partners and the University of Southampton.

Competing interests KAL reports grants from The Health Foundation, non-financial support from NIHR CLAHRC Wessex, during the conduct of the study; personal fees from Glaxo Smith Kline, grants and personal fees from Boehringer Ingelheim, personal fees from Teva, outside the submitted work.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data are available.

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