University of Southampton

Faculty of Environmental and Life Sciences

School of Health Sciences

What is Burden of Treatment and how is it experienced by patients living with lung cancer or chronic obstructive pulmonary disease?

by

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Abstract

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People living with illness experience a potentially modifiable treatment workload which can be exacerbated or ameliorated by the organisation and delivery of healthcare. Where treatment workload and the demands of daily life exceed capacity, treatment burden may occur. The ways that 'workload' and 'capacity' interact to create treatment burden have not yet been fully characterised and understood.

This thesis consists of three published or publishable papers which aimed to identify, characterise and explain treatment burden in patients living with lung cancer or chronic obstructive pulmonary disease (COPD). The papers were underpinned by an abductive approach to study design, data collection and analysis which worked iteratively and recursively with empirical and theoretical materials to identify and characterise treatment burden.

The first paper reported a systematic review and interpretative synthesis of literature concerning patients with COPD or lung cancer and their informal caregivers' interactions with health/social care. The second paper set out a cross-sectional, qualitative, comparative analysis of patients' lived experiences of treatment in lung cancer or COPD (semi-structured interviews with patients receiving specialist care *n* = 19; specialist clinicians *n* = 5; non participant observation of specialist outpatient clinics (11 hours, 52 minutes) *n* = 41). The third paper presented a conceptual model of potentially modifiable factors associated with 'workload' and 'capacity' in illness and delineated the hierarchical relationships between each.

This resulted in the development of a taxonomy of treatment burden in COPD and lung cancer, characterising how, in lung cancer, the disease was seen to exert agency over patients, taking priority over daily life. Patients were not expected to direct their intensive, hospital-based, treatment workload. Capacity (from friends/family and the healthcare system) was made available. In COPD, patients were seen to be able to exert agency over their disease and were expected to direct their intensive, home-based, treatment workload. Capacity was less readily available, and patients had to work to mobilise it. Analysis enabled the interrogation and refinement of the taxonomy of treatment burden, contrasting the biographically disruptive diagnosis of lung cancer with the biographically erosive diagnosis of COPD and associating this with both 'workload' and 'capacity'. First, the extent to which capacity was available to patients, and social skill was required to mobilise it. Second, the priority given to and the nature of the treatment workload. Conceptual modelling work identified potentially modifiable factors shaping 'workload' and 'capacity' in illness. Those shaping capacity were: 1) social skill 2) structural resilience 3) illness trajectory. Those shaping workload were: 1) structural (dis)advantage 2) how patients experience healthcare services 3) understanding of disease 4) normative expectations of motivation to participate in workload.

These series of investigations have determined that treatment burden is more than simply the work that patients must do to meet the demands of treatment regimens. Instead, treatment burden is a complex, multidimensional and situational concept which occurs as a result of interactions between illness identity, workload and capacity and the potentially modifiable factors associated with each.

Table of Contents

Table of Tables

Table of Figures

Research Thesis: Declaration of Authorship

Print name:	Katharine Alice Lippiett Chapple

Title of thesis:	What is Burden of Treatment and how is it experienced by patients living with lung cancer or chronic obstructive pulmonary disease?

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Parts of this work have been published as:

Lippiett KA, Richardson A, Myall M*,* Cummings A, May, CR (2019)
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 doi: 10.1136/bmjopen-2017-020515

8. The project supervisors, Professors Carl May and Alison Richardson oversaw the design, conduct and write up for each of these papers. Dr Michelle Myall and Dr Amanda Cummings provided assistance with the literature searches and screening of papers in addition to supporting the development of the coding framework used in the systematic review and commented on the draft of the paper. They are therefore listed on co-authors on the systematic review paper. Dr Jonathan Harvey also provided assistance with literature searches and screening and supporting the development of the coding framework. Dr Katherine Hunt acted as impartial arbiter in cases of disagreement about inclusion of papers

in the systematic review. The late Mark Stafford-Watson (a patient living with chronic respiratory disease) helped develop the research questions that underpinned this thesis. Martin Simpson-Scott, Jamie Stevenson, Jonathan Lightfoot and the Southampton Design Centre assisted with formatting of tables and figures. No changes in intellectual content were made as a result of this assistance.

9. I designed, analysed, interpreted and wrote this thesis with supervision, advice and comments from the project supervisors, Professors Carl May and Alison Richardson.

Signature:		Date:	01 October 2019

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This thesis is dedicated to the memory of Olivia Tamsin Morgan 31.12.2014 to 24.2.2016 whose little, but joyous, life ended shortly after my PhD journey began. There are many similarities between a PhD and a quest, and Olivia's memory has been to me as Galadriel's glass was to Frodo and Sam in JRR Tolkien's 'Lord of the Rings' "a light to [me] in dark places when all others go out" (1).

This thesis is also dedicated to the memory of Norman Kenneth Chapple 17.3.1926 to 12.7.2019 whose long life ended shortly before my PhD journey finished. Despite Norman's advanced dementia, he never failed to check on my PhD progress.

I'd like to acknowledge the support of my supervisors, Carl May and Alison Richardson who have supported me both professionally and personally over the past four years. They have completely changed the way that I think and helped me piece it back together. They have supported me in times of trouble and been my cheerleaders in good times. I could not have completed this journey without their inspiration, support, mentorship and kindness.

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Chapter 1 Introduction

1.1 Background

1.1.1 Epidemiological and demographic shifts in healthcare

Health care has been transformed globally through the eradication of previously lethal infectious diseases and the development of more effective medication and technologies (2, 3). Populations are ageing and, concomitantly, behaviours not conducive to positive health outcomes (such as alcohol and tobacco use) are escalating on a global scale (4, 5). This means that, increasingly, people are living longer with non-communicable diseases (NCDs). Particularly common are cardiovascular and respiratory disorders, cancer and diabetes (5). NCDs have been characterised as diseases of often long duration, and generally slow progression (6). NCDs are the chief cause of worldwide adult mortality and morbidity, with 63% of deaths attributed to NCDs (7).

These epidemiological and demographic changes have brought about a concomitant shift amongst healthcare providers (systems and professionals), from treating and (possibly) curing discrete incidences of acute illness to managing disease (and potentially co-morbidities) over a lifetime (8, 9). This has fuelled a policy response aiming to re-orientate the provision of healthcare from hospital-based models to approaches where patients are managed or "self-manage" increasingly complex treatment regimens in the home (10). Thus, health systems increasingly expect patients to participate actively in the management of their disease, sharing the work of healthcare with the professional workforce (2, 11-13).

1.1.2 The work of *illness* for patients

As people live longer with disease, they will almost inevitably have to engage with healthcare systems for treatment of their illnesses. This engagement with healthcare systems for treatment has been characterised by various writers as '*work'*.

Such characterisation is not new. An influential American sociologist, Anselm Strauss (1973) first characterised the demands of chronic illness in *social* rather than purely biomedical terms (14). He identified the tasks that people living with chronic illness were obliged to carry out daily: the prevention/management of medical crises, managing treatment regimens and symptoms, time management, dealing with social isolation, adjusting to changing disease trajectories and normalising interactions in everyday life. Strauss began to articulate the, as yet undefined, concept of treatment burden, highlighting the potential difficulties of such healthcare work, and particularly stressing this in relation to adherence to treatment regimens: “regimens can sometimes set problems so difficult that they may present more hardships than the symptoms themselves” (ibid, p.109). Additionally, he suggested that, in order to meet these demands, people living with chronic illness had to organise the efforts of family, friends and healthcare professionals. According to Strauss, patients required “interactional and social skills” to mobilise material resources (familial, medical and financial) to establish and maintain this organisation of effort (ibid, p.108).

Subsequently, Strauss and colleagues (1982), in a multi-hospital field research and interview study, explicitly conceptualised patients’ participation in their own care as “work” (p.977), emphasising that much of this work is invisible to both healthcare professionals and patients (9). In 1985, Strauss and his colleague, Juliet Corbin, went on to interview 60 couples with multiple chronic conditions to examine the work done by people living with chronic conditions and their spouses (15). Their pivotal paper explicating the data from this study, ‘Three Lines of Work’, discussed the interplay between illness work (managing symptoms, taking medications and managing crises), everyday work (domestic tasks such as housework and childcare and paid employment) and biographical work (the work individuals might have to do to reconstitute identity following a diagnosis of chronic illness). Alongside the concept of work, Corbin & Strauss discussed the concept of the resources required to meet the demands of each “line of work” (ibid, p.234). These resources might be material – for example, technology, space or finances; affective, or relational – for example, the emotional support of others. Corbin & Strauss emphasised that, frequently, resources were inadequate and therefore each line of work competed for priority in order to determine how finite resources should be allocated.

Charmaz, at one point a doctoral student of Anselm Strauss, has also written extensively on the experience of living with chronic illness. In multiple formal and informal interviews with patients, informal caregivers and healthcare providers. Charmaz (1991) explored, amongst other things, how patients fitted the experience of living with chronic illness into the context of everyday life (16). She suggested that people living with chronic illness must plan and manage the tasks relating to their illness alongside the tasks of daily life. This organisation of tasks might involve not only the person living with chronic illness but the whole family. Importantly, like Corbin & Strauss, Charmaz emphasised how illness work is biographical work: work that requires the re-constitution of identity. Thus, people living with chronic illness must revise their future plans and their expectations of self. This revision might happen repeatedly throughout an illness trajectory as pathophysiological deterioration impacts on physical functioning.

1.1.3 The work of *treatment* for patients

In 2009, May, Montori & Mair published a paper based on their separate but complementary bodies of work on healthcare interventions for diabetes and heart failure; patient experiences of new technologies and the routinisation of patient work in chronic disease in the United Kingdom (UK) and United States of America (USA). This paper called for "minimally disruptive medicine", an approach to healthcare that takes into account patient priorities, multi-morbidity and the impact of treatment workload on patients and family members (2).

This paper distinguished between the workload of illness (the unavoidable workload that disease inevitably confers on patients/family members) and the workload of treatment (a potentially *modifiable* workload which treatment for that illness creates). Importantly for this thesis, May and colleagues articulated the concept of treatment burden, suggesting that the work of managing chronic disease, with its ever more multifaceted treatment regimens, might overwhelm patients. Consideration of treatment burden is important because it could lead to poor adherence to prescribed treatments and self-management regimens, potentially resulting in adverse clinical outcomes. These adverse clinical outcomes could include increased hospitalisation, higher mortality and worse health-related quality of life (2). Subsequent studies have repeatedly re-emphasised these potentially negative consequences of treatment burden (17-20). Additionally, others have highlighted how treatment burden might lead to an inefficient use of healthcare resources (8, 21). Elements of treatment burden could be exacerbated or ameliorated by health policy and/or how health services were provided and configured (22).

1.2 Thesis research question, aim and objectives

1.2.1 Research question

What is Burden of Treatment and how is it experienced by patients living with chronic obstructive pulmonary disease (COPD) or lung cancer?

1.2.2 Aim

The body of work described in this thesis aims to identify, characterise and explain treatment burden through a comparison of patients' common and specific experiences of workload and capacity in two common respiratory conditions, COPD and lung cancer.

1.2.3 Objectives

1. To identify, characterise and explain patients' experiences of workload and capacity in people living with COPD or lung cancer
2. To interrogate and refine the concept of burden of treatment itself, specifically focusing on the constructs of workload and capacity
3. To identify and characterise potentially modifiable factors associated with workload and capacity, either condition specific or applicable to both COPD and lung cancer
4. To identify and characterise if and how treatment burden is manifest in the clinical encounter for patients with COPD and lung cancer
5. To build an empirically derived conceptual model to explain common and specific features of burden of treatment with recourse to COPD and lung cancer
6. To use the empirically derived conceptual model to identify targets for supportive interventions which might be introduced into routine clinical practice to ameliorate treatment burden

1.3 Overview of thesis

The work presented in the thesis is for the purposes of a PhD by publication. This thesis sets out to tell the story of a body of work, explaining how each of the studies described in the three papers interweave and integrate to create a conclusion that is greater than the sum of the papers themselves. The thesis comprises an introduction, three papers and a discussion of the findings. The three papers include:

1. A qualitative systematic review and interpretative synthesis of the international literature concerning patients with COPD or lung cancer and their informal caregivers' interactions with health and social care systems. This developed a taxonomy of patients' experiences of treatment aiming to identify and characterise treatment burden in COPD or lung cancer.
2. A cross-sectional, qualitative comparative analysis of patients' lived experiences of treatment in COPD or lung cancer using two complementary qualitative methods (non-participant observation and semi-structured interviews). This interrogated and refined the taxonomy developed from the systematic review, further identifying and characterising treatment burden in COPD or lung cancer.

3. A systematic, abductive integration of the theoretical and empirical literature developing a conceptual model of burden of treatment in illness. This aimed to identify, characterise and *explain* treatment burden in illness.

Figure 1 summarises the interrelationships between the three papers constituting the core of the thesis.

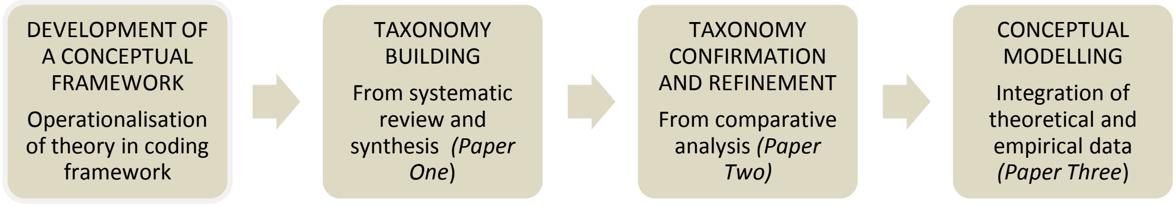


Figure 1: Overview of thesis

1.4 The literature on treatment burden

This section outlines the key empirical and theoretical literature on treatment burden and explores the fundamental constructs of treatment workload and patient capacity that make up the concept of treatment burden.

1.4.1 The empirical literature on treatment burden

Research explicitly seeking to identify and characterise treatment burden has grown exponentially in the past decade since May et al's influential paper (2). It now includes a plethora of qualitative studies, mainly focusing on patients living with multiple or various chronic conditions (17, 18, 23-26). Qualitative research also covers specific conditions such as cystic fibrosis (27), heart failure (19), end-stage renal disease (28), chronic kidney disease (29), asthma (30), COPD (31), stroke (22) and kidney transplants (32). Alongside these qualitative studies sit several systematic reviews. These are condition-specific systematic reviews (heart failure (33), stroke (20), chronic kidney disease (34), COPD and lung cancer (35) and systematic reviews that include studies of treatment burden in a range of chronic conditions (36-39). The literature also includes a scoping review of literature on the measurement of the burden of treatment in chronic disease (8).

These qualitative studies/reviews have been supplemented by quantitative research using survey methods in stroke/diabetes and multi-morbidity (40-42) and a retrospective cohort study in lung cancer (43). Other studies have also used mixed methods (interview and survey) in multi-morbidity (44-46). One further study used quantitative content analysis to analyse videos of consultations with patients with diabetes (47)

Many of the quantitative studies set out to conceptualise and operationalise the measurement of treatment burden. Eton and colleagues from the Mayo Clinic in the USA have developed and validated a 78-item patient reported measure for treatment burden (40). Duncan and colleagues in the UK have based their 10-item measure of treatment burden in multimorbidity on Eton's work (46). Similarly, Tran and colleagues have developed a 13-item Treatment Burden Questionnaire, originally developed in French and translated to English (48). Sav and associates acknowledge these measures provide a useful preliminary basis for the understanding of levels of treatment burden. However, they emphasise how time constraints may prevent clinicians from assessing treatment burden through the administration of lengthy questionnaires (8).

1.4.2 Workload

Treatment burden has been predominantly characterised in relation to workload. So, treatment burden was defined by Eton and colleagues in 2012 as "the workload of health and its impact on functioning and well-being" (18)(p.40). This definition, with its emphasis on treatment burden as the *workload* of healthcare, has persisted in the literature (22-24, 31, 32, 40, 41, 49).

In the literature discussed and referenced above, the workload of treatment for patients is mainly characterised in practical terms – describing the material tasks that patients and their family members are expected to do. These include:

- learning about illness, its treatments and their consequences
- adhering to complex treatment and medication regimens
- changing lifestyle behaviours
- attending medical appointments
- monitoring/appraising self-care activities

The workload of treatment has also been characterised in terms of its psychosocial impact on patients. Demain et al (36) have identified and characterised the psychosocial impact of treatment workload on an individual's identity, relating this to Bury's work on "biographical disruption" (50) (p.13). A diagnosis of chronic illness was seen by Bury as a disruptive event, requiring the individual to “re-think fundamentally their biography and self-concept” (ibid, p.169). Demain and colleagues have described how “biographically disruptive” the impact of the treatment workload itself can be on an individual’s identity, restricting important activities, curtailing independence and often provoking negative affective states (36)(p.15). Gallacher and associates have similarly characterised the impact of treatment workload on identity, using normalisation process theory to highlight how patients and family members must adapt to the altered sense of self that illness and treatment regimens for illness confer (20).

Additionally, Demain et al characterised how “relationally disruptive” the impact of the treatment workload can be, placing strain on family and other relationships often leaving patients feeling isolated (36). Likewise, May et al further characterised the work of healthcare in relational terms, suggesting that, in order to meet the demands of treatment, patients must work to form and sustain relational networks (3). Within these relational networks, patients must allocate and undertake tasks delegated to them by healthcare providers/systems, evaluating their performance against expected tasks and applying this appraisal to the reconfiguration of work over their illness trajectory.

There is an acknowledgement in the literature of the importance of recognising that the work of healthcare for patients and their family members does not exist in a vacuum. Thus, workload is often characterised as the work of everyday life, illness *and* treatment – indeed “all the tasks and responsibilities people grapple with on a day to day basis” (21). This resonates with the characterisations of work as ineluctably embedded in a social context discussed in section 1.1.2 (9, 14-16)

1.4.3 Capacity

In addition to the concept of workload, the literature on treatment burden discusses the concept of *capacity*. Capacity is a more nebulous concept than workload and is thus more difficult to define and measure (49). Shippee and colleagues have characterised capacity as “the abilities, resources or readiness to address demands, including physical/mental functioning, socioeconomic resources, social support, literacy and attitudes/beliefs” (21)(p.1042). Boehmer’s (2016) influential systematic review suggested that patient capacity is associated with interactions between “biography, resources, environment, patient and life work and social network” (49) (p.4). The ability to reframe one’s biography to encompass the diagnosis of illness and its treatments was associated with capacity. Capacity was also associated with an individual’s own qualities (for example a person’s skill in socialising) and those of their social network (to what extent their social network was able to accept their diagnosis and to provide support).

It has been argued that capacity should not be simply defined as resources but rather resources that patients must *mobilise* (3, 49). This resonates with Strauss's contention discussed in section 1.1.2 above that patients require "interactional and social skills" to mobilise resources (14). May and colleagues also suggested that patients require social skill – the extent to which they can secure the cooperation of others (51) – to mobilise capacity (3). Thus, capacity is *maintained* through structural resilience – (the ability of an individual and their significant others to absorb adversity) (3). Capacity is an important concept as it may explain why patients differ in their capability to enact treatments and engage with healthcare providers (22).

Neither workload nor capacity is static. Indeed, both are likely to fluctuate over an individual's illness trajectory with disease progression, decline in physical function and as patients' social networks change or as the patient is able to accept, adapt and normalise their condition into their daily life (21, 22, 39, 49). Both capacity and workload are likely to be context-specific. For example, depending on the healthcare system within which the patient is sited, patients might have to negotiate insurance or welfare systems to pay for their treatment (34). Workload and capacity do have significant differences however. The demands of workload are potentially infinite, but capacity is finite and thus an important element of mobilising capacity is making decisions about how it might be shared between the demands of different lines of work (e.g. the work of illness/treatment and everyday life) (21, 49).

1.4.4 The theoretical literature on treatment burden

Underpinning the literature described above are two significant conceptual models/theories. First a heuristic conceptual model, integrating existing literature on patient complexity, developed by Shippee and colleagues: the cumulative complexity model (21). Second, burden of treatment theory (BoT), a middle range theory developed through discussions between May and colleagues and based on their accumulated empirical research on the work of patient-hood (3). Middle range theories apply to discrete conceptual ranges rather than aiming to explain systematically society's uniformities (52).

1.4.4.1 The cumulative complexity model

In the cumulative complexity model, Shippee and colleagues set out to explain the relationship between workload and capacity and characterised the cumulative complexities that may arise and accumulate from interactions between patients and healthcare providers over an illness trajectory (21). Importantly, the cumulative complexity model suggests that treatment burden, which is defined as "disruptions in care, self-care and outcomes", is primarily driven by a "workload that exceeds capacity" (ibid, p.1042). This proposition that a workload that exceeds capacity is the primary driver of burden has had perhaps the most influence on driving this body of work. It has been used as a guiding proposition throughout each stage of this series of investigations which have empirically demonstrated its likelihood by the collation of plausible and credible evidence (53).

1.4.4.2 Burden of treatment theory

May and colleagues (2014) in their explication of burden of treatment theory also identified and characterised the interaction between work and capacity, suggesting that interventions that allowed patients to mobilise social skill and bolster their structural resilience were likely to increase their capacity to undertake their treatment workload (3).

Both of these pivotal works were based on retrospective reviews of the authors' previously undertaken empirical work allied to narrative reviews of the literature. While these works provide an important starting point, the literature itself makes it clear that there remains further work to be done to conceptualise the emergent concept of treatment burden (36). Gallacher's ground-breaking series of studies on the burden of treatment in stroke (20, 22) demonstrated the importance of condition-specific conceptualisations of treatment burden. Sav et al's (2017) useful scoping review of treatment burden concluded that there is "much to gain" from further exploratory qualitative research in "specific populations" to conceptualise and understand treatment burden (8)(p.10).

1.5 Complementary theory: status passage theory

In addition to using burden of treatment theory and the cumulative complexity model, this thesis has used status passage theory as a lens through which to approach the research question framing this body of work. Glaser & Strauss (1971) developed their characterisation of the phenomena of "status passages" through their empirical work on careers: in organisations, in institutions, in illness, in dying patients and in clinical education (54). Their theory outlined how individuals traversed different stages, "status passages" throughout their lives**.** These statuses were societally ascribed and temporally limited – no individual was assigned or assumed a status passage forever. Thus, status passages are not static but are rather processes of biographical *change.* Glaser & Strauss articulated 14 key properties of status passage as fruitful questions for the social scientist (see Table 1 below).

Table 1: Key properties of status passage

Is the status passage desirable? (e.g. marriage is generally thought to be desirable)
Is the status passage inevitable? (e.g. the passage from childhood to adulthood)
Is the status passage reversible (totally or to some degree)? (e.g. an individual may recover from an illness)
Is the passage repeatable or non-repeatable? (e.g. a politician may repeat his/her term in office)
Does the passagee (the individual traversing the passage) go through the passage alone, collectively or in aggregate with others? (e.g. students may go through university in cohort with others)
Is the passagee aware of others going through the same or similar passages? (e.g. people living with illness may join peer groups)
Is the passagee aware of others going through similar status passages but may be unable to communicate with them? (e.g. junior executives in a large organisation who are simultaneously being demoted)
Is the status passage involuntary or is there a degree of choice in the passage? (e.g. imprisonment is an involuntary passage)
What amount of control do different agents (including the passagee) have over features of the passage? (e.g. parents may choose schools for their children)
Does the status passage entail legitimation by one or more societally sanctioned agents? (e.g. a priest may officiate at a marriage)
How clear are the signs of status passage to the passagee and to other relevant parties? (e.g. an individual may not be aware that s/he is ill)
Is the status passage clear to the passagee and/or relevant parties? (e.g. an individual may conceal their illness from family members; a clinician may conceal the severity of an illness from a patient)
How central is the passage to the passagee – i.e. how much difference does the passage make to him/her? (e.g. imprisonment may make a significant difference to the passagee)
How long is the passage? (passages may be of short duration (e.g. a university course) or of long duration (e.g. marriage)

Individuals are likely to be traversing more than one passage simultaneously. Multiple passages may be complementary, supporting one another, or competitive, their demands on the limited resources of individuals jostling for position.

This thesis has chosen to use the theory of status passage to approach the characterisation of treatment burden for several reasons.

First, although status passage theory is a middle range theory and, therefore, is not solely applicable to illness, Glaser & Strauss often used the illness trajectory as an *example* of status passage. So, they characterised the illness passage as an undesirable, inevitable, involuntary and often irreversible status passage, legitimised by doctors as societally sanctioned “authorised agents”.

Second, status passage theory was an apposite tool to support the conceptualisation of how the phenomenon of treatment burden might change over time. The cross-sectional rather than longitudinal design of the comparative analysis of patients’ experiences of treatment in COPD or lung cancer set out in chapter three makes this theoretical consideration particularly useful.

Third, status passage theory facilitated the consideration of the illness trajectory and its associated workload of treatment in the context of the demands of other status passages. The cumulative complexity model’s characterisation of treatment burden as a workload which exceeds capacity, defined workload as not only treatment workload but “all the tasks and responsibilities people grapple with on a day-to-day basis. This encompasses everyday life demands *plus* the responsibilities of patient-hood, including job/family, self-care, clinical appointments and other priorities” (21)(p.1042). So, workload was the sum total of the demands of all the status passages in an individual’s life. Status passage theory was, therefore, particularly helpful in conceptualising how workload in one status passage might affect others. Importantly, Glaser & Strauss related this specifically to the illness trajectory. They suggested that the priority given to illness passages might vary depending on how they were experienced by individuals (and the ones closest to them). Illness passages might be experienced as a “crisis” (54)(p.144), a shock that, temporarily or sometimes permanently, subsumed the demands of other status passages, both of the passagee and of their significant others (usually close family members). Contrastingly, Glaser & Strauss also argued there might be situations in which individuals were unaware that they were going through an illness passage and, indeed, even doctors as legitimising agents might not be aware that the passage existed (54).

1.6 Epistemology and ontology

1.6.1 My own position

I am a white, English, female, respiratory nurse in my early forties with some prior experience of undertaking both qualitative and quantitative research. I have worked in the English National Health Service (NHS) both as a clinician treating patients with respiratory disease, particularly COPD, and as a manager in a variety of roles over the past twenty years. I have, therefore, been extensively immersed in NHS culture and this is likely to have influenced my approach to the research design, data collection and analysis. I have significantly more clinical experience in the care of patients living with COPD than I do of patients living with lung cancer which is also likely to have influenced my approach to this body of work. With my supervisors, I have considered my position reflexively throughout research design, data collection, and analysis, and in the writing up of this thesis.

1.6.2 Subtle realism

I have chosen to conduct this research from a subtle realist perspective. Hammersley (1992) defined knowledge in subtle realism as beliefs about whose validity the researcher is *reasonably confident* of, rather than *certain* about (53)(p.50). He argued that such confidence should be based on the "plausibility and credibility" of the evidence for such beliefs. In Hammersley's explication of subtle realism, he argued that there might be "independent, knowable phenomena" but the researcher did not have "direct access" to these phenomena (ibid, p.52). Instead, access to such phenomena is mediated through the cultural assumptions of the researcher and the subject(s) of research (53, 55). Murphy (2004) suggests that such a methodological underpinning is an apposite one for researchers into healthcare provision and organisation, recognising as it does, the impact of cultural assumptions upon accounts, whilst allowing for the search for knowledge about whose validity researchers are reasonably confident (56).

Hammersley concluded that the aim of social research was to *represent* rather than to *reproduce* reality as there could be "multiple, non-contradictory and valid" accounts of the same phenomenon (53)(p.51). This epistemological approach, therefore, allies itself well to the collection of accounts from a variety of sources.

1.6.3 Abductive approach

This thesis has taken an abductive approach to study design, data collection and analysis. This is a qualitative data analysis approach underpinned by pragmatism with the aim of constructing or developing theory (57-59).

The commonly used approach to the development or generation of theory in health services research is ‘grounded theory’, an inductive data analysis methodology developed by Glaser and Strauss in the 1960s (55, 57, 60, 61). Murphy and colleagues suggested that researchers who used ‘grounded theory’ would include the following approaches:

- The investigation would be driven by the aim to ascertain social/psychological processes
- Data collection and analysis would proceed concurrently
- The analytic methods used would lead to **theory discovery and refinement rather than the confirmation of preceding theory**
- Theoretical sampling would develop, elaborate and exhaust conceptual sets
- Methodical application of grounded theory analytic processes would gradually lead to more abstract analytic levels

(55) (p.143)

Thus, one of the key tenets of ‘grounded theory’ is the importance of an inductive approach, where theoretical analyses result from the data rather than explicitly considering existing theories. Therefore, such an approach would not appropriately answer the research question underpinning this body of work. Indeed, the approach to this body of work is predicated on *multiple* theories: burden of treatment theory, the cumulative complexity model and status passage theory. Abductive analysis emphasises the importance of the detailed knowledge of multiple theories, thus it contrasts not only with grounded theory but also with a deductive approach which may assume that only one theory at a time can be used to approach a research study (57). In abductive analysis, as empirical data collection continues, complementary theories may be added in to illuminate insights generated from the empirical materials (57, 58). An abductive approach, therefore, depends on moving iteratively and recursively between an initial theoretical framework and accumulated empirical and theoretical materials to identify, characterise and explain the phenomenon of interest. This allows the researcher to better understand both the initial theoretical framework, the empirical phenomena under study and, ultimately, to develop or construct new theory (57, 58).

Timmermans and Tavory (2014) argued that the systematic analysis of variation underpins an abductive approach (57). The search for variation allows the researcher to identify similarities and difference in the phenomenon of interest. Timmermans & Tavory suggested three key ways of exploring variation:

1. Dataset variation (where different data about the phenomenon of interest are collected in similar situations)
2. Variation in the phenomenon of interest over time
3. Inter-situational variation (where data on the phenomenon of interest are collected in different settings and situations)

This body of work is designed, therefore, systematically to identify and characterise variation in the phenomenon of interest, burden of treatment, through an iterative and recursive examination of the accumulated theoretical and empirical data. Specifically, this thesis aims not only to identify and characterise similarities and differences in the features of the primary constructs of 'workload' and 'capacity' but to explain how the phenomenon of interest, treatment burden, occurs by careful mapping of the mechanisms through which such variations are generated (57, 58)

Silverman also emphasised the potentialities of the comparative method of sociological research. Indeed, he described comparison as "the backbone…of good sociological thinking" (62) (p.290). He suggested that identifying and characterising the similarities and differences between alike but different phenomena allows the researcher to identify and characterise the "deeper processes" behind these initially identified similarities and differences. Silverman argued that this enabled the researcher to create "sociological knowledge of the world", facilitating the construction or development of theory, explanation of phenomena (ibid, p.290).

1.7 Research design

1.7.1 Qualitative

I chose to use qualitative methods as the research question framing this thesis 'What is Burden of Treatment and how is it experienced by patients living with COPD or lung cancer?' aims to identify, characterise and explain patients' experiences of treatment. Qualitative research is a mode of enquiry that concentrates on the ways in which people understand their own experiences and make sense of the social world (63). Qualitative research aims to identify, characterise and explain "social phenomena in natural…settings" (64), exploring the behaviour, experiences and views of individuals, groups and cultures (63). Qualitative evidence has also been shown to be particularly well suited to research that aims to provide a detailed, rich and more complete exploration of complex phenomena (65), such as the phenomenon of interest for this body of work, burden of treatment. As previously discussed in section 1.4.4.2, researchers have suggested that further qualitative research is required to characterise and explain this emergent concept (8). Allied both to a subtle realist perspective which accepts the existence of more than one representation of reality, and to an abductive approach which systematically seeks out variation, and in discussion with my supervisors, both of whom are experienced qualitative researchers, I chose to use *multiple*, complementary qualitative methods to identify, characterise and explain burden of treatment.

1.7.2 COPD and lung cancer

I chose to look at burden of treatment in respiratory disease because of my background as a respiratory nurse. COPD and lung cancer are the most common cause of respiratory-related mortality in the United Kingdom (UK), excluding pneumonia (66). COPD is “characterised by persistent respiratory symptoms and airflow limitation…due to airway and/or alveolar abnormalities usually caused by significant exposure to noxious gas or particles” (67) (p.4). Interestingly and pertinently for this body of work, COPD is difficult to define precisely as it is a *mixture* of diseases, “small airways disease…and parenchymal destruction (emphysema)” (67)(p.4). The relative contribution of each of these pathologic states varies from individual to individual and may evolve at different rates over time (67). Again, interestingly and pertinently for this body of work, it has been difficult to *find* a useful working clinical or lay definition of lung cancer, perhaps because cancer is so generally understood. Lung cancer is very generally defined as a cancer that starts in the lungs, categorised by the type of cells in which the cancer begins. Non-small cell lung cancer is the most common type of lung cancer. Small cell lung cancer is less common but generally spreads faster (68).

In both conditions, tobacco smoking is the main risk factor, linked to an estimated 86% of lung cancer and 90% of COPD cases in the UK (69, 70). Tobacco is a legal drug which has, until recently, been broadly socially acceptable. More recently, recognition of the potentially substantial health risks and consequent public health strategies ‘de-normalising’ tobacco smoking have contributed to a social transformation where smokers appear to be actively stigmatized (71). Thus, both COPD and lung cancer have been shown to carry the stigma of ‘self-inflicted’ diseases caused by smoking (72, 73).

Cancer, the “emperor of all maladies” has a distinct public narrative globally and in the UK (74). In the UK, the risk of developing cancer over a lifetime is now 50% (75). Thus, patients usually understand what a diagnosis of cancer means and do not have to explain the disease to others as it is broadly understood by the general public. More than a quarter of all deaths (28%) in the UK are related to cancer (76). A recent survey showed that people feared cancer more than other diseases (77). Patients, family members and healthcare professionals recognise that the diagnosis of cancer may mean that death is imminent. Conversely, there is a lack of public awareness of COPD: most of the general public have never heard of COPD (78). Patients are given the diagnosis of COPD, but they and their informal caregivers may not understand what the disease is and its potentially life-limiting implications. Indeed, patients may continue with daily life as usual until, over time, the symptoms of the disease become disabling. Patients may not be given a formal diagnosis at all, instead accidentally discovering they have COPD through interactions with healthcare providers (for example, being told their inhalers are for COPD when visiting the pharmacist).

COPD generally has a prolonged trajectory of progressive respiratory worsening, often interspersed with persistent flare ups of the condition, known as exacerbations (79). Globally, COPD is a major cause of chronic morbidity and mortality; prognosis is often difficult to determine, but many people die prematurely because of the disease or its complications (80). Conversely, lung cancer typically has a short trajectory of steady progression with a distinct terminal phase (81). Lung cancer has a poor prognosis; only one in ten patients in the UK live for more than five years after diagnosis. The main treatments for lung cancer in England are hospital-based. Patients attend specialist units, usually as outpatients, to receive chemotherapy or systemic anti-cancer treatment. Alternatively, they may undergo surgical treatment as an inpatient in a hospital (82). In contrast, the emphasis on treatment for COPD is on 'self-management' (management and treatment of the condition by patients/family members in the home) (83). The treatment workload may, therefore, be very different for patients living with these two common respiratory disorders.

Furthermore, the research evidence suggests that there are more healthcare resources (in burden of treatment terms 'capacity'), especially palliative care, available for patients with cancer than patients with chronic long term conditions such as COPD (84-87). Thus, patients with COPD may experience treatment burden differently to patients with lung cancer because of the differing support processes available to patients living with each condition.

1.7.3 The literature on treatment burden in respiratory disease

There has been little specific qualitative research explicitly identifying and characterising treatment burden in adult respiratory disease.

A recent qualitative study of burden of treatment in COPD has been undertaken in Australia, interviewing 26 patients (31). This study provided a useful description of the practical issues of treatment burden in COPD and had sensible recommendations for clinical practice. However, it had limitations: the researchers did not make it clear who undertook the interviews and there was little rich description in terms of patient quotes. Although the researchers did briefly report interpersonal challenges for patients living with COPD and the social and emotional impacts of treatment, they themselves suggested that further research on how the results of their study related to “clinical, psychosocial and social aspects of treatment burden” in COPD was required (31) (p.1650). To the best of my knowledge, this was the only primary qualitative study to date carried out on burden of treatment in COPD. There have been none undertaken in the UK. There has been one retrospective cohort study using a Medicare linked database to quantify treatment burden in lung cancer in the USA but no primary qualitative research studies undertaken on patients’ experiences of treatment burden in lung cancer in the UK or elsewhere (43).

This gap in evidence for this patient group demonstrated a need for research in patient experiences of treatment in lung cancer and COPD in order to identify and characterise treatment burden in these specific populations. Identification and characterisation of treatment burden in patients living with respiratory disease is important. First, to identify and characterise the drivers for treatment burden in respiratory disease at an individual patient level. Second, to identify and characterise potentially modifiable factors associated with treatment burden that could be addressed by healthcare professionals, providers and systems to ameliorate burden and thus improve outcomes for patients.

Having given an explication of the major concepts being traversed, the approach taken and the specific aims and objectives of this body of work, this thesis will now proceed to set out the sequence and content of each paper.

1.8 Paper One: A qualitative systematic review and interpretative synthesis of patients and informal caregivers’ interactions with health and social care

1.8.1 Aim and purpose

The purpose of this paper was to answer the research question ‘What is burden of treatment in lung cancer and COPD, and how is it experienced by patients and their informal caregivers’?

This qualitative systematic review and interpretative synthesis aimed to identify and characterise patients living with COPD or lung cancer and their informal caregivers' lived experiences of workload and capacity. Thus, this paper addressed the following thesis objectives:

1. To identify, characterise and explain patients' experiences of workload and capacity in people living with COPD or lung cancer
2. To interrogate and refine the concept of burden of treatment itself, specifically focusing on the constructs of workload and capacity
3. To identify and characterise potentially modifiable factors associated with workload and capacity, either condition specific or applicable to both COPD and lung cancer

1.8.2 Operationalisation of theoretical literature in preliminary conceptual framework

In line with the abductive approach to this body of work, we operationalised key components of the theoretical literature on burden of treatment theory, the cumulative complexity model and status passage theory. From this work, we developed a preliminary conceptual framework (88).

Table 2: Conceptual framework: operationalisation of theory

Pathway and capacity	
1.1 Pathophysiological status	(a) Involuntary diminution of physical and cognitive function brought about by the natural progression of the disease. This includes the psychological impact of symptom exacerbation, disease progression, and aggressive treatment on the patient.
	(b) The impact of involuntary diminution of physical and cognitive function brought about by symptom exacerbation, disease progression, and aggressive treatment on the caregiver.
1.2 Status passage	Processes taking place over time and across settings in which the patient or caregivers' identity and status are reformulated through the effects of institutionally defined and sanctioned interactions, relationships, and practices.

1.3 Personal capacity	Personal resources (which may be affective, cognitive, informational, material, physical and relational) that are available to be mobilised by patients/caregivers.
1.4 Distributed capacity	Resources (which may be affective, cognitive, informational, material, physical and relational) that are available to be mobilised by members of patients/caregivers’ wider social networks`
1.5 Workload	Goal-oriented affective, cognitive, informational, material, and relational tasks that are assigned to patients/caregivers
1.6 Interactional quality	Experienced interaction quality with healthcare workers
1.7 Structurally induced non-adherence	Non-adherence to treatment due to structural factors such as having insufficient capacity to adhere to treatment regimes
1.8 Volitionally induced non-adherence	Non-adherence to treatment due to personal choice
Context	
2.1 Action environment	Physical or virtual transaction spaces in which patients/caregivers interact with each other, mobilise capacity, and perform tasks.
2.2 Structural advantage	Structural advantage: social structural factors that shape personal and distributed capacity, including structural inequalities (socio-economic status, education, gender, sexuality, ethnicity, age); access and location (proximity to health services, housing class, quality and availability of transport); and health system (availability of service, cost of service, quality of service).
Power and control	
3.1 Experienced control	Patients/caregivers’ ability to achieve goals within an action environment or across a status passage by influencing the beliefs and actions of relevant others.
3.2 Accountability	The ability to mobilise capacity (affective, cognitive, informational, material, physical and relational resources available to patients or care-givers) in relation to expected beliefs, behaviours, responsibilities and actions.

3.3 Negotiated obligations	Negotiated agreement about of future actions and the degree of accountability (expected beliefs, behaviours, responsibilities and actions).
3.4 Cognitive authority	Patients/caregivers' ability to define and determine goals, workload, resource mobilisation, (and to resist others' attributions of expectations and responsibilities) in any given action environment.
Burden	
4.1 Mapping emergence	Adaptive and reflexive behaviours and practices through which patients/caregivers apprehend changing self-identity and work with changing attributions about their identity and status, and about the nature of self-identified and institutionally sanctioned goals, workload and accountability that stem from these.
4.2 Resource identification	Adaptive and reflexive behaviours and practices through which patients/caregivers define and determine their wants and needs in relation to their personal and distributed capacity (affective, cognitive, informational, material, physical and relational) to meet self-identified and institutionally sanctioned goals, workload and accountability.
4.3 Resource mobilisation	Adaptive and reflexive behaviours and practices through which patients/caregivers operationalise elements of personal and distributed capacity (affective, cognitive, informational, material, physical and relational) to meet self-identified and institutionally sanctioned goals, workload and accountability.
4.4 Relational monitoring	Adaptive and reflexive behaviours and practices through which patients/caregivers make sense of interactions and relationships between self-identified wants and needs, capacity and workload, cognitive authority and experienced control.

This conceptual framework evolved throughout not only this study but throughout this whole body of work as it moved recursively between empirical and theoretical work. In this study, the theoretical conceptual framework was used as an investigative tool (coding framework) with which to approach the included literature (57, 58).

1.8.3 Taxonomy building

This study developed a theoretically underpinned and empirically derived taxonomy, identifying and characterising the common and specific features of patients with COPD or lung cancer and their informal caregivers' lived experiences of workload and capacity (see Table 4). A taxonomy describes discrete domains and dimensions, enabling the researcher to dissect complex concepts into their fundamental components. It is, therefore, an important first step in the exploration of multi-faceted, complex phenomena (89). Taxonomy building has been used successfully by other research teams as a first step in the identification and characterisation of treatment burden in areas other than that of respiratory disease. In the UK, Gallacher and colleagues undertook a qualitative review and synthesis of the international literature to develop a taxonomy of burden of treatment in stroke (20). In France, Tran et al and associates used mixed methods (qualitative and quantitative analysis of online survey data) to build a taxonomy of burden of treatment across multiple chronic conditions (42).

1.8.4 Why qualitative?

This study reviewed the qualitative literature because it aimed to identify and characterise patient and informal caregivers' lived experiences of treatment burden. Qualitative evidence is well suited to research that, as in the case of this literature review and synthesis, aims for an in-depth exploration of peoples' articulated experiences, needs and observed behaviours (65, 90). It has increasingly been recognised that healthcare practice and policy has need of evidence which complements the quantitative 'rationalist' model of systematic reviewing (90, 91).

1.8.5 Why systematic?

Campbell and colleagues described the purpose of a systematic literature review as a "seeking out, sifting through, reading, appraising and describing relevant research evidence" (65)(p.5). Tong (2012) proposed that two approaches might be taken to qualitative systematic reviewing. First, a pre-planned approach to reviewing the literature, systematically and comprehensively searching with the intention of identifying all available studies. Second, an iterative approach, aiming to identify concepts rather than studies until saturation is achieved (90). This study adopted the former rather than the latter strategy. This was because the study approached the systematic review with an *a priori* conceptual framework (Table 2 above) rather than seeking to identify concepts from the studies identified. Furthermore, a specific contention was the starting point for this systematic review: that a workload exceeding capacity might be the primary driver of treatment burden (21). Thus, the study aimed to examine this contention exhaustively in the differing context of many healthcare systems and settings and through a heterogeneous selection of papers using a multiplicity of theoretical lenses.

Two limits were deliberately placed on this systematic search. First, the search was limited to relatively recent publications (from 2006 onwards). In their helpful discussion of the methodological challenges of conducting qualitative systematic reviews of patient experiences of treatment burden in stroke, heart failure and diabetes, Gallacher and colleagues highlighted how the management of chronic disease has changed dramatically in recent years (92). As Gallacher and colleagues highlighted, it was, therefore, important that pertinent (and thus more recent) literature was reviewed to ensure that the identification and characterisation of patient experience of treatment burden was based on current rather than historical healthcare practices (92). Second, searches were limited to countries with advanced healthcare systems comparable to the UK as the purpose of this review and synthesis was to inform the empirical phase of this body of work that was to take place in the NHS in England.

1.8.6 Why synthesis?

Campbell and colleagues described a synthesis as the “process of extracting data from individual research studies and interpreting them and representing them in a collective form” (65)(p.5). They argued that qualitative research synthesis aligns with a subtle realist position. As argued above in section 1.6.2, this body of work has adopted a subtle realist approach, accepting the possibility of the study of different constructions of reality (65).

Qualitative synthesis may both aggregate and interpret data from a range of participants, across a range of contexts (65, 90). This study undertook an interpretative rather than aggregative approach to synthesis. It could not identify and include studies that explicitly addressed the topic of treatment burden in lung cancer and/or COPD, given the paucity of evidence in this area outlined in section 1.7.3 above. Instead, the review searched for primary qualitative studies examining patients with COPD or lung cancer and their informal caregivers’ interactions with health and social care. Therefore, rather than aggregating the results of studies that explicitly addressed the research question, it interpreted verbatim quotes from patients and informal caregivers and authors’ discussions in the context of the two primary treatment burden constructs of ‘workload’ and ‘capacity’. The synthesis was further interpretative in that, through the comparison and contrast of how the primary constructs of workload and capacity were identified and characterised in the literature, it developed secondary (interpretative constructs). This interpretative process was an integral part of the taxonomy building, allowing the detailed characterisation of a discrete set of domains and dimensions.

1.8.7 Why the comparison of lung cancer and COPD?

The comparison of lung cancer and COPD was significant as it allowed the identification and characterisation of *specific* and, crucially, common features of the primary constructs of workload and capacity. As Timmermans and Tavory argue,

> Looking for variation...means searching for shared facets of semiotic chains that can be grouped into a set in a theoretically cogent manner while differentiating from those that seem unfamiliar
>
> **(57)(p.70).**

Thus, it was important to identify and characterise features of workload and capacity that were condition-specific and might lead to treatment burden in individuals with either lung cancer *or* COPD. Equally, it was important and theoretically fruitful to identify features that were common to both diseases, despite the marked differences in the nature and type of workload and the capacity available to patients and informal caregivers to mobilise. For example, through the contrast of a generally well-known disease (lung cancer) with a little known and often poorly understood disease (COPD), ‘illness identity’ was identified as a potentially modifiable feature associated with both workload and capacity, common to both conditions and possibly generalisable to other diseases. This construct was a surprising, theoretically fruitful finding that became an important construct in the comparative analysis that formed the next stage of this body of work (discussed in detail in chapter three).

1.8.8 Comparison of long-term condition and acute condition

As previously discussed in section 1.7.2 above, COPD is typically a disease with an uncertain but generally prolonged trajectory (93). Its chronicity, allied to a general lack of understanding of its implications and consequences, meant that the interpretative synthesis identified and characterised a recurrent simile of ‘patient as agent’ as healthcare systems and providers sought to delegate the mundane work of routine chronic disease maintenance and monitoring away from healthcare professionals onto patients and their informal caregivers in the home. Although cancer is often now perceived as a chronic condition, important work undertaken by McConnell and colleagues has categorised the likely survival from cancer into longer-term, intermediate and shorter-term (94). Lung cancer sits in the shorter-term survival category. Its acuity and clearly understood existential threat meant patients experienced a highly specialised, hospital-based workload of treatment, led by healthcare professionals with very few tasks delegated to patients/informal caregivers to manage in the home. Thus, a contrasting but equally recurrent simile of 'disease as agent' was identified and characterised in the interpretative synthesis (discussed in detail in chapter two).

1.8.9 How did this inform paper two?

The taxonomy developed from the systematic review and synthesis provided a broad yet robust empirical foundation for the subsequent comparative qualitative analysis which was the next step in this body of work. The taxonomy played a key role in the development of the comparative analysis. First, the taxonomy provided an empirically-derived conceptual framework, complementary to the theoretically-derived conceptual framework which had guided the analysis of the systematic review and interpretative synthesis. Both conceptual frameworks guided the approach to empirical data collection, informing the development of the interview schedule and structuring the approach to observations and their related field notes. Second, the taxonomy was used as an investigative tool (coding framework) for data analysis. Finally, the taxonomy was developed from a series of propositions about 'workload' and 'capacity' that were interrogated and refined as the comparative analysis developed.

1.9 Paper Two: a cross-sectional, comparative analysis of patients' lived experiences of treatment using complementary qualitative methods

1.9.1 Aim and purpose

The purpose of this paper was to answer the research question 'What is burden of treatment in lung cancer or COPD and how is it experienced by patients'? Thus, the paper addressed the following thesis objectives (recapitulated from section 1.2.3):

1. To identify, characterise and explain patients' experiences of workload and capacity in people living with COPD or lung cancer
2. To interrogate and refine the concept of burden of treatment itself, specifically focusing on the constructs of diagnosis, illness identity, workload and capacity
3. To identify and characterise potentially modifiable factors associated with workload and capacity, either condition specific or applicable to both COPD and lung cancer

4. To identify and characterise how treatment burden is manifest in the clinical encounter for patients with COPD and lung cancer

This paper described the results of a cross-sectional, comparative analysis of patients' lived experiences of treatment using complementary qualitative methods (semi-structured interviews with patients receiving specialist care *n* = 19, specialist clinicians *n* =5; non-participant observation of patient encounters with healthcare professionals in specialist outpatient clinics (11 hours, 52 minutes) *n* = 41). The consultations observed were of patients with lung cancer visiting the specialist oncology clinic whilst having various forms of treatment or of patients with COPD having been referred to specialist respiratory clinics because of complex needs.

It is important to note that the objectives of papers one and two overlapped. The reason for this was twofold. First, the subtle realist stance taken meant that the aim of this body of work was to produce a "plausible story" (95)(p.247), rather than to gain direct access to a knowable reality of the phenomenon of treatment burden. Thus, the design of this body of work acknowledged the importance of the *representation* rather than the *reproduction* of reality through "multiple, non-contradictory and valid" accounts of the same phenomenon (53)(p.51). In papers one and two, therefore, different, complementary methods were used to build up evidence for the plausibility and credibility of the identification and characterisation and subsequent explanation of variation in relation to the phenomenon of treatment burden. The systematic review and interpretative synthesis identified and characterised similarities and differences in the phenomenon of treatment burden at a *macro* level – in a variety of countries and healthcare systems and settings. These identifications and characterisations were refracted through the multiplicity of ontological and epistemological lenses researchers assumed to approach their data collection and analysis. In contrast, the comparative analysis identified and characterised similarities and differences in the phenomenon of treatment burden at a *micro* level – in one country (England), in one healthcare setting (specialist outpatient clinics in the English NHS) with one (my own) ontological and epistemological lens as the primary "research instrument" (collecting, transcribing and analysing the data)(64).

Second, the abductive approach that this body of work has taken. In addition to the principle of variation, abductive reasoning emphasises the importance of the researcher's understanding of how experienced and explained phenomenon are related to other observations of that phenomenon. A key precept of the abductive approach is, therefore, the method of "revisiting" (57) where the researcher continually revisits the same phenomenon using different methods with the intent of identifying and characterising its features, thus rendering it comparable to other phenomena. The purpose of this process is to deconstruct the phenomenon into concepts which may then be associated with other concepts to generate or develop theory (*explanation* of the phenomenon). This body of work was designed in such a way, therefore, to revisit the identification and characterisation of the primary constructs of workload and capacity, using different methods with the intention of developing theory (explanation) of treatment burden.

1.9.2 Why qualitative observation?

Observation in qualitative research is the process of systematically watching, listening and making detailed records of people and events in order to investigate behaviours and interactions in natural settings (64, 96). The researcher acts as the "research instrument" by "entering the field", describing, and analysing what he or she observes (64). Indeed, Murphy & Dingwall describe observation as the "gold standard for the study of processes" (97)(p.2230). Up to this point, the only research using observation as a method to identify and characterise treatment burden was a study retrospectively examining videographic evidence of primary care encounters between clinicians and diabetic patients in the USA (47). This study was limited by its use of quantitative content analysis which enumerated discussion and assessment of treatment burden in the clinical encounter, rather than supplying the rich and thick characterisation of treatment burden that qualitative analysis would provide. In order to address the research aim and objectives of this body of work, I believed that observation would allow the characterisation of multiple representations of the enactment and articulation of the primary treatment burden constructs of 'workload' and 'capacity' in the clinical encounter.

1.9.3 Why *non participant* observation?

Observation or participant observation is sometimes used as a synonym for ethnography (98). Ethnography is the description and interpretation of a group or culture (99). In an ethnography, the researcher immerses themselves in a group or culture, 'getting inside' the way in which the group or culture views the world (53, 99). Rather than studying a culture, the purpose of observation in this study was to identify and characterise how the primary constructs of workload and capacity were represented through the behaviours, interactions and practice of individuals belonging to two groups (patients and healthcare professionals) in the specific context of the outpatient hospital setting in the English NHS.

The involvement of the researcher in observation sits on a continuum, ranging from non-participation (complete observer) to complete participation (full participant) observation (100-102). This continuum of complete participant to complete observer discussed above has been criticised as having limited value when understanding the researcher's role in fieldwork, as it did not consider how this related to the researcher’s positioning as an insider/outsider (103). As previously stated, I have worked in the English NHS, first as a manager and second as a nurse and, as such, have been immersed in NHS culture for 20 years. I therefore chose to use non-participant observation which allows the researcher to observe independently, being able to step in and out of the group under observation without becoming a member (96). My identity as a nurse meant that I was, to an extent, a member of one of the groups (healthcare professionals). This ‘insider’ status was an advantage in some ways, it facilitated access to participants and allowed me to understand the essentials of what was going on (98, 103). However, ‘insider’ status was also a disadvantage. Although I had chosen to use *non-participant* observation, I had to be reflexively conscious of my ‘insider’ status and previous experience as this might lead to assumptions where, because of my familiarity with the clinical encounter, I took things for granted, missing salient detail obvious to a complete outsider (98, 104).

To preserve the distinction between my insider (nurse) and outsider (researcher) status as far as possible, I chose hospital sites in which I had not worked clinically with COPD outpatients or lung cancer patients. The purpose of non-participant observation in this study was, in line with the abductive approach, to render familiar experiences unfamiliar in order to generate creative insights (57).

1.9.4 Why interviews?

Interviews are the most common method of data collection in qualitative research and have a long history: Beatrice Webb in the 19th century described interviews as “conversations with a purpose” (63) (p.87). Qualitative interviews might offer participants the opportunity to define the experiences which are the focus of the research in their own words (55). A more structured approach such as a quantitative survey might limit participants to the researcher’s own definitions of experience rather than allowing perspectives on the depth and breadth of individuals’ emotions and thoughts (55). Moreover, qualitative interviews might allow the researcher to identify and characterise features of the phenomenon of interest that cannot be directly observed, allowing the researcher to accumulate data from a wider range of settings than is possible for observation (55).

Holloway suggested that interviews were a direct conduit to the reality of human experience; that, through interviewing, the researcher discovered how participants feel, perceive or think (63). This does not align with a subtle realist stance which contends that “the definition of ‘knowledge’ as beliefs whose validity are known with certainty is misconceived” (53). Rather, this thesis aligns itself with critics who suggest the interview is an “artefact”, created by “the self-presentation of the respondent and whatever interactional cues have been given off by the interviewer about the acceptability or otherwise of what is being interviewed" (105). Holstein & Gulbrium agreed arguing "both parties to the interview are necessarily and ineluctably active" (106)(p.114). Atkinson & Coffey further emphasised how interviews were occasions "in which are enacted particular kinds of narratives and in which informants construct themselves and others as particular kinds of moral agents" (107) (p.422). This aligns with the subtle realist approach taken by this body of work, where the cultural assumptions of both researcher and researched must be taken into account (53). Murphy and colleagues argued that a subtle realist approach which regards interview data as representing participants' perspectives rather than directly accessing the reality of human experience "has been shown to have considerable potential for health service provision" (55)(p.122).

1.9.5 Why combine observation with interviews?

Section 1.6.3 discussed how an abductive approach emphasises the importance of combining data from multiple sources so the researcher might discover new dimensions of the phenomenon under consideration (57, 58). Timmermans & Tavory described the purpose of methods in an abductive approach as

> codified processes...in which we force ourselves to remain with the phenomenon and try to form as many links and hypotheses as possible in the light of our theoretically positioned knowledge
>
> **(57)(p.61).**

The two particular qualitative data collection methods of non-participant observation and semi-structured interviews have long been compared by qualitative researchers (63, 107). Several studies have shown differences between how patients behave in a clinical encounter and how they articulate their thoughts and feelings in a different setting (95, 108). Indeed, Strong pointed out in his ground-breaking study, 'The Ceremonial Order of the Clinic' (2001), "there is no necessary relationship between what patients do in medical consultation and what they say they do in another context" (95)(p. 225). He suggested that this is not a necessarily intentional difference, people attend to the things that concern them most and therefore interview data generally lacks routine daily details. Murphy has applied this specifically to healthcare professionals where, through the realities of daily work, they stopped noticing the mundane elements of their practice and the constraints that the setting might impose on their practice (56). Hammersley more generally described observation and interviewing as complementary techniques:

> To rely on what people say about what they believe and do without also observing what they do, is to neglect the relationship between attitudes and behaviour; just as to rely on observation without also talking with people in order to understand their perspectives is to risk misinterpreting their actions.
>
> **(53)(pp11-12)**

The complementary nature of interviews and observations was further confirmed by Dubois and Gadde who suggested that interviews might allow the researcher to explore issues that arise in observations (58).

It is important to note that this combination of methods was used as a strategy to add "rigor, breadth, complexity, richness and depth" to the collection of empirical material (109)(p.5) and to avoid making superficial inferences from a limited range of data (55). It was not intended to be a test of validity – that is scrutinising the *accuracy* of the data (58). As several commentators point out, data from different sources might contradict rather than confirm findings (57, 58, 62, 110). Indeed, in this body of work, the process of integrating these seemingly contradictory data proved a theoretically fruitful part of the research process. As Eisenhardt (1989), argues:

> Creative insight often arises from the juxtaposition of contradictory or paradoxical evidence…the process of reconciling those contradictions forces individuals to reframe perceptions into a new gestalt
>
> **(111)(p.546).**

For example, I was surprised to discover, both in the systematic review and interpretative synthesis and in the qualitative comparative analysis, that patients with lung cancer were generally reluctant to stop treatment, despite potentially debilitating side effects. Contrary to my initial expectations predicated on the initial conceptual framework (based on burden of treatment theory and the cumulative complexity model), patients with lung cancer generally perceived their heavy treatment workload as bringing hope rather than being burdensome. Status passage theory was a helpful lens with which to reconcile this seeming contradiction. The use of this theory facilitated the understanding of how treatment for an illness trajectory like lung cancer, experienced by patients and informal caregivers and understood by healthcare professionals as a "crisis"(54) (p.144) could temporarily or permanently take precedence over the workload of other status passages.

Section 1.6.3 discussed how an abductive approach emphasises the importance of the systematic examination of variation, across datasets, time and situations. This study systematically analysed the variation in ‘capacity’ and ‘workload’ in number of ways.

First, within and between datasets. This study examined how ‘capacity’ and ‘workload’ was manifest in the patient-clinician encounter, specifically in outpatient settings. It traced the similarities and differences in the enactment and articulation of ‘workload’ and capacity in each patient-clinician encounter in COPD, and in lung cancer. It then compared the similarities and differences in the patient-clinician encounter between conditions.

Second, across time. Although the study was cross-sectional, the study deliberately had broad inclusion/exclusion criteria so that a range of patients were observed, some who had been recently diagnosed, others who had been diagnosed for some time and some who were at the end of their life. The study was thus able to examine variation in ‘workload’ and ‘capacity’ across different time points in patients’ illness trajectories. Variation across time was further explored in the interview component of the study where patients gave detailed chronological accounts of their experiences of diagnosis, illness and treatment across their illness trajectory.

Third, across situations. Although the observations took place in outpatient settings, many patients discussed their experience of other healthcare settings (for example, attending pulmonary rehabilitation, attending GP appointments or having to go to hospital as an emergency) within the clinical encounter with their specialist clinician. The interviews allowed for further examination of this intersituational variation, as patients recounted their experiences of treatment in multiple circumstances (for patients with lung cancer, generally in hospital, for patients with COPD, their experiences of interactions with generalist healthcare, again, generally attending GP appointments or attending hospital in emergency situations).

This examination of variation led to a more detailed characterisation of the construct of illness identity that had begun to be examined in paper one and how this related to the key constructs of ‘workload’ and capacity’. It identified variation in patients’ experience of diagnosis in an illness where its meaning and existential implications were clear compared to the experience of diagnosis in an illness where its meaning and significance were unclear. This led to the addition of Bury’s (1982) theory of biographical disruption as an additional theoretical lens with which to consider treatment burden (50). Bury’s pivotal study of patients with rheumatoid arthritis at the point of first referral to specialist rheumatology clinics, characterised the onset of illness as a “biographical disruption”, requiring the individual to re-think fundamentally their “biography and self-concept” (ibid, p.169). Following a diagnosis of chronic illness, an individual’s biography was shifted from an expected trajectory, with relatively foreseeable chronological stages, to an abnormal trajectory with an uncertain future. Consequently, the individual was obliged to relinquish previously held unconscious assumptions and behaviours. Juxtaposing this theoretical concept of biographical disruption against status passage theory, allowed the identification and characterisation of the point of diagnosis as an important variation in the lived experiences of 'workload' and 'capacity' between COPD and lung cancer. Patients with lung cancer and, in many cases, their family members too, experienced the diagnosis of lung cancer as a clear biographical disruption; in status passage terms a "crisis" (54) (p.144). Thus, patients with lung cancer prioritised the demands of their illness trajectories and treatment for those illness trajectories over the demands of other status passages. Conversely, in COPD, the diagnostic process was fragmented. Patients were often not formally diagnosed or told of their diagnosis for many years. When diagnosed, both patients and family members had little understanding, in Bury's terms (112), of the significance and/or consequence of the disease. The often long and uncertain disease trajectory conferred a gradual understanding of both. Rather than a biographical disruption or crisis, the experience of diagnosis in patients living with COPD was that of a biographical *erosion* over time. This will be discussed in more detail in chapter three.

1.9.6 Integration of papers one and two:

Paper one (the qualitative systematic review and interpretative synthesis) and paper two (the qualitative comparative analysis) were integrated through the taxonomy of treatment burden. In the systematic review and synthesis, the taxonomy was built from a series of simple explanatory propositions which characterised variation within the primary constructs of 'workload' and 'capacity'. Data from the comparative analysis were used to interrogate and refine the original set of explanatory propositions and to develop further propositions. Additionally characterised features of 'workload' and 'capacity' were then added to the taxonomy. Further detail is given in chapter three.

1.10 Paper Three: development of a conceptual model of treatment burden in illness

1.10.1 Aim and purpose

The purpose of this paper was to answer the research question 'What is burden of treatment and how is it experienced by patients'? Thus, the paper addressed the following objectives:

1. To identify and characterise potentially modifiable features of patient experience in relation to the measurement of treatment workload
2. To identify and characterise potentially modifiable features of patient experience in relation to the measurement of patients' potential to mobilise capacity
3. To model the hierarchical relationships between the factors associated with workload and the factors associated with capacity
4. To explain how the interactions between these two primary constructs and their associated factors may drive treatment burden at an individual patient level

These related back to the original thesis objectives outlined in section 1.2.3 above:

5. To build an empirically derived conceptual model to explain common and specific features of burden of treatment with recourse to COPD and lung cancer
6. To use the empirically derived conceptual model to identify targets for supportive interventions which might be introduced into routine clinical practice to ameliorate treatment burden

In this paper, theory was used in three ways. First, in order to *orientate* myself to the empirical data (113). Second, to *explain* generalisations drawn from the empirical data (57). Third, to *connect* this body of work to a wider community of enquiry that seeks to identify, characterise and explain burden of treatment (57). I will explain each of these points in greater detail below

1.10.2 Theory as orientation

Table 2 presented the conceptual framework operationalising key components of burden of treatment theory, the cumulative complexity model and status passage theory which framed the approach to papers one and two. An abductive approach emphasises not only the importance of using multiple theories but revisiting these theories multiple times in light of the results of the empirical data. As Tavory & Timmermans argued "careful coding almost inevitably requires further definition and operationalisation of concepts, processes and theoretical links" (57)(p.61). Thus, the original framework is modified as a result of novel and unanticipated findings and of theoretical insights gained during the analytical process (58). Therefore, paper three returned to the theoretical literature behind the original theoretical framework: the cumulative complexity model, burden of treatment theory and status passage theory. As discussed above, in order to support the characterisation of the construct of illness identity, paper three added in additional theoretical material: Bury's (1982) theory of *disrupted* identity at the beginning of an illness trajectory (50) juxtaposed against Glaser & Strauss's (1971) theory of *changing* identity throughout an illness trajectory (54). I reviewed this theoretical literature in light of unanticipated findings from the empirical work, for example the key finding from papers one and two, the importance of the construct of illness identity in the consideration of 'workload' and 'capacity'. In line with the approach taken throughout this body of work, paper three characterised the key components of this theoretical literature through a series of simple explanatory propositions

1.10.3 Theory as explanation

Paper three used the simple explanatory propositions developed from the empirical work in papers one and two and integrated these with the theoretical propositions. This "process of double-fitting theory and observations" (p.99) facilitated the development of explanatory generalisations about the phenomenon of burden of treatment (57).

1.10.4 Theory as connection

Paper three interrogated, refined and confirmed these explanatory generalisations against other empirical evidence from the wider community of enquiry on burden of treatment (other systematic reviews examining 'workload' and 'capacity' in disease (20, 33, 34, 36, 39, 49, 114). In an abductive approach, such a community fulfils two purposes. As demonstrated in the conceptual framework described in section 1.8.2 above, it provides the conditions from which theory can be developed. It also allows a researcher to compare how his or her own generalisations align with the generalisations of other researchers, in order to assess the likelihood of whether conclusions on the relationship between theory and observations are credible and plausible (53).

1.10.5 What is the purpose of the conceptual model?

The conceptual model not only provided a detailed identification and characterisation of the primary constructs of workload and capacity but an *explanation* of how these constructs interact to produce treatment burden at the level of the individual patient.

Importantly, the conceptual model identified potentially modifiable factors associated with workload and capacity. Potentially modifiable factors associated with workload were:

- Structural advantage
- How services are experienced
- Understanding of disease

- Normative expectations of motivation to participate

Potentially modifiable factors associated with capacity were:

- Social skill
- Structural resilience
- Illness trajectory

Thus, through the “double fitting” of theoretical and empirical material, the conceptual model made a novel and substantial contribution to the theory of treatment burden

- *Relationally* in the construction and negotiation of status passages
- *Existentially* through a juxtaposition of the concept of a diagnosis of illness as biographically erosive against biographically disruptive
- *Dynamically and cumulatively* in the fluctuations in workload and capacity over an illness trajectory.

1.10.6 What is the practical value of the model?

I am a nurse by background and a strong driver for me undertaking this body of work was to improve patient care. In my opinion, this model can be used to improve patient care through the support of healthcare professional understanding for the potential for treatment burden at an individual patient level. Healthcare professionals might use the constructs outlined in the model to support their understanding both of the extent and volume of a patient’s workload and the resources that a patient has to cope with the demands of this workload, the social skill that they have to mobilise these resources and the structural resilience that they have to meet the demands of adversity. The model demonstrated the importance of healthcare professional understanding of these constructs throughout the patient journey as it found both workload and capacity to be dynamic states which a patient might experience differently at diverse points across an illness trajectory.

The model also demonstrated potentially modifiable factors associated with burden at a health system level. How services are structured, delivered and experienced might have a significant impact on the workload of treatment. The conceptual model could be used at the healthcare system level to support the practical implementation of patient-centred initiatives that support the promotion of healthcare driven by patient rather than organisational priorities

1.10.7 How does the model answer the research question?

The abductive approach taken to this body of work has resulted in a robust, empirically and theoretically derived, explanatory conceptual model of burden of treatment in response to the research question ‘What is burden of treatment and how is it experienced by patients?’

The conceptual model identified and characterised the primary constructs of workload and capacity and, crucially, mapped the interactions between each and their associated factors to conceptualise and explain treatment burden in illness.

Chapter 2 A systematic review and interpretative synthesis

2.1 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 that contain descriptions of experiences of interacting with health or social care in Europe, North America and Australia.

Results

We identified 127 articles with 1,769 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.

Systematic review registration number:

PROSPERO CRD42016048191

2.2 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 (3).This workload consists of affective, cognitive, informational, material, physical and relational tasks delegated to patients and/or their informal caregivers by HCPs (3, 36). 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 (3, 21, 115). Capacity may be viewed at an individual (i.e. the patient) or collective level (i.e. the patients’ social network) (116). Capacity may be affected by a range of variables, from socio-economic factors such as ethnicity and poverty, to the social skill necessary to engage and mobilise stakeholders (3, 19-21, 25, 33, 36, 37, 39, 92, 115). A workload that exceeds capacity might, in some cases, be a primary driver of BoT for patients (3, 21). Neither workload nor capacity are static. They may fluctuate over time as illness progresses, functional capacity declines and patients’ social networks change (3, 21, 115) or, indeed, as the patient is able to accept, adapt and normalise their condition into their daily life (20, 26, 36, 39).

The literature (2, 3, 18, 25, 92) 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” (2). This is an approach to healthcare that takes into account patient priorities, multi-morbidity and seeks to reduce the BoT on the patient and informal caregiver (2).

COPD and lung cancer are the most common causes of respiratory-related mortality in the United Kingdom (UK), excluding pneumonia (117). 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 (69, 70). Thus, both may carry the stigma of a ‘self-inflicted’ disease (72, 73).

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 ‘de-normalise’ tobacco have contributed to a social transformation that actively stigmatizes smokers (71).

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) (118). Conversely, lung cancer typically has a rapid trajectory involving steady progression with a clear terminal phase (81). 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 anti-cancer treatment or inpatient surgical treatment (82). In contrast, treatment for COPD generally involves self-management (management of treatment regimens by patients and informal caregivers in the home) (119). BoT may, therefore, be experienced very differently by patients living with these two common respiratory conditions.

2.3 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.

2.4 Research question

What is burden of treatment in lung cancer and COPD and how is it experienced by patients and their informal caregivers?

2.5 Methods

2.5.1 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 (120):

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 Appendix A. 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 (NHS) in England. We limited our search to publications from the year 2006 onwards. This is because, like Gallacher et al (92), 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 3 details inclusion/exclusion criteria for the systematic review.

Table 3: Inclusion/exclusion criteria for systematic review

Inclusion criteria	Exclusion criteria
Participants: aged >18, 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, mixed methods 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	

2.5.2 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 (JH, 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 JH independently double screened all 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 (KH, see acknowledgements) resolved eligibility disputes at this stage.

2.5.3 Quality assessment

MM, AC, JH and KAL undertook quality assessment of included papers using a modified version of the qualitative appraisal tool: RATS (relevance, appropriateness, transparency, soundness) guidelines (121) (see Appendix B). 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.

2.5.4 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 (36). 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 of studies included HCPs). CRM, AR, KAL, MM, AC and JH developed a coding framework, underpinned by robust, empirically derived, middle-range theories: BoT theory (described above) (3) and status passage theory (54). 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 (122). Status passage theory describes people as constantly in passage between temporally limited and societally ascribed statuses (for example, 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 legitimized by authorized agents. Status passage theory is a particularly useful tool when considering illness, which is an undesirable, involuntary and often irreversible passage, legitimized by HCPs as authorized agents (54).

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 (123). KAL, MM, AC and JH then independently used the coding framework to code a selected group of data and compared results. Once inter-coder 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 (89) and coded data using the coding framework described above. KAL, supported by CRM and AR analysed data using directed qualitative content analysis (123) and constant comparison (124). We grouped related codes into sets for each condition and compared sets within and between conditions. We used Shippee et al's (21) 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 4).

Table 4: Taxonomy of treatment burden in lung cancer or 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 socio-cultural resonance (therefore understood by patient/informal caregiver/HCP)	50, 53, 64	Unclear illness identity, without socio-cultural 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 overriding 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		35, 57, 70, 113, 123

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	REFERENCES	COPD	REFERENCES
		Decision to cede control over choice of treatment options to trusted HCPs	86, 93, 97, 99, 121, 122	Lack of treatment options (lack of information or feeling that ‘nothing can be done’ from HCPs)	
	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		

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
	Healthcare professionals	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

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	REFERENCES	COPD	REFERENCES
	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 pulmonary rehabilitation	40, 68, 82, 108 PR: 56, 57, 100-105, 107, 115, 135, 155
				Shared experiences with peers reduce 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, 147
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 stigmatized by society	151, 158	Patients are considered culpable for their illness and stigmatized 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	40, 101
				Patients experience ‘enacted’ stigma from HCPs, making access to treatment challenging	36, 38, 39, 40, 44, 71, 74, 75, 118, 126-128

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	REFERENCES	COPD	REFERENCES
	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 co-morbidities lead to avoidance of social situations	53, 156	Logistical difficulties of treatment workload limits 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 co-morbidities lead to avoidance of social situations	78, 79, 82, 101, 102

2.5.5 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.

2.5.6 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

2.6 Results

2.6.1 Characteristics of studies

Figures 2 and 3 show each stage of the review process. We identified 127 articles: 85 COPD and 42 lung cancer. The papers included 1,233 COPD patients, 251 informal caregivers of COPD patients; 536 lung cancer patients and 240 informal caregivers of lung cancer patients. 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 Appendix C.

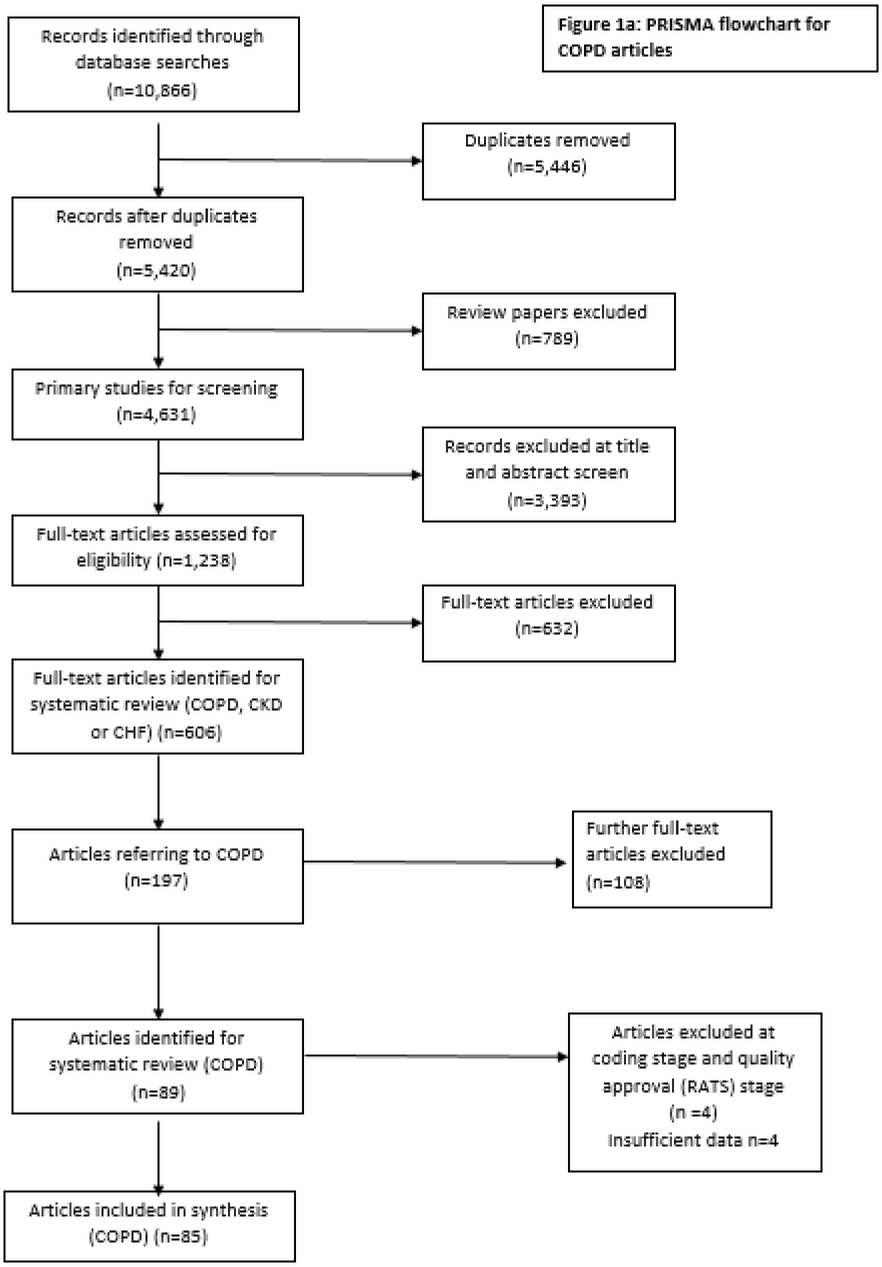


Figure 2: PRISMA COPD

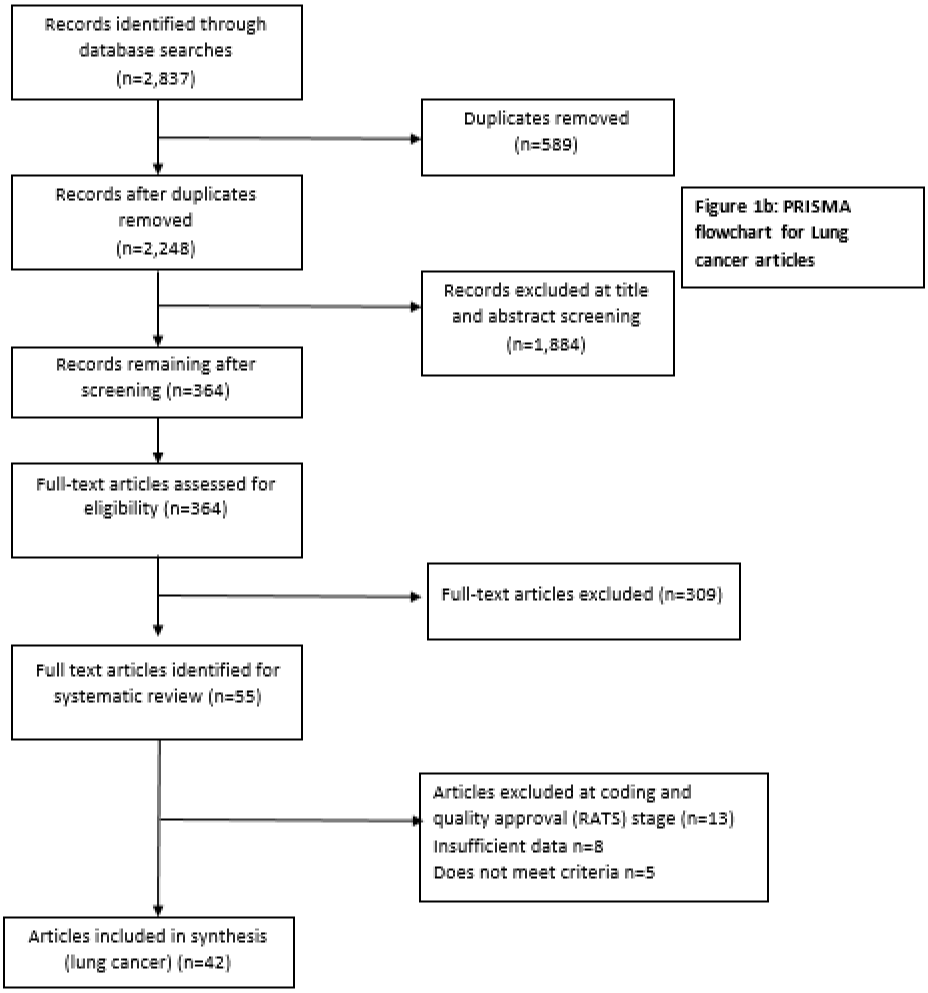


Figure 3: PRISMA lung cancer

2.6.2 Workload (primary construct)

2.6.2.1 Diagnosis (secondary construct)

For the majority of patients with COPD, the experience of receiving a diagnosis of COPD was not a memorable event (125-138) ; “a story without a beginning” (135). 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 (134). 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” (127) (p.706).

In contrast, patients with lung cancer almost universally described the moment of diagnosis as a “shock” (139-145), an unexpected and undesirable “crisis” which “flooded” patients’ lives (54) (p.144). Patients felt overwhelmed by the existential threat of cancer that took away their ability to plan for or even imagine a future (140, 146, 147).

2.6.2.2 Illness identity (secondary construct)

Several studies demonstrated a lack of public understanding of COPD (125-127, 129, 131, 134, 135, 137, 148-151). 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” (126) (p.558). Conversely, cancer has a recognisable public narrative, replacing tuberculosis as the disease the public most fears (77, 152-154). In several of the studies, the patient’s experience reflected this narrative shift (142, 145, 155): “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”” (155) (p.1207).

2.6.2.3 Attitude towards treatment (secondary construct)

Consequently, treatment for the illness – often became the overriding priority in life for patients with lung cancer (155-158), 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” (157) (p.5). Conversely, patients often saw COPD as a “way of life” (135) 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 (86, 127, 135, 149, 151, 159-163). Many patients with COPD, even with advanced illness, did not regard themselves as unwell (86, 135, 151, 161, 163). 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 (86).

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 (134, 162, 164-169). This was complicated by the uncertainty of the illness trajectory making disease fluctuations difficult to anticipate and, consequently, to manage (86, 125, 129, 131, 170-174). Less commonly, patients with lung cancer also described the importance of planning and managing their own treatment workload (139, 157, 158, 175-177). More commonly, patients with lung cancer were overwhelmed by the debilitating pathophysiological side effects of their treatment such as breathlessness, fatigue, nausea and vomiting and were unable to focus on anything apart from treatment completion (140, 147, 156-158, 176, 178-182). 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 (143, 145, 176, 183). Patients repeatedly used the metaphor of treatment as "hope", a lifebelt in the existential flood caused by the diagnosis of lung cancer (141, 143, 155, 176, 177, 181, 184, 185)**.** Indeed, some patients reported a sense of "limbo" once the practical workload of treatment had finished (140, 157, 186-188). This "limbo" was both existential (157, 188): "Now I have lived for something, to complete and survive the treatment and suddenly the priority of life is gone" (157) (p.5) or structural, where patients felt in transition between healthcare institutions (140, 186, 187). 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" (176) (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 (158, 177, 189).

Patients with COPD reported how elements of treatment that supported self-management (for example, educational sessions at pulmonary rehabilitation (PR)) provided a much needed sense of control over their condition (127, 162, 168, 190-197). 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 (125, 129, 133, 150, 163, 198, 199):

> "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."
>
> **(133) (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 hospitalisation, PR, day hospice and specialist outpatient care) brings (149, 150, 174, 194, 199-209):

> "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."
>
> **(201) (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 (133, 169, 206, 210). Thus, some patients might try to avoid hospitalisation (129, 133, 210).

2.6.2.4 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 (158, 181, 183, 187, 211). Whilst 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 (183, 187, 189). Indeed, frequently patients reported choosing to cede the cognitive burden of decision-making over treatment options to a trusted HCP (176, 183, 187, 189, 211, 212).

For patients with COPD, identification of treatment options could, itself, be problematic (86, 127, 149, 203, 213). Patients described being repeatedly told that "nothing could be done for them" by HCPs in both primary and secondary care (86, 127, 149, 203, 213). Thus, papers reported patients identifying treatment options from other sources of information such as the experience of peers or through their own research (148, 149, 159, 198, 203). Once treatment options were identified, patients could experience difficulty in accessing them (86, 126, 127, 131, 132, 134, 136-138, 150, 163, 164, 166, 193, 198, 199, 206, 210, 214-220).

2.6.2.5 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 co-ordinate its treatment workload (141, 158, 175, 211, 221, 222). Furthermore, patients with lung cancer appeared to follow a relatively structured treatment pathway (141, 145, 157, 158, 175, 211, 221, 222). In contrast, patients with COPD described encounters with gatekeeping generalist HCPs who did not recognise or understand their disease (136, 137, 150, 168, 199, 202, 203, 206, 214, 216, 219) 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 (126, 129, 134, 136, 137, 150, 163, 164, 166, 193, 198, 199, 206, 210, 216, 217, 219). Furthermore, patients described being expected to act as custodians of their own medical history, having to update HCPs with changes to their treatment (199, 223).

2.6.2.6 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 (144, 181, 224) and occurring in a variety of settings for COPD (163, 191, 198, 210, 213, 215, 223, 225). 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 (126, 131, 134, 144, 150, 163, 181, 191, 198, 199, 210, 213, 215, 216, 219, 224, 225).

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 (125, 127, 134, 162, 164-166, 170, 199, 219, 220, 226), the operation of technologies such as oxygen (134, 137, 150, 151, 163, 169, 173, 196, 198, 199, 216, 217, 226-233), nebulisers (125, 159, 170, 216, 217, 230) and non-invasive ventilation (160, 234). These also included self-management of the illness itself: avoiding exacerbation triggers, monitoring physical symptoms and help-seeking when appropriate (127, 129, 159, 162-164, 166, 170, 193, 204, 220, 223, 235). In contrast, patients with lung cancer described receiving highly specialised, predominantly hospital-based therapies with little delegation of material treatment tasks (140, 142, 144, 145, 156-158, 176, 179, 181, 183, 187-189, 211, 221, 236). The exception was a study interviewing patients receiving oral targeted therapies who described the rigorous process they underwent when securing and taking medication (177). 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 (177).

2.6.2.7 Informational workload of treatment (secondary construct)

Patients with both conditions described being required to comprehend a large amount of information about their treatment (127, 129, 143, 148, 155, 157-159, 163, 173, 175, 178, 179, 184, 186, 187, 189, 193, 198, 211, 220, 222, 223, 226, 231, 237-240). Commonly, patients with lung cancer felt that high quality information about their treatment was available to them when they required it (155, 158, 175, 183, 187-189, 211, 222, 237, 238, 241). 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 (145).

Some patients with lung cancer wanted to be fully informed about their condition and treatment by their HCP, including prognosis, however bleak this was (158, 175, 188, 211, 222, 237, 238). In contrast, other patients found being fully informed overwhelming and frightening, particularly when given comprehensive written materials (145, 187, 237). They wanted limited information from HCPs, appearing to use this as a coping strategy to maintain hope for as long as possible, (140, 143, 155, 157, 187, 189, 211, 212, 242, 243) preferring not to be “frightened with too much…knowledge” (187) (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 (184, 189, 212, 237). 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 (125-138, 164, 166, 168, 171, 198, 213, 217, 220, 223, 227, 244). This could be as fundamental as being given an inhaler without instructions on how to use it (134, 137).

Information could become a source of anxiety in both COPD and lung cancer when it was inconsistent or contradictory (128, 136, 148, 169, 179, 186-188, 199, 200, 212). 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 (178, 179).

2.6.3 Capacity (primary construct)

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

2.6.4 Capacity enhanced following diagnosis

2.6.4.1 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 (129, 141, 147, 150, 157, 158, 163, 164, 166, 169, 170, 177, 198, 215, 220, 222, 237). 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.
>
> **(158) (p.24)**

There could be an explicit recognition that this was possible owing to the short disease trajectory in lung cancer (146).

Informal caregivers’ participation in the treatment workload, whilst practically onerous, was often seen as an affirmation of the strength of their relationship with the patient (147, 157, 222, 241). This was echoed in many of the COPD studies (128, 163, 169, 170, 220). 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 (150, 164). 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 (128, 129, 164, 166, 170, 220, 223, 226).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 (128, 164, 166, 220, 223, 226). The studies included repeatedly show that informal caregivers might find this practically limiting and affectively and cognitively demanding (128, 129, 160, 164, 166, 170, 173, 220, 223, 226, 227, 235).

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 (141, 144, 146, 175, 176, 181, 185, 186, 189, 222, 237). This was less common in the COPD studies (134, 165, 191, 217), 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.

2.6.4.2 Health care professionals (secondary construct)

Patients with lung cancer frequently reported the importance of support from empathetic, trusted specialist HCPs in whom they had faith (141, 145, 157, 175-177, 183, 187, 211, 212, 221, 222). Patients with COPD also described positive experiences of interactions with HCPs (215, 219), particularly those with a specialist interest in COPD (149, 168, 170, 193, 196, 199, 210, 217) or those with whom they had relational continuity (170, 199, 215, 219). Patients with COPD described lack of relational continuity with HCPs as making access to, and navigation of, the healthcare system more challenging (171, 199, 201, 219). In a small minority of lung cancer cases, patients had lost confidence in their HCPs (175, 212). This loss of confidence in HCPs appeared more common in COPD (127, 130, 133, 136, 137, 163-166, 199, 203, 213, 216).

2.6.4.3 Peer support (secondary construct)

Patients with COPD appeared to benefit hugely from peer support (132, 159, 172, 198), which they generally accessed through PR (148, 149, 190-195, 197, 205, 225, 245). Peer support had both psychosocial benefits as patients felt less isolated (148, 190-192, 194, 195, 197, 205, 225) and practical benefits as a means of information-sharing about treatment options (148, 149). 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 (181, 187, 246) perhaps because of the typically short disease trajectory of lung cancer.

2.6.4.4 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 (127, 129, 134, 159, 163, 193, 204, 240). Patients attending PR reported the importance of support to self-manage, and education and information about their condition from specialist HCPs (168, 191-196, 205). 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 (182). 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.

2.6.5 Capacity diminished following diagnosis

2.6.5.1 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 (247). Scambler (2008) usefully distinguishes between ‘enacted’ and ‘felt’ stigma (153). ‘Enacted’ stigma is actual discrimination by society against people with stigmatizing conditions. ‘Felt’ stigma is internalised stigma by people with stigmatizing 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 stigmatized by society (130, 132, 165, 203, 216, 241, 248). Patients with both conditions clearly internalised this stigma, repeatedly describing their diseases as “self-inflicted” (125, 127, 136, 165, 167, 169, 175, 191, 248-250). They experienced ‘felt’ stigma of self-blame, guilt and shame (130, 132, 136, 141, 165, 169, 175, 191, 235, 242, 248, 249). Some patients with COPD described how this internalised stigma led them to believe they do not deserve treatment (132, 191) : “I refused to go to the doctor. I thought it [COPD] was self-inflicted. If it’s self-inflicted, why bother anyone?” (191) (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 (237).

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 (130, 132, 141, 242). Thus, patients with both conditions attempted to impose a “closed awareness context” (54), 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 (134, 177, 181, 227, 233). 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” (54) patients have carefully maintained around their illness identity, leading to patients avoiding social situations and, consequently, social isolation (134, 216)

Patients with COPD often described feeling stigmatized by their HCPs (131, 132, 136, 161, 164, 165, 208, 216-218). 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 (131, 165, 216, 218):

> "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"
>
> **(128) (p.161).**

Consequently, patients were reluctant to access treatment for fear of such enacted stigma (130, 132). Several papers reported the difficulties of accessing treatment for patients who had smoked (128, 165, 216, 218). 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 (208).

In contrast, in the studies included, patients with lung cancer did not describe encountering stigmatizing 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 (248).

2.6.5.2 Social isolation (secondary construct)

2.6.5.3 Self imposed social isolation

Frequently, patients with lung cancer and COPD experienced social isolation because of their illness (128, 129, 134, 145, 157, 164, 166-170, 172, 186, 191, 192, 201, 204, 216, 217, 223, 226, 229, 233, 235, 246, 251, 252). 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 (134, 167, 177, 180, 181, 227, 232, 233). 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) (166, 201).

2.6.5.4 Involuntary social isolation

Social isolation might likewise be involuntary in both lung cancer and COPD as friends withdrew and social networks contracted (142, 145, 172, 191, 226, 233, 246). Patients reported feeling "contagious" (142)(p.734), (226)(p. 145). 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 (145, 168, 169, 172, 191, 192, 246).

Patients with COPD reported that the practical and logistical challenges of the treatment workload itself (for example, 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 (130, 134, 150, 151, 160, 163, 169, 198, 201, 216, 227, 229-231, 233). In COPD, involuntary social isolation also appeared to worsen with disease progression and the consequent relentless deterioration of physical function (129, 164, 170, 172, 217, 229, 251, 252). This clearly extended beyond the patient to affect the informal caregiver as their responsibilities increased with the pathophysiological decline of the patient (128, 129, 164, 166, 170, 223, 226). In the papers included, there were fewer accounts of this from patients with lung cancer, perhaps because of the typically short disease trajectory (186).

2.7 Discussion

2.7.1 Illness as agent; patient as agent

The overriding 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 overriding 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 (84, 253)

2.7.2 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 co-operation and co-ordination of others) and social capital (their ability to access informational and material resources), bolstering their structural resilience (their potential to absorb adversity) (3). 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” (254) 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.

2.7.3 Strengths and limitations

This systematic review and qualitative synthesis differs from previous reviews on BoT. BoT has been examined generally across many conditions (36, 39), with capacity considered specifically (115). Other systematic reviews are condition specific: heart failure (19, 33) and stroke (20). Yet more consider treatment burden in multiple chronic conditions: diabetes, chronic kidney disease and heart failure (37) and chronic kidney disease, heart failure and COPD (114). This review, like May et al (114), considers patient and caregiver interactions with health care 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 burden of treatment 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. 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 Table 5.

Table 5: Recommendations for clinical practice

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 4) 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 burden of treatment (255). 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 (3). Furthermore, qualitative research is, necessarily, interpretative and therefore the data analysed, whilst 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- December 2015 as we intended to identify burden of treatment in COPD and lung cancer with the aim of informing *current* health care practice and policy. In their discussion of the methodological challenges of reviewing patient experience of treatment burden in stroke, Gallacher et al (92) 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 (i.e. grey literature) and studies that are not in the English language because of resource constraints which could be regarded as a limitation.

2.7.4 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 (256).They do not discuss the issue of multimorbidity which is common in both conditions (257) (258) and is likely to have a significant impact on BoT (21).

2.8 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 socio-cultural status of cancer as one of the most feared of all diseases (77, 152) 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 neurone disease) (152, 259, 260).

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.

Chapter 3 Comparative analysis

3.1 Abstract

Objective

To identify, characterise and explain common and specific features of patients' with lung cancer or chronic obstructive pulmonary disease lived experience of the primary treatment burden constructs of 'workload' and 'capacity'

Methods

Cross-sectional, comparative analysis using complementary qualitative methods (semi-structured interviews with patients receiving specialist care *n* = 19, specialist clinicians *n* = 5; non-participant observation of specialist outpatient consultations in two English hospitals (11 hours, 52 minutes) *n* = 41.) Interviews and observations were audio-recorded and transcribed verbatim. An abductive approach, working recursively with empirical and theoretical materials, was taken to study design, data collection and analysis.

Results

Diagnosis of illness might be experienced as a shock, with a biographically disruptive illness identity or as imperceptible with a biographically erosive illness identity. This experience of diagnosis/illness identity was associated with both 'workload' and 'capacity'. First, the extent to which capacity was available to patients and social skill was required to mobilise it. Second, the priority patients gave to the treatment workload. Third, the nature of the treatment workload, specifically, whether it was delegated by healthcare professionals to patients to undertake at home or done to patients by healthcare professionals in hospital.

Conclusion

Treatment burden is more than simply the work that patients must do to meet the demands of treatment regimens. Instead, treatment burden is a complex, multidimensional and situational concept which may occur as a result of interactions between illness identity, workload and capacity.

3.2 Introduction

Over the past century, a spread of non-communicable diseases (NCDs), often caused by tobacco smoking, has placed an increasing burden on health systems worldwide. In 2015, tobacco smoking was attributable to 6.4 million deaths (261, 262). Tobacco smoking has been linked to approximately 90% of lung cancer and COPD incidence in the United Kingdom (UK) (263). This rise of NCDs, coupled with ageing populations means people are living increasingly with chronic disease requiring *management* rather than cure (4). Healthcare systems increasingly expect patients and family members to take on this management, directing and coordinating their own care and adhering to complex treatment regimens. Patients may be unable to meet such expectations, leading to poor adherence to medication and treatment regimens and, consequently, negative outcomes such as increased hospitalisation, increased mortality and impaired health related quality of life which impact both individuals and healthcare systems (2, 17-22, 26). The negative experiences of undertaking this work of managing treatment have been termed “burden of treatment” (BoT) (3, 8)

A number of systematic reviews (8, 20, 33-36, 38, 39) and primary empirical studies (17, 18, 23, 24, 26, 28, 29, 31, 34, 40, 44, 45, 47) have identified and characterised the multidimensional nature of the affective, cognitive, informational, material and relational work that patients/their social networks have to do to meet the demands of their treatment. They also identify and characterise factors that may add to or alleviate this work and the impact of this on patients. For example, the quality and design of healthcare systems may influence patient work(22).

The literature also discusses the construct of “capacity”: the affective, cognitive, informational, material and relational resources available to patients/their social networks to mobilise to meet the demands of illness, its treatments and daily life (21, 35). A recent systematic review suggests that, like workload, capacity is a complex, multi-dimensional concept which encompasses the resources held by patients/their social networks, the biographical reshaping that occurs following a diagnosis and the extent to which the workload of treatment ‘fits’ into patients’ daily lives (115).

The cumulative complexity model (CuCoM) and burden of treatment theory (3, 21) usefully discuss the symbiotic relationship between workload and capacity, suggesting that BoT may occur when capacity is outweighed by workload.

The literature discussed above has identified and characterised treatment in heart failure, stroke, diabetes, chronic kidney disease and in multi-morbidity. Only one qualitative study in Australia has characterised BoT in COPD (31). To the best of our knowledge, there have been no qualitative studies of BoT in lung cancer.

This study is part of a series of work aiming:

1. to identify, characterise and explain patients' experiences of 'workload' and 'capacity' in COPD or lung cancer
2. to interrogate and refine the concept of BoT itself, specifically focusing on the constructs of workload and capacity.

We have previously undertaken a systematic review and synthesis of the qualitative literature on people living with COPD or lung cancer and informal caregivers' interactions with healthcare systems (35). Underpinning this was a theory-informed coding framework that drew together BoT, CuCoM and status passage theory (3, 21, 54). We have discussed the key concepts of CuCoM, BoT theory above. The influential theory of "status passage" characterises individuals as constantly traversing multiple, temporarily limited, societally ascribed and legitimised statuses (54). The use of status passage theory in this paper was to support the conceptualisation of the phenomenon of treatment burden over time and to consider the illness trajectory and its associated treatment workload in the context of the workloads of other status passages.

This paper takes a structured, abductive approach to study design, data collection and analysis. An abductive approach allows for the recursive working of empirical and theoretical materials to explore systematically variation in representations of the phenomenon of interest, in our case BoT. This approach facilitates the incorporation of insights from multiple theories (57). In this paper, BoT, CuCoM and status passage theory are used as theoretical lenses through which the primary constructs of workload and capacity are approached and interrogated.

From our systematic review, we developed a taxonomy identifying and characterising patient experiences of 'workload' and 'capacity' with recourse to COPD and lung cancer, finding that diagnosis (and subsequent illness identity) could initiate significant differences in treatment workload(35).

This cross sectional, comparative analysis follows sequentially on from our systematic review, using the taxonomy as a foundation on which to build a comparative analysis of lived experiences of 'workload' and 'capacity' in two diseases, COPD and lung cancer. It aims, therefore, to answer the question 'What is burden of treatment and how is it experienced by patients living with lung cancer or COPD'?

3.3 Methods

Research Ethics Committee approval for the study was granted by NHS (England) South West. REC reference: 17/SW/0162. The study protocol is available in Appendix D.

In line with our abductive approach, we used two complementary qualitative data collection methods (semi-structured interviews and non-participant observation) to support the identification and characterisation of variation.

We pragmatically selected two hospital sites in the South of England providing services for patients with COPD and lung cancer. Sites were chosen in which KAL (a respiratory nurse and researcher who undertook both the observations and the interviews) had not worked clinically with these patient groups.

Specialist respiratory and oncology clinicians in participating sites screened potential patients attending outpatient clinics during the period of recruitment (December 2017-August 2018) against the following broad inclusion/exclusion criteria. Patient participants had to be English speakers, aged ≥18 with a diagnosis of either lung cancer or COPD and under the care of either the oncology or the respiratory service respectively. Patients were excluded if they were deemed unfit to participate in the study owing to their medical condition (physically and/or psychologically) or could not provide informed consent. Clinicians either mailed or gave study information to eligible patients attending outpatient consultations. There were two separate sets of study particulars for interview and observation. Patients were invited to participate in *either* an interview *or* observation. For observation, KAL recruited consenting patients consecutively as they attended outpatient consultations. For interview, interested patients contacted KAL. Maximum variation sampling (264) was used so that participants reflected a range of different ages, sexes, living situations, employment status, disease stages and treatment regimens.

After the necessary ethical and governance approvals had been granted and prior to formal data collection, KAL spent some weeks “entering the field” (64) to facilitate familiarisation with the research settings. Potential clinician participants were given study information during this time. Clinician participants had to work in specialist respiratory and oncology services on participating sites and be present at the outpatient consultations KAL was observing. Clinicians were eligible to participate in the observation *and* interview components of the study. A convenience sample of five clinicians was recruited.

3.3.1 Data collection:

KAL undertook semi-structured interviews with patients at a venue of participants’ choice (mainly in their homes). Interviews were participant led, allowing participants to highlight areas important to them but focused on the key constructs of diagnosis (illness identity), workload and capacity. We developed a patient interview schedule based on these constructs and schedules used in other studies exploring BoT (18, 31) (see Appendix E).

Once the observation component of the study had been completed, KAL undertook semi-structured clinician interviews in hospital. Interviews focused on the clinician's approach to outpatient consultations and how they sought to consider patients/family members' treatment workload and capacity to undertake this workload. We developed a clinician interview schedule based on these constructs (see Appendix F).

KAL also undertook the non-participant observations of outpatient consultations, supported by an observation record guide (see Appendix G).

Both observations and interviews were audio-recorded (with participant consent). Interviews lasted between 23 and 63 minutes. Observations lasted between 5 and 52 minutes and audio-recorded observations totalled 11 hours, 52 minutes on 42 separate occasions (excluding the weeks spent 'entering the field'). Interviews and observations were transcribed verbatim except for potentially identifiable information which was omitted. Participants were offered the opportunity to comment on the interview transcripts to ensure they accurately reflected the interview. KAL took field-notes during the observations and directly after the interviews in order to capture immediate insights and to consider the data collection process reflexively.

KAL obtained informed written consent from all patients and clinicians interviewed and observed, and verbal consent from friends or family members present during observations or interview. For observed patients, KAL gathered additional demographic data (age, stage of condition, employment status, living situation, treatment regimen) from the patient healthcare record (with participant consent).

3.3.2 Data analysis

KAL coded each observation/interview separately using a coding framework based on the taxonomy from our systematic review. She abductively explored variation (57) in workload and capacity through grouping related codes into datasets (conditions and perspectives of patients/family members and clinicians). Variation was also explored at different time points of the patients' illness trajectory and in different situations (e.g. treatment workload in hospital was contrasted with treatment workload at home). Simple explanatory propositions were formulated to identify and characterise both variation and generalisation in the primary constructs of workload and capacity.

KAL, AR and CRM met often throughout the data collection and analysis process to discuss findings generated from the data and to think reflexively about assumptions made by KAL as the primary research instrument (265).

3.3.3 Patient and public involvement:

We worked closely with the late Mark Stafford Watson (see acknowledgements) to develop the initial research question and objectives for the systematic review that informed the subsequent empirical study. Findings from the systematic review were discussed with members of a local Breathe Easy (British Lung Foundation patient support group); these discussions facilitated the development of the cross-sectional empirical study following the review. KAL worked with clinical staff, patients and informal carers to develop appropriately worded study literature. Findings generated from the cross-sectional study have been discussed with the same local Breathe Easy group. KAL drew on the expertise of three patient members of the NIHR CLAHRC Wessex PPI group to develop lay summaries to communicate the key research findings to patient participants in studies.

3.4 Results

KAL interviewed 19 patients: 10 with COPD and 9 with lung cancer and observed 41 outpatient consultations, involving 24 patients with COPD and 17 patients with lung cancer. KAL observed and interviewed 5 clinicians: 3 respiratory clinicians (1 doctor, 2 nurses) and 2 lung cancer clinicians (1 doctor, 1 nurse). Characteristics of and conventions for describing participants are available in Tables 6 and 7. Exemplar quotes are available in Appendix H.

Table 6: Characteristics of patient participants

CHARACTERISTICS	**NUMBER OF PATIENTS**
Condition: (lung cancer/COPD)	26/34
Stage:	
Non-small cell lung cancer Stage 2b	1
Non-small cell lung cancer Stage 3a	2
Non-small cell lung cancer Stage 3b	1
Non-small cell lung cancer Stage 3c	1
Non-small cell lung cancer Stage 4	9
Small cell lung cancer Stage 3b	1
Small cell lung cancer Stage 4	1
Mesothelioma Stage 2	1
No access to clinical notes, stage unknown	19 (patients interviewed)
Mild COPD	3
Moderate COPD	6
Severe COPD	9
Very severe COPD	2
Stage of COPD not documented	4
Sex: (female/male)	27/33
Age: (years; mean (SD; range))	70 (9; 41-88)
Living situation:	
Lives alone	19
Lives with partner/spouse	33
Lives with adult offspring	4
Lives with partner/spouse + adult offspring	1
Lives with partner/spouse + children <16	1
Lives with partner/spouse + wider family	1
Lives with wider family	1
Employment status:	

Retired Employed Housewife Unemployed	48 10 1 1
Treatment regimens: (N.B. patients may be on more than one regimen so number >60) Chemotherapy Radiotherapy Surgery Immunotherapy EGFR-TK inhibitor Active surveillance (mesothelioma) Pulmonary rehabilitation Smoking cessation Weight management Inhalers Nebulisers Oxygen Anti-inflammatory macrolide Standby antibiotics ‘rescue pack’	 10 4 1 9 4 2 14 4 2 14 2 7 4 8

Table 7: Conventions for describing participants

PARTICIPANT TYPE	DESCRIPTION OF IDENTIFICATION METHOD	EXAMPLE
Patients	Identified by component of the study in which they were participating (OBS for observation and INTS for interview), then PA for patient, then by order in which they were recruited	Example [OBS-PA-001, INTS-PA-001]

PARTICIPANT TYPE	DESCRIPTION OF IDENTIFICATION METHOD	EXAMPLE
Clinicians	Identified by component of the study in which they were participating (OBS for observation and INTS for interview), then CL for clinician, then by order in which they were recruited	Example [OBS-CL-001, INTS-PA-001]

3.4.1 Workload

3.4.1.1 Diagnosis as shock

Status passage theory suggests that an unexpected and undesirable “crisis” may “flood” individuals’ lives to such an extent that all other status passages have to be temporarily or permanently put on hold (54)(p.144). In this study, participants appeared to view the lung cancer trajectory as a “crisis”, universally describing their experience of receiving a diagnosis of lung cancer as a shock.

3.4.1.2 Clear illness identity

In Western countries such as the UK, cancer has a distinct public narrative as a feared disease, often equated with death (152). Consequently, patients and family members understood, from diagnosis, that the lung cancer trajectory was likely to be short. Patients could describe treatment as something they felt obliged to undergo, as an alternative to death:

Patient: When I do have [chemotherapy], it’s like every other folk, I’m on the toilet for a few days, and I feel quite rough and that, but if that’s the only treatment available, that’s what you’ve got to take, isn’t it?…We’ve just got to smile and take the medicine and that’s it!...I don’t know, you’ve got to die of something haven’t you? But not particularly, yet (INTS-PA-016)

3.4.1.3 Treatment as priority

A sense of treatment as hope, a bulwark against the existential threat of cancer was widely apparent throughout the data. An important focus of a lung cancer consultation appeared to be continuing to identify further treatment options so that the end of treatment was not reached. Treatment for lung cancer was a priority for patients and their family members, taking precedence over the claims of other status passages (such as employment) that were often temporarily or permanently suspended.

3.4.1.4 Imperceptible diagnosis

In stark contrast to participants with lung cancer, whose moment of diagnosis was inscribed indelibly on their memory, participants living with COPD could struggle to pinpoint the moment of diagnosis. Some participants suggested they had not been offered a formal diagnosis of COPD, with many years elapsing between symptom presentation and confirmation by a doctor of the underlying condition.

3.4.1.5 Unclear illness identity

Unlike cancer, COPD has no clear public narrative (266) Thus, where a diagnosis had been formally confirmed by clinicians, many participants described an initial lack of understanding of the term 'COPD', its meaning and significance: "I didn't really take much notice of it [COPD] because it's just a name" (INTS-PA-006). Indeed, many participants made sense of their COPD diagnosis by relating it to other illnesses, expressing relief it was not cancer or conflating it with other respiratory diagnoses such as asthma that they may have previously been given.

COPD is a term for several complex, heterogeneous and dynamically interacting components relating to airway/lung disease (267). Some participants found this heterogeneity confusing, leading participants who had been formally diagnosed with COPD to believe that they did not have COPD:

> Doctor: And let's be clear what's going on here. You've got **two** diseases…You've got definitely emphysema, there's definitely damage there, that's an element and you know your lung function will never get to 100%...But there is a reversible element and a steroid responsive element here which, if you want to label it asthma, you can label it asthma, I don't…whatever, it's just a word…
>
> Patient: It's not COPD is it? [laughs]
>
> **(OBS-PA-013)**

Participants reported little discussion of disease trajectory or prognosis at diagnosis and thus a consequent lack of understanding about the trajectory, meaning or potentially life-limiting implications of COPD:

> Patient: I had heard the term [COPD]. It wasn't something I had any particular knowledge of… The first indications were a GP saying, 'Well, you know your respiratory

> really ought to be a bit better than it is'. That was the diagnosis…I felt very strongly later that what I needed was a hard, sharp look, 'You've got the onset of something really serious here, and if you don't take it really seriously *now* this is probably going to be what kills you', and that just was not said, not at all.
>
> **(INTS-PA-007)**

3.4.1.6 Lack of treatment options

Several participants described how, at diagnosis, they were not offered any treatment for COPD: "nothing happened" (INTS-PA-001, INTS-PA-009). This did not appear to be questioned by participants in the early stages of COPD, where symptoms were typically insidious, often viewed as natural sequelae of a smoking history and thus something to be endured and accepted, rather than identified as an illness and treated. Thus, initially treatment was often not a priority for patients with COPD. Indeed, many participants reported being explicitly told by clinicians in primary care that there *were* no available treatment options for COPD.

3.4.1.7 Treatment workload balanced with workload of daily life

Treatment appeared to assume more of a priority for participants with COPD later in the disease trajectory, when pathophysiological deterioration meant that symptoms were overtly impacting on physical functioning. Participants then reported a process of re-engagement with healthcare, sometimes having to negotiate and renegotiate barriers to access specialist healthcare services.

Some participants described how they had identified treatment options themselves through their own research or through the experience of peers. Interestingly, one patient with both lung cancer and COPD, described how she had only been able to access specialist respiratory healthcare and consequently treatment options for COPD after undergoing treatment for lung cancer:

> Patient: I didn't have any support [for the COPD] until, really, I had the [lung] cancer… It [healthcare support] all stemmed from that…
>
> **(INTS-PA-004)**

Once access to specialist respiratory healthcare had been negotiated, specialist clinicians made a range of treatment options available to participants with COPD. Awareness that treatment options were available could bring hope to participants but, at the same time, participants were often given more information about their condition and began to appreciate fully that it was incurable, progressive and potentially life-limiting. Some patients could find it dispiriting that treatment was not going to result in a cure. This was compounded by the fact that, throughout the often long illness trajectory, even when symptoms had become disabling, many patients and family members had to balance the treatment workload against the demands of other status passages such as employment. Often, the workload of daily life took precedence.

3.4.1.8 Immediacy of access to healthcare

Prior to diagnosis, many participants with lung cancer described how they had to mobilise resources to access healthcare, engaging and re-engaging with healthcare. In contrast, once diagnosed with lung cancer, specialist healthcare became almost immediately available.

3.4.1.9 Work of accessing healthcare

In contrast, participants with COPD had to work hard to access healthcare, often having to exercise considerable social skill (the degree to which they were able to secure the cooperation of others) to do so (51). Once participants had accessed specialist respiratory healthcare this could, in itself, enhance their capacity to manage their illness through the provision of knowledge and skills about their condition. Some participants did, however, report feelings of frustration that more and better information was not readily available for them from specialist respiratory healthcare and subsequently undertook their own research to find out more about their condition and its treatments.

3.4.1.10 Work of navigating between healthcare professionals/organisations

Despite all COPD participants having accessed specialist respiratory care, most participants described having to have frequent contact with primary care (generally GP/practice nurse). Participants and family members often had to follow up recommendations made by specialists and to navigate any complications that arose from communication and communication deficits between primary and specialist care. Participants could even describe conflicts between advice from primary and specialist clinicians that they were obliged to reconcile:

> Patient: …I did have a problem…the [respiratory practitioners] … said I was to take two antibiotics straightaway…and then one in the morning and one at night for the seven days. The [GP] insisted, 'No, you take two straightaway and then one a day', and he would only prescribe me the - I think was nine, and not the 14 that I needed. So, anyway, what I did, I just used some out of the rescue pack, and I always kept a pack in front of him, if you know what I mean? A bit naughty, I know. But I took the [respiratory practitioners]' advice and not the doctor's.
>
> **(INTS-PA-004)**

In contrast, other participants with COPD described how they had developed a good working relationship with GPs and valued their support in managing their disease.

3.4.1.11 Practical workload of treatment

Tables 8 and 9 characterise the treatment tasks in lung cancer and COPD observed or inferred from clinician/patient interaction in the outpatient consultations and described by patients in interviews.

Table 8: Treatment tasks in lung cancer

LUNG CANCER TASKS	**TASK TYPE**	**LOCATION**	**DIVISION OF LABOUR**
Attend appointment with HCP (lung cancer surgeon)	Medical appointments	Hospital	Co-present
Attend appointment with HCP (oncology healthcare professional)	Medical appointments	Hospital	Co-present
Attend appointment with HCP (GP)	Medical appointments	Hospital	Co-present
Attend appointment with HCP (for other comorbidity)	Medical appointments	Hospital	Co-present
Have blood test(s)	Medical appointments	Hospital	Co-present
Have urine test	Medical appointments	Hospital	Co-present
Have treatment (radiotherapy)	Medical appointments	Hospital	Co-present
Have treatment (immunotherapy)	Medical appointments	Hospital	Co-present
Have treatment (outpatient based chemotherapy)	Medical appointments	Hospital	Co-present
Have treatment (surgery)	Medical appointments	Hospital	Co-present
Have treatment (trial drug)	Medical appointments	Hospital	Co-present
Have hearing test	Medical appointments	Hospital	Co-present

LUNG CANCER TASKS	TASK TYPE	LOCATION	DIVISION OF LABOUR
Have scan(s)	Medical appointments	Hospital	Co-present
Inpatient stay in hospital	Medical appointments	Hospital	Co-present
Have biopsy	Medical appointments	Hospital	Co-present
Have bronchoscopy	Medical appointments	Hospital	Co-present
Pay for hospital parking	Medical appointments	Hospital	Delegated
Pay for scan	Medical appointments	Hospital	Assumed
Visit HCP at private hospital	Medical appointments	Hospital	Assumed
Implement breathing techniques	Health behaviours	Home	Delegated
Help seeking: attend A&E out of hours	Health behaviours	Hospital	Delegated
Help seeking: seek advice from GP (over telephone/in person/at home)	Health behaviours	Home	Delegated
Help seeking: seek advice from oncology team	Health behaviours	Home	Delegated
Help seeking: monitor for fits	Health behaviours	Home	Delegated
Help seeking: monitor self for infection	Health behaviours	Home	Delegated

LUNG CANCER TASKS	TASK TYPE	LOCATION	DIVISION OF LABOUR
Have injection (monoclonal antibody)	Medications	Home/hospital	Co-present
Collect medication	Medications	Pharmacy	Delegated
Take medication (steroids, antibiotic, painkillers, anti-seizure medication)	Medications	Home	Delegated
Give blood boosting injections	Medications	Home	Delegated
Take medication for SE of treatment	Medications	Home	Delegated
Have treatment (take chemotherapy tablets)	Medications	Home	Delegated
Have treatment (take tyrosine kinase inhibitor tablets)	Medications	Home	Delegated
Learn about scan(s)	Learn about conditions and care	Hospital	Shared
Consent to treatment	Learn about conditions and care	Hospital	Shared
Decide to have/not have treatment	Learn about conditions and care	Hospital	Shared
Learn about blood test	Learn about conditions and care	Hospital	Shared
Find out about complementary therapies	Learn about conditions and care	Home/Hospital	Shared
Learn about research (potential new treatment)	Learn about conditions and care	Hospital	Shared

LUNG CANCER TASKS	TASK TYPE	LOCATION	DIVISION OF LABOUR
Consent to participate in research	Learn about conditions and care	Hospital	Shared
Find out about benefits (social services)	Learn about conditions and care	Home	Shared
Contact support group	Learn about conditions and care	Home	Delegated
Learn about breathing techniques	Learn about conditions and care	Hospital	Shared
Learn about condition	Learn about conditions and care	Hospital	Shared
Discuss weaning/titrating of medications	Learn about conditions and care	Hospital	Shared
Discuss pathophysiological side effects of treatment	Learn about conditions and care	Hospital	Shared
Discuss treatment options (continuing with tyrosine kinase inhibitor)	Learn about conditions and care	Hospital	Shared
Discuss treatment options (immunotherapy)	Learn about conditions and care	Hospital	Shared
Discuss treatment options (radiotherapy)	Learn about conditions and care	Hospital	Shared
Discuss treatment options (admit to hospital)	Learn about conditions and care	Hospital	Shared
Learn about treatment (chemotherapy)	Learn about conditions and care	Hospital	Shared
Learn about treatment (radiotherapy)	Learn about conditions and care	Hospital	Shared

LUNG CANCER TASKS	TASK TYPE	LOCATION	DIVISION OF LABOUR
Learn about treatment (immunotherapy)	Learn about conditions and care	Hospital	Shared
Learn about treatment (tyrosine kinase inhibitor)	Learn about conditions and care	Hospital	Shared
Learn about treatment (additional written information given by HCP)	Learn about conditions and care	Home	Delegated
Complete claim forms	Learn about conditions and care	Home	Delegated
Arrange oxygen	Medical equipment and devices	Home	Shared
Have radiotherapy mask fitted	Medical equipment and devices	Hospital	Shared

Table 9: Treatment tasks in COPD

COPD TASKS	TASK TYPE	LOCATION	RESPONSIBILITY
Attend appointment with HCP (respiratory physiotherapy)	Medical appointments	Hospital	Co-present
Attend appointment with HCP (respiratory nurse)	Medical appointments	Hospital	Co-present
Attend appointment with HCP (respiratory doctor)	Medical appointments	Hospital	Co-present
Attend appointment with HCP (for other comorbidity)	Medical appointments	Hospital	Co-present
Attend appointment with HCP (GP)	Medical appointments	GP	Co-present
Attend appointment with HCP (practice nurse)	Medical appointments	GP	Co-present
Attend pulmonary rehabilitation	Medical appointments	Community	Co-present
Attend maintenance (post PR)	Medical appointments	Community	Co-present
Home visit from respiratory team (oxygen assessment)	Medical appointments	Home	Co-present
Home visit from respiratory team (supported discharge)	Medical appointments	Home	Co-present
Inpatient stay in hospital	Medical appointments	Hospital	Co-present
Have scan(s)	Medical appointments	Hospital	Co-present
Have blood test(s)	Medical appointments	Hospital	Co-present

COPD TASKS	TASK TYPE	LOCATION	RESPONSIBILITY
Have flu/pneumococcal vaccination	Medical appointments	GP	Co-present
Have breathing test(s)	Medical appointments	Hospital	Co-present
Have 6MWT	Medical appointments	Hospital	Co-present
Have ECG	Medical appointments	Hospital	Co-present
Have spirometry	Medical appointments	Hospital/GP	Co-present
Have sputum test	Medical appointments	Hospital/GP	Co-present
Have bronchoscopy	Medical appointments	Hospital	Co-present
Pay for hospital parking	Medical appointments	Hospital	Delegated
Contact smoking cessation team	Medical appointments	Home	Delegated
Weight/diet management	Health behaviours	Home	Delegated
Increase/maintain physical activity	Health behaviours	Home	Delegated
Smoking cessation (patient to cease)	Health behaviours	Home	Delegated
Implement breathing techniques	Health behaviours	Home	Delegated
Help seeking: monitor self for infection	Health behaviours	Home	Delegated

COPD TASKS	TASK TYPE	LOCATION	RESPONSIBILITY
Help seeking: call ambulance	Health behaviours	Home	Delegated
Help seeking: seek advice from GP (telephone/in person/at home)	Health behaviours	Home	Delegated
Help seeking: seek advice from specialist respiratory team	Health behaviours	Home	Delegated
Help seeking: seek advice from family member	Health behaviours	Home	Delegated
Help seeking: decide to take rescue pack	Health behaviours	Home	Delegated
Help seeking: negotiate with ambulance crew	Health behaviours	Community/home	Delegated
Avoid infections	Health behaviours	Home	Delegated
Monitor peak flow	Monitor health status	Home	Delegated
Monitor oxygen saturations	Monitor health status	Home	Delegated
Take medication (diuretic, nebulisers, painkillers, steroids, anti-inflammatory macrolide, antibiotics, anti-hypertensives, beta-blockers, statin, inhalers, diabetic medication)	Medications	Home	Delegated
Titrate medication according to symptoms	Medications	Home	Delegated
Use oxygen as prescribed	Medications	Home	Delegated

COPD TASKS	TASK TYPE	LOCATION	RESPONSIBILITY
Restock rescue pack	Medications	Home	Delegated
Go to chemist (for inhaler preparation)	Medications	Pharmacy	Co-present
Learn about condition (COPD)	Learn about conditions and care	Hospital	Shared
Learn about condition (COPD)	Learn about conditions and care	Home	Delegated
Learn about breathing tests	Learn about conditions and care	Hospital	Shared
Learn about scan(s)	Learn about conditions and care	Hospital	Shared
Learn about treatment (medications)	Learn about conditions and care	Hospital	Shared
Learn about treatment (smoking cessation)	Learn about conditions and care	Hospital	Shared
Learn about treatment (oxygen)	Learn about conditions and care	Hospital	Shared
Learn about treatment (lung surgery)	Learn about conditions and care	Hospital	Shared
Learn about treatment (breathing techniques)	Learn about conditions and care	Hospital/community	Shared
Learn about treatment (BIPAP)	Learn about conditions and care	Hospital	Shared
Learn about treatment (additional written information given by HCP)	Learn about conditions and care	Home	Delegated
Discuss weaning/titrating of medications	Learn about conditions and care	Hospital	Shared

COPD TASKS	TASK TYPE	LOCATION	RESPONSIBILITY
Discuss treatment options (long term oxygen therapy)	Learn about conditions and care	Hospital	Shared
Discuss treatment options (starting/changing/continuing medication)	Learn about conditions and care	Hospital	Shared
Discuss treatment options (lung surgery)	Learn about conditions and care	Hospital	Shared
Discuss treatment options (smoking cessation)	Learn about conditions and care	Hospital	Shared
Discuss treatment options (breathlessness classes)	Learn about conditions and care	Hospital	Shared
Join Breath Easy (peer support) group	Learn about conditions and care	Home	Assumed
Explain condition to general public	Learn about conditions and care	Home	Assumed (involuntary)
Teach other people how to manage treatment	Learn about conditions and care	Home	Assumed
Research alternative treatment options	Learn about conditions and care	Home	Assumed
Research Singing for Lung Health	Learn about conditions and care	Home	Assumed
Use acapella	Medical equipment and devices	Home	Delegated
Have oxygen delivered	Medical equipment and devices	Home	Delegated
Negotiate with oxygen company re holiday	Medical equipment and devices	Home	Delegated

COPD TASKS	TASK TYPE	LOCATION	RESPONSIBILITY
Have treatment (BIPAP)	Medical equipment and devices	Hospital	Co-present
Purchase oxygen saturation probe	Medical equipment and devices	Home	Assumed/delegated
Purchase nebuliser machine	Medical equipment and devices	Home	Assumed/delegated

3.4.1.12 Hospital based workload: few delegated tasks

Treatments for participants with lung cancer: surgery, chemotherapy, radiotherapy, immunotherapy or other anti-cancer drug therapy, were highly medicalised and generally hospital-based. Clinicians negotiated and agreed the division of treatment work with participants and family members and tasks were often shared (e.g. patients/family members and clinicians discussing and agreeing treatment options in outpatient appointments). Alternatively, clinicians and patients could be co-present, but be required to perform different tasks (e.g. chemotherapy required the specialist knowledge of clinicians to prescribe and administer while patients had to attend hospital for treatment, usually accompanied by their family members).

Clinicians delegated few treatment tasks for participants with lung cancer and their family members to carry out at home. Using Eton, Ramalho de Oliveira (18)'s categorisation of workload, the majority of tasks delegated by clinicians to participants with lung cancer involved learning about their condition and care, medication taking and health behaviours (specifically, help-seeking as appropriate for issues related to cancer treatment).

3.4.1.13 Home based workload: delegated tasks

Contrastingly, in COPD, clinicians negotiated and agreed the division of treatment work and delegated most treatment tasks to participants with COPD and their family members to undertake at home. Again, using Eton et al's (ibid) workload categories, in addition to those tasks delegated to participants with lung cancer described above, many participants with COPD described the work of managing medical equipment and devices at home.

3.4.1.14 Health behaviours

The bulk of the delegated treatment workload was the numerous and extensive changes clinicians directed participants to make to health behaviours. Participants were expected to exercise, manage their weight and stop smoking. These health behaviours might be supported by healthcare resources (e.g. pulmonary rehabilitation supported exercise and weight management, smoking cessation services supported quitting tobacco). Participants were expected to continue to modify health behaviours independently at home. These were less obviously treatment tasks than conventional treatments (e.g. taking medication) and were thus often not recognised by participants/family members as treatment and not given priority.

3.4.1.15 Help-seeking behaviours

Clinicians expected participants with COPD to develop more sophisticated monitoring and help-seeking health behaviours at home than those expected of participants with lung cancer.

Participants with lung cancer were generally given simple pathophysiological parameters to measure and, invariably, a named nurse/dedicated number to call when help-seeking was required. In contrast, participants with COPD were expected to accumulate a detailed knowledge of a range of symptoms that were 'normal' for them (e.g. the colour of their sputum). They were expected to monitor these symptoms daily to identify signs of deterioration. Their family members, particularly partners, invariably supported them in these monitoring tasks:

> Patient: [My wife] keeps on top of me and my medication… she'll be the one that will first say, 'You are struggling more than usual, have you thought…I think you should start that [rescue pack]'
>
> **(INTS-PA-012)**

If symptoms changed, participants with COPD (and their family members, again generally their partners) were obliged to make *clinical* judgements about the next step they should take, e.g. starting antibiotics and steroids from a rescue pack at home. Unlike lung cancer participants, participants with COPD described different sources of support for help-seeking (generally either their GP or a family member). These sources of support were generally reported to be identified through trial and error over time rather than there being a formalised route for patients to follow.

3.4.1.16 Performance management against delegated tasks

In outpatient consultations, clinicians frequently performance managed participants with COPD against these delegated tasks. When the delegated task involved changing health behaviours, participants frequently reported feeling "told off" by clinicians (and family members) in situations where they had not performed the delegated tasks adequately:

> Patient: What I have been doing is, when my breathing gets worse and I start coughing up more coloured sputum, and when my oxygen readings with me finger thing are not very good, it's then I should do something about it. I have to hold my hand up and say I don't…I delay it sometimes longer than I should…That's me own fault, that's nobody else's fault at all, and that's when I get told off! ...So, I get told off by the wife, I get told off by the daughter, I get told off by the son. I get told off by the GP. When the ambulance guys come here, they tell me off. When I go into hospital they tell me off, and fair play to them, I don't mind, I don't mind.
>
> **(INTS-PA-001)**

Where consultations also involved family members, family members could contradict participants' testimony, reporting the patient's inability to meet the negotiated health behaviour obligations agreed with the clinician:

> Specialist respiratory doctor: How are you doing with the smoking?
>
> Patient: Packed it in.
>
> …Doctor: When did you last have a fag?
>
> Patient: [Sighs]
>
> Daughter: [laughs]
>
> Patient: Can't remember now.
>
> Doctor: Yesterday, today?
>
> Patient: Nah.
>
> Doctor: This weekend? [pauses]…
>
> Daughter: Come on dad…
>
> Doctor: I can smell a little bit of it, OK
>
> Patient: No, I, I…
>
> Daughter: He desperately wants to…
>
> Doctor: Do you want to stop? Do you want to stop?
>
> Patient: Definitely.
>
> Doctor: Good. That's where we start.
>
> **(OBS-PA-003)**

3.4.1.17 Assumption of additional treatment tasks

Unlike patients with lung cancer, many COPD participants also *assumed* several treatment tasks. These could be voluntary (e.g. purchasing a pulse oximeter to measure their oxygen levels) or involuntary (e.g. having to explain their condition to members of the general public who wanted to summon help for breathlessness).

3.4.2 Capacity

3.4.2.1 Healthcare professionals

Participants with lung cancer were almost exclusively supported by specialist clinicians (doctors and nurses) whom they saw repeatedly, often having appointments every 3-4 weeks, and, consequently, with whom they were able to build a rapport. Most participants described the importance of this relational capacity (268); support from empathetic, specialist clinicians to whom they were known and in whom they had faith. Some participants placed such faith in their specialist clinicians they could *choose* to relinquish control over the cognitive task of decision making about treatment options. Less frequently, participants described how a lack of specialist knowledge *obliged* them to relinquish control of decision making over treatment options to their specialist clinicians.

Participants appeared rarely to have contact with their GP and, indeed, could express anxiety when doing so because of the GP's perceived lack of familiarity with their disease and its treatment.

In addition to regular face-to-face appointments with specialist clinicians, participants and their informal caregivers were able to contact a named lung cancer nurse specialist who provided emotional support such as counselling for patients who were struggling to come to terms with their diagnosis and, crucially, practical support; co-ordinating healthcare:

> Patient: I was assigned a nurse contact… She had a phone number and email, that I could get in touch with her if I needed to, and I did a couple of times because I think it just gets really complicated. She was just always very approachable and matter-of-fact…she was there for the practical side of things, but actually that's what I needed, really…because, well, you do feel a little bit like a boat tossed in a storm…Sometimes, it's nice just to have someone to check where am I meant to go and have an appointment at 10 a.m., is it with so-and-so or so-and-so [chuckling]
>
> **(INTS-PA-017)**

Interestingly, although participants and family members gave priority to the patient's illness and its treatments, it was apparent that specialist clinicians (both doctors and nurses) encouraged participants to have priorities other than lung cancer and its treatment in their life. Specialist clinicians worked hard to provide participants with a flexible and responsive treatment experience, organising or rearranging treatments around competing status passages such as employment and/or parenthood, and encouraging holidays:

> Doctor: If you can just forget you've got cancer and get on with your life… I spend a huge amount of my time talking about bloody travel insurance. They can't get travel insurance to go on holiday…why keep someone alive for an extra ten years if they can't do anything nice… What's the point in them having this treatment if they sit at home…I really feel strongly about that. My job is to try and let them get a few more years of good quality life.
>
> **(INTS-CL-004)**

Because of the duration and chronicity of the illness, participants with COPD saw their specialist clinicians less frequently than participants with lung cancer. Thus, participants with COPD and their family members were often obliged to update clinicians about changes to their medication, co-morbidities and even their disease status that had arisen in the interim. Some participants with COPD might not see the same specialist clinicians and described this lack of relational continuity as challenging:

> Wife: We were…Well, I was really glad when we didn't get any more appointments at [local teaching hospital] because …we thought we were seeing the consultant and we saw a lovely registrar, but it's not the same.
>
> Patient: No, you hardly remember his name and you don't see him again.
>
> **(INTS-PA-009)**

Like participants with lung cancer, participants with COPD valued relational continuity with specialist clinicians with whom they had developed relationships over time and to whom they were known. Indeed, it appeared that participants chose to assume additional work to maintain relational continuity with these specialist clinicians, e.g. declining appointments geographically closer, trading this off against the extra work that they would need to undertake in order to re-establish relationships with new clinicians.

Although individual clinicians clearly worked hard to provide as flexible a service as possible to their patients, it was apparent that inflexibility in the healthcare system meant it could be difficult for clinicians to tailor service provision to the needs of the individual patient. Many participants reported how this lack of flexibility made the work of undertaking treatment more challenging.

3.4.2.2 Family and friends

The support that participants with lung cancer received from family and friends enhanced their capacity to meet the demands of treatment for their illness. Many participants reported how family members temporarily suspended other status passages (such as employment) in order to support participants. Participants described the importance of this support, both emotionally and practically, helping participants make sense of disease progression and the complex treatments that they had to undergo for this.

Many participants with lung cancer observed were accompanied by a friend/family member (usually partner or adult offspring). Partners tended to play a significant role in outpatient consultations, frequently undertaking the bulk of reporting of symptoms and repeatedly using the pronoun “we” to respond to clinicians’ treatment queries, almost as if patient and partner were collectively undergoing treatment. Adult offspring also took an active role, often taking notes of discussions and asking questions.

Participants with COPD too reported how the support they received from family and friends enhanced their capacity to manage their treatment workload. Unlike lung cancer, family members did not appear to be able to suspend the demands of other status passages. Many participants (and their family members) reported how family members *had* to assume the participants’ share of the domestic workload as pathophysiological deterioration increased over the disease trajectory. Family members were also obliged to support participants with complex treatment tasks at home: assisting the patient to manage health technologies (such as oxygen), monitoring the patient for signs of a ‘flare up’ of their condition, advising the patient on taking stand-by medication and help-seeking in the case of emergencies. It was apparent that the demands of multiple workloads could be, at times, very hard work for family members and that these could accumulate over the illness trajectory.

3.4.2.3 Stigma

Unlike participants with lung cancer in this study, participants with COPD reported how the capacity available to them to manage their illness and its treatments could be diminished by diagnosis. Participants described experiencing the ‘felt’ stigma of guilt and shame of having a self-inflicted disease:

> Patient: …I was then told I was suffering from COPD. It's smoking related - I presume, anyway. I remember being quite shocked, and ashamed to a degree. I think this is very much an element of people with COPD that have been smokers - self-blame, you know,

> and not expecting any sympathy, really… there's an element of: Well, it serves you right. You smoke….I feel responsible…
>
> **(INTS-PA-005)**

Patients also reported experiencing ‘actual’ stigma from clinicians and the general public. Furthermore, as some treatments were not available on the National Health Service (NHS) if the patient was still smoking(263), this could be seen by the patient to add to their stigma:

> Patient: …every time you’ve [doctor] explained... [option of lung volume reduction surgery], it’s just me that’s been lacking… holding everything up by smoking…it was all there for me in the past.
>
> **(OBS-PA-010)**

3.4.2.4 Social isolation

Capacity could also be diminished for participants with COPD through the significant involuntary social isolation brought about by pathophysiological deterioration. Participants described reluctance to go on holiday as this highlighted physical limitation which they were able to disguise in familiar environments by planning routes to avoid obstacles such as stairs. Some participants were averse to even leaving the house because of disabling symptoms. Other participants used voluntary social isolation during the winter months as a deliberate tactic to avoid infection. It was apparent that social isolation affected both participants and their partners/spouses.

3.5 Discussion

Many of these findings resonate with our previous systematic review. We did characterise additional elements of workload and capacity not identified during the systematic review and these have been added to our taxonomy (see Table 10). There were some differences between this study and our systematic review. For example, participants with lung cancer did not discuss stigma and social isolation that might diminish capacity in their interviews, and it was not apparent in observations. This may be because we did not explicitly ask participants about stigma or social isolation in interviews. Yet, both were apparent in interviews/observations of participants with COPD.

Table 10: Taxonomy of treatment burden in lung cancer and COPD (systematic review and empirical study integrated)

PRIMARY CONSTRUCT	**SECONDARY CONSTRUCT**	**LUNG CANCER**	**DATA SOURCES** **ES = Empirical study** **SR = Systematic Review**	**COPD**	**DATA SOURCES** **ES = Empirical study** **SR = Systematic Review**
Workload (the affective, cognitive, informational, material and relational tasks delegated to patients/caregivers)	Diagnosis /illness identity	Diagnosis as shock	SR, ES	Diagnosis imperceptible	SR, ES
		Obvious illness identity with socio-cultural resonance (therefore understood by patient, caregiver, HCP)	SR, ES	Unclear illness identity, without socio-cultural resonance (therefore poorly understood by patient, caregiver, HCP)	SR, ES
		Short disease trajectory (clear to patient and informal caregiver)	SR, ES	Long and uncertain disease trajectory (unclear to patient and informal caregiver)	SR, ES
				Diagnostic ambiguity	ES
	Attitude towards treatment	Demands of treatment workload as overriding life priority (for both patient and informal caregiver)	SR, ES	Demands of treatment workload balanced with domestic/professional/ sentimental demands of everyday life (for both patient and informal caregiver)	SR, ES

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	DATA SOURCES ES = Empirical study SR = Systematic Review	COPD	DATA SOURCES ES = Empirical study SR = Systematic Review
		Practical demands of treatment workload as a relief from the existential threat of cancer	SR	Practical demands of treatment workload as hard work	SR, ES
		Treatment as hope	SR, ES	Institutionalised care as respite from unrelenting demands of self-management	SR
		Sense of ‘limbo’ once treatment completed	SR		
		Reluctance to stop treatment despite debilitating pathophysiological side effects	SR, ES		

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	DATA SOURCES ES = Empirical study SR = Systematic Review	COPD	DATA SOURCES ES = Empirical study SR = Systematic Review
		Treatment for family rather than for patient	SR, ES		
	Treatment options	Lack of options: treatment or death	SR, ES	Lack of treatment options (lack of information or feeling that 'nothing can be done' from HCPs)	SR, ES
		Decision to cede control over choice of treatment options to trusted HCPs	SR, ES		
	Access to/navigation of healthcare system/ Institutions	Immediacy of availability of specialist healthcare	SR, ES	Work (for patients and informal caregivers) of accessing healthcare	SR, ES
		Specialist HCPs with specific knowledge of lung cancer	SR, ES	GPs/practice nurses who lack specific knowledge of COPD	SR,ES
		Structured treatment pathway	SR, ES	Fragmented treatment pathway	SR,ES

PRIMARY CONSTRUCT	**SECONDARY CONSTRUCT**	**LUNG CANCER**	**DATA SOURCES** **ES = Empirical study** **SR = Systematic Review**	**COPD**	**DATA SOURCES** **ES = Empirical study** **SR = Systematic Review**
	Practical workload of treatment	Specialist treatment workload in secondary care with debilitating pathophysiological side effects	SR, ES	Multiple appointments for treatment in primary, secondary care and in the community	SR,ES
		Limited delegated tasks from HCPs	SR, ES	Significant workload of delegated treatment tasks at home from HCPs	SR,ES
				Workload of changing health behaviours at home	ES
				Clinicians performance manage patients against delegated tasks	ES

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	DATA SOURCES ES = Empirical study SR = Systematic Review	COPD	DATA SOURCES ES = Empirical study SR = Systematic Review
				Informal caregivers report failure of patients to perform against delegated tasks to clinicians	ES
	Informational workload of treatment	Generally high quality information provided in written form and from specialist HCPs	SR, ES	Patients typically poorly informed about condition from diagnosis to death adding to treatment workload	SR,ES
		Lack of information as a deliberate choice on the part of patients – a tactic for maintaining hope in the face of a poor prognosis	SR, ES	Conflicting/contradictory information adds to patient/informal caregiver distress	SR,ES
		Conflicting/contradictory information adds to	SR		

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	DATA SOURCES ES = Empirical study SR = Systematic Review	COPD	DATA SOURCES ES = Empirical study SR = Systematic Review
		patient/informal caregiver distress			
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)	SR, ES (no mention fear of burden in ES)	Family and friends are seen as the main source of support post diagnosis	SR,ES
		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	SR, ES	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	SR,ES

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	DATA SOURCES ES = Empirical study SR = Systematic Review	COPD	DATA SOURCES ES = Empirical study SR = Systematic Review
		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	SR	Support for the patient's treatment workload may be seen as an affirmation of the strength of the patient/family member relationship	SR
				Caregivers feel compelled to take on a care-giving role over the long duration of the disease trajectory	SR,ES
				Delegated workload of treatment tasks that informal carer has to carry out	SR
				Informal carer has to undertake domestic tasks previously undertaken by patient	SR

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	DATA SOURCES ES = Empirical study SR = Systematic Review	COPD	DATA SOURCES ES = Empirical study SR = Systematic Review
	Healthcare professionals	Importance of support from empathetic, trusted HCPs in whom patients have faith	SR, ES	Importance of support from trusted HCPs, especially those with specialist knowledge of COPD	SR,ES
		Less commonly, loss of faith in HCPs	SR	Importance of relational continuity with HCPs making access to and navigation of the healthcare system and its institutions easier	SR,ES
		Specialist clinicians encourage priorities other than treatment	ES	Loss of faith in HCPs	SR,ES
		Flexible and responsive treatment experience	ES	Knowledge and skills gained from specialist care vital	ES
				Inflexibility of treatment experience	ES

PRIMARY CONSTRUCT	**SECONDARY CONSTRUCT**	**LUNG CANCER**	**DATA SOURCES** **ES = Empirical study** **SR = Systematic Review**	**COPD**	**DATA SOURCES** **ES = Empirical study** **SR = Systematic Review**
	Peer support	Little peer support available for patients with lung cancer. What is available appears impromptu and transitory	SR, ES	Peer support is an important resource and is generally accessed through pulmonary rehabilitation	SR,ES
				Shared experiences with peers reduce isolation	SR,ES
				Peer support is used as a resource for information sharing	SR,ES
	Disease trajectory	Short disease trajectory: ill equipped to self-manage symptoms at home	SR	Long disease trajectory: get to know their bodies and symptoms, through trial and error	SR,ES
Capacity (the affective, cognitive, informational, material	Stigma	Patients are considered culpable for their illness and stigmatized by society	SR	Patients are considered culpable for their illness and stigmatized by society	SR,ES

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	DATA SOURCES ES = Empirical study SR = Systematic Review	COPD	DATA SOURCES ES = Empirical study SR = Systematic Review
and relational resources available to be mobilised by patients/caregivers) Diminished by diagnosis		Patients consider themselves culpable for their illness: a "self-inflicted" disease	SR	Patients consider themselves culpable for their illness: a "self-inflicted" disease	SR,ES
		Patients experience 'felt' stigma of blame, guilt and shame	SR	Patients experience 'felt' stigma of blame, guilt and shame	SR,ES
		Patients attempt to conceal their condition owing to fear of 'enacted' stigma leading to social isolation	SR	Patients attempt to conceal their condition owing to fear of 'enacted' stigma leading to social isolation	SR,ES
			SR	Patients feel 'marked' by visible treatment leading to social isolation	SR,ES

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	DATA SOURCES ES = Empirical study SR = Systematic Review	COPD	DATA SOURCES ES = Empirical study SR = Systematic Review
		Patients feel 'marked' by visible treatment leading to social isolation		Patients internalise stigma, considering themselves undeserving of treatment	SR,ES
				Patients experience 'enacted' stigma from HCPs, making access to treatment challenging	SR,ES
	Social isolation (Self-imposed)	Embarrassment about symptoms, medications and treatment technologies which mark the patient as ill leading to fear of 'enacted' stigma	SR	Embarrassment about symptoms, medications and treatment technologies which mark the patient as ill leading to fear of 'enacted' stigma	SR,ES
				Exacerbation triggers – leads to avoidance of social situations	SR,ES
	Social isolation (Involuntary)	Illness as contagious: social networks contract as friends withdraw	SR	Illness as contagious: social networks contract as friends withdraw. Isolation	SR,ES

PRIMARY CONSTRUCT	SECONDARY CONSTRUCT	LUNG CANCER	DATA SOURCES ES = Empirical study SR = Systematic Review	COPD	DATA SOURCES ES = Empirical study SR = Systematic Review
				worsens with disease progression and deterioration of physical function	
		Psychological co-morbidities lead to avoidance of social situations	SR	Logistical difficulties of treatment workload limits patient to home	SR,ES
				Social isolation extends beyond patient to affect informal caregiver	SR,ES
				Psychological co-morbidities lead to avoidance of social situations	SR

3.5.1 Biographical disruption or biographical erosion?

Diagnosis was a significant point of departure between COPD and lung cancer in terms of patients' experience of workload and capacity. Bury's (50) influential paper characterises the experience of being diagnosed with illness as a "biographical disruption" where the individual must fundamentally rethink their "biography and self-concept" (p.169). Diagnosis moves the individual's biography from an anticipated trajectory with relatively predictable chronological stages, to an abnormal trajectory where the future is uncertain.

In this study, patients living with lung cancer (and, in many cases, their family members) experienced the diagnosis of lung cancer as a biographical disruption. Conversely, in COPD, the diagnostic process was fragmented. When diagnosed, patients (and, in many cases, their family members) had little understanding, again in Bury's terms, of the significance and consequence of the illness (269, 270). Patients came to an understanding of each over the long, and often uncertain disease trajectory. Rather than experiencing diagnosis as biographically disruptive, therefore, the experience of diagnosis in patients living with COPD was biographically *erosive*. We found that this experience of diagnosis and the subsequently biographically erosive/disruptive illness identity conferred by this might influence:

1. The capacity available to patients and the extent to which it had to be mobilised
2. The priority that patients/family members and clinicians attach to the treatment workload
3. The nature of the treatment workload

3.5.2 Mobilising capacity

Once diagnosed, participants with lung cancer found healthcare almost immediately available; they were not obliged to mobilise capacity. A well-defined and highly structured treatment pathway was available to them, in addition to practical and emotional support from a team of specialists with whom they were able to develop relational capacity. Specialist clinicians appeared to have discretion to allocate certain healthcare resources that considered patient priorities other than treatment, thus providing a flexible and responsive treatment experience, tailored to individual needs. Practical and emotional support from family and friends was also readily available, with close family members often being able to suspend temporarily the demands of daily life to support patients in managing their treatment workload. Indeed, our data suggests that the family assumed a *collective* illness identity, allowing for collective action and bolstering patients' structural resilience (their potential to absorb adversity). In contrast, participants with COPD were obliged to exercise considerable social skill in order first to identify, and then mobilise, capacity to access healthcare. Participants had to engage and re-engage with healthcare providers in order to be given and subsequently understand a diagnosis and secure access to different treatment options. Once treatment options had been identified, participants with COPD had to work hard to access a fragmented and confusing treatment pathway which they themselves had to co-ordinate between primary and secondary care. Where relational capacity was established, participants valued support from clinicians in both primary and secondary care. However, clinicians appeared to have less discretion than those in cancer services to allocate healthcare resources, meaning that the treatment experience could appear inflexible. Practical and emotional support from family and friends was highly valued but family members' capacity to support patients could itself be diminished by multiple workloads. Rather than assuming a collective illness identity as in lung cancer, our data suggests a clear separation in identity between patient and family member with respect to COPD. Participants reported feeling 'told off' by clinicians and family members for failure to perform against agreed treatment tasks which might diminish their structural resilience (their potential to absorb adversity). Structural resilience had already been diminished by internalised stigma, where participants blamed themselves for their "self-inflicted" smoking related disease.

3.5.3 Priority given to treatment workload

For participants with lung cancer, the recognition of the threat of death from their illness and hope that treatment might be life-prolonging or even be curative meant that participants were allowed and, indeed, *expected* to adopt a more traditional sick role. Thus, they were temporarily exempted from the demands of other status passages in order to prioritise treatment of their illness (271). Despite a heavy treatment workload with potentially debilitating pathophysiological side effects, participants could be reluctant to stop treatment as this could be viewed as tantamount to accepting death. Participants did not appear to view the heavy treatment workload as burdensome but rather as providing hope.

Conversely, participants with COPD initially had little or no understanding of the meaning of their disease and its implications. The unclear, uncertain and often prolonged illness trajectory meant that participants were obliged to balance the demands of the treatment workload with the demands of daily life. When participants with COPD did gain knowledge about the progressive, potentially lethal nature of their disease and its trajectory, its treatments and their limited curative value, this could take away hope and, consequently enthusiasm for undertaking the demands of the treatment workload.

3.5.4 Nature of treatment workload

For participants with lung cancer, treatments (e.g. chemotherapy, immunotherapy, radiotherapy, surgery) required the specialist knowledge of clinicians to administer them and, as such, were *done to* patients in hospitals rather than *delegated to* patients and family members to manage at home. Treatments were generally clearly temporally limited, involving defined periods of time and "cycles" of treatment, whose likely duration was clear to patients.

In contrast, participants with COPD, once treatment options had been identified and accessed, were delegated treatment tasks to manage at home, that frequently involving changing or maintaining health behaviours. These treatments were often intended to be lifelong. Our data suggests that this treatment workload of delegated tasks could be hard for both patients and family members to manage and could accumulate over the prolonged illness trajectory, especially in combination with pathophysiological deterioration and consequent rise in symptom burden.

3.5.5 Strengths and limitations

The abductive approach taken to study design, data collection and analysis means this comparative study builds iteratively and recursively on a theory-informed systematic review. These studies have enabled the robust, empirically and theoretically informed characterisation of the constructs of workload and capacity in lung cancer and COPD. Importantly, these studies have interrogated and refined the nascent theoretical concept of BoT itself. This benefits researchers seeking to understand BoT. It also benefits clinicians seeking to provide "minimally disruptive medicine" to patients living with respiratory disease and their family members. Healthcare teams could use the taxonomy developed to understand the potential impact of the workload of treatments delegated to patients. Health care teams could also use the taxonomy to aid consideration of patients' capacity to undertake this treatment workload.

A potential limitation of this study is, owing to resource limitations, it is cross-sectional rather than longitudinal. A longitudinal design may be particularly well suited to understanding the evolving and dynamic nature of treatment burden (8).

A further potential limitation is that the comparative analysis has only recruited participants from two UK hospital sites. This limitation is mitigated by our abductive approach, where we used robust, empirically grounded mid-range theories to integrate international findings from our systematic review with those of the comparative analysis.

Had resources permitted, it would have been ideal to observe primary care consultations with patients living with COPD and GPs/practice nurses as the delegation of treatment workload to patients often occurs within these clinical encounters.

3.6 Conclusion

Lung cancer is a widely understood and clearly defined illness in which patients are assumed to be dependent on the clinical service, itself well defined and highly structured around a set of treatments considered to be more or less independent of the motivation of patients. COPD is an often poorly understood term for a heterogeneous mixture of airway/alveolar abnormalities. Patients are expected to be motivated to assume agency over their treatment workload independent of the clinical service (and yet to seek help only as the clinical service deems appropriate). The clinical service provided to patients with COPD is organised around a delegated workload of health behaviour rather than what might conventionally be understood as treatment and appears to be, at times, characterised by ambivalence about patients' moral character and motivation.

By comparing and contrasting the constructs of illness identity, capacity and workload in lung cancer and COPD, we have shown that treatment burden is not simply the work that patients have to do to meet the demands of their treatment. Our comparative analysis suggests that diagnosis and illness identity affect the priority that patients, family members, clinicians and society itself give to meeting the demands of that treatment workload. Thus, treatment workload in lung cancer may bring hope rather than burden. In COPD, the treatment workload must be balanced with the demands of daily life and may, therefore, accumulate over the uncertain but often long illness trajectory to burden patients and their family members.

Diagnosis and illness identity may also affect the nature of the treatment workload, so in chronic non-malignant conditions, tasks may be delegated by clinicians to patients to manage independently at home over the lifespan. In lung cancer (and possibly other cancers), temporally limited tasks are more likely to be undertaken by clinicians and patients in hospital together.

Diagnosis and illness identity may also affect the capacity of patients and their relational networks to meet the demands of the treatment workload and, crucially, the social skills required to mobilise this capacity and the structural resilience required subsequently to sustain it.

Chapter 4 Conceptual model

4.1 Abstract

Objectives

This study aims to identify and characterise aspects of patient experience that can be constructed as potentially modifiable factors in the measurement of treatment workload and capacity. It aims to explain how interactions between workload, capacity and their associated factors may drive treatment burden.

Methods

We combined integrated empirical data from two studies (a systematic review and synthesis of patients with lung cancer or COPD/informal caregivers' interactions with health and social care and a comparative qualitative analysis of patients' experiences of treatment in COPD or lung cancer) with the theoretical literature on burden of treatment, cumulative complexity, status passage and biographical disruption. From this, we characterised the key components of the primary constructs of 'workload' and 'capacity' through simple explanatory propositions. We interrogated and refined these simple explanatory propositions against findings of other systematic reviews examining 'capacity' and 'workload' in disease. We extracted factors that shape patients' experience of the primary construct and then modelled the relative significance and position of each of the constructs in relation to the others, creating hierarchical models of potentially modifiable and measurable factors that shape the primary constructs.

Results

We found that the key potentially modifiable factors shaping capacity were likely to be: 1) social skill (ability to secure cooperation) 2) structural resilience (adaptiveness) 3) illness trajectory. The key factors shaping workload were likely to be: 1) structural advantage 2) how healthcare services are experienced by patients 3) understanding of disease 4) normative expectations of motivation to participate in workload.

Treatment workload did not automatically lead to treatment *burden*. Indeed, treatment workload itself could confer capacity. Treatment burden was a complex set of interactions between workload, capacity and the factors associated with each.

Chapter 4

Conclusion

This conceptual modelling work has shown the importance of the consideration of both of the primary constructs of ‘workload’ and ‘capacity’ in the detection of treatment burden at an individual patient level.

4.2 Introduction

4.2.1 An epidemiological shift

The landscape of healthcare has been transformed globally by the eradication of, previously lethal, infectious diseases and the development of more effective medication and other technologies. An ageing population allied to a worldwide spread of risk factors, particularly tobacco use, means that, increasingly, people are living longer with, often slowly progressive, non-communicable diseases (4, 5, 272). Especially common are cardiovascular and respiratory disorders, cancers and diabetes (273)

4.2.2 The work of being a patient

As people live longer with one (or often more) diseases (272), they will almost inevitably have to engage with healthcare systems for treatment for that illness. This engagement with healthcare systems for treatment has been characterised as *work*. This characterisation is not new. Corbin & Strauss's (1985) influential paper, 'Three Lines of Work', discussed the interplay between illness work, everyday work and biographical work (the work individuals might have to do to reconstitute identity following a diagnosis of chronic illness)(15). Later, Charmaz (1991) explored how people fit the experience of living with chronic illness into the context of everyday life. She characterised how people living with chronic illness must plan and manage the tasks of illness alongside the tasks of daily life. Like Corbin & Strauss (1985), Charmaz emphasised how illness work is biographical work: work that requires the re-constitution of identity. Thus, people living with chronic illness must revise their plans for and expectations of self. This biographical re-constitution may happen repeatedly throughout an illness trajectory as pathophysiological deterioration impacts on physical functioning (16).

More recently, the cumulative complexity model (CuCoM) (21) and burden of treatment (BoT) theory (274) have interrogated the idea of illness as work, differentiating between the inexorable work of illness and a potentially *modifiable* workload of treatment for that illness. These theories/conceptual models have been augmented by a range of primary qualitative studies which have identified and characterised this emergent concept of treatment burden. These studies focus both on people living with multiple chronic conditions(17, 24, 26, 275-277); or specific conditions such as cystic fibrosis (27), heart failure (19), diabetes (47), end-stage renal disease (278), chronic kidney disease (29), asthma (30), Chronic Obstructive Pulmonary Disease (COPD) (279), stroke (22) and kidney transplants (32). In addition to these primary qualitative studies, there have been a number of systematic reviews that focus again on both people living with multiple chronic conditions (36, 38, 39, 280); or specific conditions such as heart failure (33), stroke (281), chronic kidney disease (34), COPD and lung cancer (35).

This literature has been supplemented by quantitative research using survey methods in stroke/diabetes and multiple chronic conditions (40-42) Two studies have also used mixed methods (interview and survey) in multiple chronic conditions (44, 45). Much of this quantitative research focuses on the creation of frameworks against which treatment burden can be measured (40, 42, 45). While these measures provide a useful preliminary basis for the understanding of levels of treatment burden, time limitations may prevent the measurement of treatment burden through lengthy questionnaires in clinical practice (8)

4.2.3 Burden of treatment theory

4.2.3.1 Workload

In this literature cited above, workload has been defined as the "affective, cognitive, informational, material, physical and relational tasks" (35)(p.1) that patients/family members may have to carry out to undertake treatment and the *impact* of these on the individual (22, 36). These tasks have been identified and characterised in the literature (references given above) as specifically:

- learning about illness, its treatments and their consequences
- adhering to complex treatment and medication regimens
- changing lifestyle behaviours
- attending medical appointments
- monitoring/appraising self-care activities

The impact of the treatment workload on the individual has been characterised in the literature in both biographical and relational terms. The impact of the treatment workload can "biographically disrupt" an individual's identity, restricting important activities and curtailing freedom (36, 50). This biographical disruption may lead to negative affective states for patients such as shame or anger; patients may also experience enacted or felt stigma (35, 36). The impact of the treatment workload has also been characterised as relationally disruptive, placing strain on family and other relationships and leaving the patient feeling isolated (36). May et al (2014) characterise the relational impact of the treatment workload in detail, suggesting that in order to enact the expected tasks of treatment, patients must work to form and sustain relational networks. Within these relational networks, patients must allocate and undertake the expected tasks, evaluating their performance against expected tasks and applying this appraisal to the reconfiguration of work over the illness trajectory (3)

4.2.3.2 Capacity

Capacity has been characterised as the “affective, cognitive, informational, material, physical and relational resources” (35)(p.1) available for patients to mobilise (115). Capacity may be personal (for example, the ability to drive) or distributed (for example, a supportive family that drives patients to appointments). Capacity is also likely to be very sensitive to socioeconomic inequalities (for example, having the financial resources to own a car). Capacity is finite and thus has to be shared out amongst the work of illness/treatment and everyday life (115).

Both workload and capacity are dynamic concepts that have been shown to fluctuate over the course of illness trajectories (8, 21, 22, 35).

4.2.3.3 Burden

Much of the literature equates ‘workload’ with ‘burden’, so BoT has been defined as the workload of healthcare and the negative impact of this workload on patients’ identity, function and well-being (8, 22, 23, 31, 36, 42).

Importantly, the CuCoM/BoT (3, 21) move beyond this idea of workload as burden. Instead, they discuss the interaction between the key constructs of workload and capacity, suggesting that a workload which is greater than the capacity to undertake it may be the primary driver of treatment burden. While the CuCoM and BoT provide a useful starting point for the consideration of treatment burden, they do not fully identify and characterise the ways in which the key constructs of workload and capacity interact with one another to produce treatment burden for the individual patient. The identification of treatment burden is important because it has been shown to lead to a range of negative outcomes for patients such as lack of adherence to treatment regimens, reduced quality of life (for patients and family members) and inefficient use of healthcare resources (3, 21, 22, 39). It is important to identify treatment burden at an individual level in addition to a population level as treatment burden is subjective so not only will the capacity available to individuals vary but an individuals’ response to the same workload may be very different (39).

4.3 Aims of this paper

"There is nothing so practical as a good theory" (282)(p.169): theory as orientation and explanation

The application of theory, "reason-giving", is often viewed as an arcane and abstract process, with little real-life applicability (283). Higher order theories provide systematic ways of explaining society's uniformities and orienting ourselves (and our own knowledge and practice) to these. Robust theoretical work moves recursively between orientation and explanation, facilitating the accumulation of knowledge and the consequent replication of learning in different contexts (283, 284). Middle range theories sit between minor working hypotheses and higher order theories, characterising discrete conceptual ranges and offering explanations of specific phenomena (52). Middle range theory may be particularly helpful in generalising learning in health services improvement so that interventions can be replicated in different contexts (283).

In this paper we use theory as a tool both to orientate ourselves to our empirical data and identify, characterise and explain generalisations drawn from our empirical data. Thus, our specific aims are as follows:

1. To identify and characterise aspects of patient experience that can be constructed as potentially modifiable factors in the measurement of treatment workload
2. Identify and characterise aspects of patient experience that can be constructed as potentially modifiable factors in the measurement of potential to mobilise capacity
3. To model the hierarchical relationships between the factors associated with workload and the factors associated with capacity
4. To explain how the interactions between these two primary constructs and their associated factors may drive treatment burden

4.4 Theoretical background

In addition to the middle range theory of "burden of treatment" described above and the cumulative complexity model, two other middle range theories that characterise treatment/illness as work have framed our approach to this paper.

4.4.1 Biographical disruption: a theory of *disrupted* identity

Bury’s seminal study of patients with rheumatoid arthritis at the point of first referral to specialist rheumatology clinics, characterised the onset of chronic illness as a “biographical disruption”, requiring the individual to re-think fundamentally their “biography and self-concept” (50)(p.169). Biography is shifted from an anticipated trajectory, with relatively foreseeable chronological stages, to an abnormal trajectory with an uncertain future. Consequently, the individual is obliged to relinquish previously held unconscious assumptions and behaviours.

Bury explains chronic illness as disruptive both in terms of its *significance* and its *consequence* (112, 270). Thus, illness may signify different things in different cultures, so this biographical disruption is mediated by the socio-cultural context in which the individual and their family members are sited. He characterises the disabling and handicapping consequences of chronic illness, its practical and socio-economic impact on the individual and their family relationships, arguing that biographical disruption requires resources to be *mobilised* (50, 112, 270).

4.4.2 Status passage: a theory of *changing* identity over time

Glaser & Strauss (54) developed their characterisation of the phenomena of “status passages” through their empirical work on careers: in organisations, in institutions, in illness, in dying patients and in clinical education. One or more individuals may enter temporally limited and societally ascribed status passages (for example, marriage is a (usually) voluntary status passage). A status passage is not identity in stasis but is rather a process of biographical *change*. This biographical change may be desirable and voluntarily undertaken or undesirable and inevitable. Individuals are likely to be traversing more than one passage simultaneously. The centrality (the relative importance of each passage to the individual) may differ and is likely to change over time. Multiple passages may be complementary, supporting one another, or competitive, their demands on the limited resources of individuals jostling for position.

Central features of status passage are *definition* and *legitimation*. The extent to which individuals can define their own passage may vary: individuals may be able to control certain features of their own passage; other agents may also have control over some features. Indeed, passages may require legitimation by authorised agents (for example, a priest may be the authorised agent required to legitimate marriage).

Pertinently for this paper, Glaser & Strauss describe the illness passage as an undesirable, inevitable, involuntary and often irreversible passage, legitimised by doctors as authorised agents (54). Similar to Bury’s concept of illness as biographical disruption(50), illness passages may be experienced by individuals (and the ones closest to them) as a “crisis” (54) (p.144), a shock that temporarily or sometimes permanently blots out the demands of other status passages, both of the passagee and of their significant others (usually close family members). Glaser & Strauss also postulate that, in contrast, there are situations in which individuals are unaware that they are going through an illness passage and, indeed, doctors as legitimising agents may not be aware that the passage exists (54).

4.5 Methods

In this paper, we present a robust conceptual model of workload, capacity and treatment burden. It is a conceptual model rather than a middle range theory because although, like a middle range theory, it focuses on a discrete set of propositions, these propositions are context dependent – i.e. they are applicable only to the area of healthcare (285).

This paper draws on our previous work:

1. a systematic review and interpretative synthesis of the qualitative literature on patient and informal caregivers’ interactions with health and social care in COPD and lung cancer (35)
2. A comparative qualitative analysis of patients’ experiences of treatment in COPD and lung cancer qualitative systematic review that compares lived experiences treatment burden in lung cancer and COPD (cross-sectional semi-structured interviews with patients, *n* = 19 and clinicians *n* = 5; non-participant observation of outpatient consultations *n* = 41). Research Ethics Committee approval for this study was granted by NHS (England) South West. REC reference: 17/SW/0162.

In these studies and in this paper, we have taken an abductive approach to data collection and analysis (57). An abductive approach allows the integration of pre-existing theory, using empirical data iteratively and recursively to identify, characterise and explain the phenomenon of interest, in our case, workload, capacity and treatment burden.

To identify core components of patient and caregiver experience, we identified key concepts of BoT, CuCoM and status passage theories from the existing literature, determining operational definitions of each in order to create a conceptual framework.

We applied this conceptual framework to data identified through the systematic review and synthesis described above. From this, we developed a taxonomy of workload and capacity in treatment burden(35), interrogating and refining this taxonomy through the comparative qualitative analysis described above.

To develop the conceptual model of treatment burden, we modified previously used methods (285)

4.5.1 Identification and characterisation of sensitising concepts

We formulated simple explanatory propositions from this integrated empirical data (what have been termed “sensitising concepts” (285)(p.3), identifying and characterising key components of the primary constructs of workload and capacity.

4.5.2 Identification and characterisation of theoretical concepts

We re-reviewed the theoretical and empirical literature on BoT (3), CuCoM (21) and added in the theoretical literature on status passage (54) and biographical disruption (50) which we have discussed in detail above. Again, we characterised the key components of this literature through simple explanatory propositions.

4.5.3 Integration and refinement of sensitising constructs/theoretical concepts

We then integrated these sensitising and theoretical concepts, confirming and refining them against the findings of other systematic reviews examining capacity and workload in disease (20, 33-36, 39, 49, 114). Citations for qualitative reviews used to refine and confirm our own analysis can be found in Tables 11 and 12 rather than the main body of the text. We also use patient quotes from our comparative qualitative analysis to illustrate findings (see tables 6 and 7 for patient characteristics and conventions for describing participants)

Table 11: Potentially modifiable factors that shape experienced workload

Factors that shape experienced workload	Appears in systematic reviews as	Example from empirical study	Supporting systematic reviews
Disadvantage (e.g. identity, gender, ethnicity, age)	Treatment workload may be associated with structural advantages or disadvantages connected to age, gender, and ethnicity.	Communications between clinicians and patients of different ethnic origins – for example, Australian Aborigines and New Zealand Maoris – was often itself a source of conflict and disadvantage because of prejudice (34) (p.14).	(34, 39, 114)
Unequal access to material resources (e.g. income inequality)	Treatment workload may be associated with inequalities related to socioeconomic status	(Undocumented immigrant in the US without access to scheduled haemodialysis) When you enter through the emergency department, you arrive in bad shape…you need to have a high potassium or they send you home even though you feel you are dying (286) cited in (34) (p.13).	(20, 34, 39, 114)
Social exclusion (e.g. access difficult or denied because services are not available) **Spatial inequalities (e.g. access denied or difficult because services are hard to reach)**	Treatment workload may be associated with unequal access to health services	Patient with COPD:…I said, 'Is there any more you can do?' [Practice nurse with responsibility for respiratory patients] said, 'Well, not really.' She said, 'What do you want me to do?' I said, 'Well, help me breathe.' And she said…I said, 'Oh, well, don't worry about it', so that was that….even the doctors, I don't think - you know, kind of, 'Oh, well, you've got COPD, you just get on with it', you know? 'Just take it easy, keep indoors, rest up, take some paracetamol, and have your puffers, and just get on.' (INTS-PA-004)	(20, 34, 35, 39, 114)
Complicatedness of services	Treatment workload may be associated with complicated (many	Patient with COPD: I felt so bad, couldn't breathe, had to sit down, couldn't walk from here to the	(20, 33-35, 39, 49, 114)

Factors that shape experienced workload	Appears in systematic reviews as	Example from empirical study	Supporting systematic reviews
Service fragmentation	different components inter and intra organisationally) and fragmented services.	door. I went to the doctor [but] she didn't know what to do with me, so she said "OK, get yourself into casualty, you have to go to hospital and casualty is the only way to get into the hospital." So all right, in casualty. There, they look at me, [they ask] "What are you doing here?" [They] don't want to admit me. [When] I'm back here, with a prescription for antibiotics, she comes in [and asks] "Why are you not in hospital?" [I answer] "Well tell ME!" (216) (p.45) from (35)	
Degree of service coordination	Treatment workload may be associated with the degree to which services are coordinated	Patient with COPD: … When we got things arranged a bit more sensibly, because we go and see the consultant every four months and the first thing she wants is an x-ray. Well, now, [name of wife] organised it so I have an x-ray three or four days before I go in. Bingo…It brings the time, the thing down, and sample, if I'm having a tough time, I'll get the sample into lab and they have a look at it. It's a bit more organised but I think that's very much a personal thing. I don't think it would happen naturally because the girls…it strikes me - and the people who manage this, the appointments are managed from a central place and there always seems to be a different lady there every time and so they're learning it all, whereas [name of wife] manages to cut through that and gets the actual phone number of the one we're dealing with. (INTS-PA-009)	(20, 33-35, 39, 49, 114)

Factors that shape experienced workload	Appears in systematic reviews as	Example from empirical study	Supporting systematic reviews
Quality of communication within and between services	Treatment workload may be associated with the quality of intraprofessional communications	Patient with COPD: we had to go and see the nurse in the surgery for a kind of yearly chat through…they just want to know, how are you doing and everything else. Of course the last time I went in which obviously was last year, I went in with this [oxygen] on and everything else and it was a bit like, 'Oh…' She said, 'We're here to discuss…' 'Yes, I know you are and this is where I'm at.' Bless her she was quite kind of shocked a bit, I think she thought I was just going in to have a bit of a chat about COPD rather than, 'Oh, well hold on a minute you're carrying oxygen round and everything else.' I do know that the hospital always sends everything to the doctors, so I mean… I guess I'm fully reliant on the hospital, as opposed to my local GP. (INTS-PA-002)	(20, 33-35, 39, 49, 114)
Institutional support	Treatment workload may be associated with institutionalised care (e.g. hospitalisation) which may be seen as a relief from the demands of a delegated workload in the home	“Well, it’s easy there in the hospital, when you know that there’s extra oxygen the min you need it, so you don’t need to think on bad days what you should do, but just wait for somebody to do it for you (150)(p.43) from (35)	(35, 114)
Understanding of disease	Treatment workload may be associated with unequal understanding of disease processes, symptoms, treatments and likely outcomes	Patient with COPD: I had heard the term [COPD]. It wasn’t something I had any particular knowledge of… The first indications were a GP saying, ‘Well, you know your respiratory really ought to be a bit better than it is’. That was the diagnosis…I felt very strongly later that what I needed was a hard,	(33-35, 39, 114)

Factors that shape experienced workload	Appears in systematic reviews as	Example from empirical study	Supporting systematic reviews
		sharp look, 'You've got the onset of something really serious here, and if you don't take it really seriously *now* this is probably going to be what kills you', and that just was not said, not at all. (INTS-PA-007)	
Predictability of disease trajectory	Treatment workload may be associated with the unpredictability and uncertain nature and trajectory of many chronic diseases	Many barriers to effective primary palliative care have been identified in the included studies. The impacts of an uncertain and unpredictable illness trajectory are most frequently cited across studies. It is more evident that COPD starts without a clear onset and is punctuated by sporadic periods of exacerbation. HF and dementia, on the other hand, are conveyed as a rather gradual deterioration. The punctuated illness trajectory results in ad hoc care, which is prominent in COPD and HF (287) (p.1092-3) from (114).	(33, 35, 36, 114)
Predictability of treatment outcomes	Treatment workload may be associated with the unpredictability and uncertain consequences of treatment for many diseases	Some uncertainty arose from the illness itself, however, some was directly attributable to the treatment. Causes of uncertainty included technological failures (e.g. feeding tubes becoming blocked), unpredictable responses to medication (botox), lack of easily observable treatment benefits (CHF, CF, TB), uncertainty about long term side effects (CHF and botox), how to administer treatments (PEG feeding) or the purpose and duration of the regime (TB). (36) (p.9)	(35, 36)

Factors that shape experienced workload	Appears in systematic reviews as	Example from empirical study	Supporting systematic reviews
Complicating effects of multimorbidity	Treatment workload may be associated with multimorbidity where treatment regimens for different diseases conflict	I've had kidney stones about 30 times and every time I get an attack I don't worry at all about my diet or anything else until I get done treating it to get the pain to go away…I don't give a single thought to my blood sugar when that happens (288) cited in (49) (p.17).	(35, 36, 39, 49, 114)
Access to information	Treatment workload may be associated with the extent to which patients/informal caregivers are able to access information about their disease and its treatment	Obtaining information on the disease and treatment was a significant burden for patients and carers. Patients reported that their information on the disease and treatment options was often insufficient or difficult to comprehend, particularly during the early stages of their trajectory, independent of income or coverage level. Patients may not have asked for clarification for fear of not understanding or because they did not even know what to ask; the desire for more patient centred care were widely expressed. (34) (p.19)	(20, 34, 35)
Quality of patient information	Treatment workload may be associated with the quality of patient information about the disease and its treatments, particularly the extent to which information is tailored to the individual, with appropriateness of timing and type of information	Patient with lung cancer: But this one [nurse], she came, and she was ever so busy because they were short. So, she came in and sat with me in the afternoon. I said, 'Well, they've given me this lot [of information about lung cancer] to read through', and she said, 'Don't worry about it. Just if you feel like reading, just read a little bit here and there, don't try and go through the whole book'. She said, 'If you come across anything you want some answers to, call me. However busy I	(20, 34, 35, 114)

Factors that shape experienced workload	Appears in systematic reviews as	Example from empirical study	Supporting systematic reviews
		am just call me and I'll come and go through it with you', which was a big relief because I thought well, there's - and she said, 'If you want to go out of the ward to sit somewhere quiet, let me know and I'll take you', and that meant such a lot. She was the only one that really treated me as a person. I know they were ever so busy, but you were just one of a number. (INTS-PA-020)	
Access to educational resources for patients and informal caregivers	Treatment workload may be associated with lack of educational resources and information about disease processes, symptoms, treatments and likely outcomes for patients and informal caregivers	Important factors associated with the failure of self-care programs included inadequate educational approach due to unskilled health educators…or a gap in provider knowledge of self-care instructions… applying too general instruction for specific situations…or inappropriate educational program-planning…lack of assessment of self-care educational programs (289) (p.11) from (114).	(20, 33-36, 39, 49, 114)
Normative expectations of motivation to participate in delegated treatment workload	Treatment workload may be associated with expectations from healthcare systems/providers that patients/family members will be motivated to participate in delegated treatment tasks in the home	Patient with COPD: Yes. But then Christmas Eve I went down with another chest infection. Specialist respiratory doctor: OK. And what happened then? Same thing? Patient: Well, no because I think he'd put an emergency pack indoors. So, I took that for a week, and I wasn't too bad. Doctor: Yep. Um. Did you take steroids or just antibiotics? Patient: No, I take steroids and antibiotics six a day for seven days.	(35, 114)

Factors that shape experienced workload	Appears in systematic reviews as	Example from empirical study	Supporting systematic reviews
		Doctor: Perfect. Yep, very good. You've got it sorted haven't you [laughs] Patient: I've taken that many [laughs] OBS-PA-023	
Negotiated obligations: delegated tasks	Treatment workload may be associated with the delegated tasks that patients/informal caregivers have to manage at home	It was a lot more work because of all the things that you had to learn…I don't eat out anymore. It's tough taking so many pills (patient with CKD) (290) cited in (34) (p.13).	(20, 33-35, 39, 114)
Help-seeking behaviours	Treatment workload may be associated with expectations from healthcare professionals that patients/family members will be able to help seek appropriately in emergency situations	Specialist respiratory doctor: Good to see you. OK, first thing. How are you doing? Patient with COPD: Reasonably well, had one little…had to use my emergency kit Doctor: That's what I was going to ask you about…tell me about that Patient: I don't know whether it did or not…all I know is that er I started bringing a little bit of phlegm up and it started to change colour…I felt reasonably…but er … Doctor: Did you take your steroids as well as your antibiotics? Patient: Yes, yep …Doctor: I'm absolutely sure that you did the right thing alright. I wanted to run it by you and run it through with you because it helps reinforce the decision you made alright um. I've always said that I don't mind if people take a course of antibiotics that they don't really need. Cos the danger is they	(35, 114)

Factors that shape experienced workload	Appears in systematic reviews as	Example from empirical study	Supporting systematic reviews
		won’t take the one they really do need, and they’ll end up in hospital or worse, OK. So, I’m trying to…as long as people aren’t abusing it, making the right decision. You made exactly the right decision, totally the right decision. That’s absolutely fine [patient’s name] (OBS-PA-019)	

Table 12: Potentially modifiable factors that shape experienced capacity

Factors that shape experienced capacity	Appears in systematic reviews as	Example	Supporting systematic reviews
Social skill **Secured cooperation**	Capacity may be associated with patient/caregiver social skill (the extent to which they are able to mobilise capacity by securing the cooperation and coordination of others)	Patient with COPD [and PhD]:…I find it easy to develop a relationship with my clinicians. We speak the same languages. We speak the same English, if you like, as well as the technical languages. We understand each other's patterns of thought, and that makes it relatively easy to develop a good clinical relationship…I trust them. They trust me. We get on… (INTS-PA-007)	(35, 49, 114)
Structural resilience **Adaptiveness**	Capacity may be associated with patient/caregiver structural resilience (their capacity to manage and adapt to adversity)	Reviews also offered evidence of adaptive processes in the face of disease progression and the disruptions that stem from this. Such adaptations included the accumulation of expertise and associated self-management strategies developed over time (114) (p.10)	(34-36, 49, 114)
Illness trajectory	Capacity may be associated with cumulative volume and complexity of treatment workload over an illness trajectory	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… increasingly complex management and treatment regimens mean that the demands of the treatment workload over the long disease trajectory accumulate (35) (p.12)	(20, 35, 114)

Factors that shape experienced capacity	Appears in systematic reviews as	Example	Supporting systematic reviews
Accumulated expertise	Capacity may be associated with accumulated patient/informal caregiver expertise over time	Patient with COPD: Because we do manage my health very well, you know, [name of wife] and myself and if I suddenly felt that there was, you know, I'm struggling a bit today or whenever it may be, if I had that for a couple of days then I have got a rescue pack I know I can go to straight away…. if I'm breathing differently [name of wife] will tell me, 'Hold on.'…To me it may not be a worry at all, but I know that sometimes it's a worry for her. She kind of would identify something like that a lot quicker maybe than me. (INTS-PA-002)	(35, 114)
Pathophysiological deterioration **Impact of symptoms on physical functioning**	Capacity may be associated with pathophysiological deterioration and the consequent impact of symptoms on physical functioning	The ability of people with ESKD to carry out daily activities, including their paid job, was limited by symptoms associated with the disease and dialysis treatment, such as pain, fatigue, anxiety, depression and sexual problems, sometimes overlooked by healthcare professionals (34) (p.19).	(34, 35, 114)
Adaptive response to biographical disruption/erosion	Capacity may be associated with the extent to which patients are able to normalise their treatment regimens into their vision of what everyday life should look like for them	Now it has passed so long [time], at the beginning it was so clear regarding how much you changed your lifestyle. Now …you begin to be more used to it, [you] are a little more withdrawn…you are going to do something and you can't do everything, then it's not as fun anymore. You go to the pub and not…yeah…can't follow the guys in the way you would want to (291) cited (49) (p.18).	(20, 34-36, 39, 49, 114)

Factors that shape experienced capacity	Appears in systematic reviews as	Example	Supporting systematic reviews
Affective response to biographical disruption/erosion	Capacity may be associated with patients' negative affective states (e.g. anxiety, fear, anger and frustration) which may be caused by both the illness and the treatment workload itself	Patients responded with frustration or anger when they perceived treatment generated burdens to be avoidable e.g. when a lack of staff expertise or knowledge caused preventable complications or wasted patient's time or when scheduling of treatments and appointments was hindered by inflexible services. Anxiety, fear and worry were highlighted in several studies. People worried about the immediate and long-term risks of treatment, the future effectiveness of treatments, experiencing pain, losing employment, being stigmatised by others, the financial implications of treatment and becoming a burden to families. Guilt was experienced in relation to the physical workload or financial costs of treatment incurred by patient's families and by patients who were unable to adhere to treatment recommendations (36) (p.9).	(20, 35, 36, 39, 114)
Allocating finite resources	Capacity may be associated with the extent to which it has to be shared between the demands of the illness/treatment workload and to the demands of everyday life	Most women are in high stress situations. Most women have children, they take care of the home, they hold down a full-time job. Things do not function if the mother's not there, mother's never supposed to be sick. She's always supposed to be there and be able to take care of everybody (292) cited in (49) (p.17).	(35, 36, 49)

Factors that shape experienced capacity	Appears in systematic reviews as	Example	Supporting systematic reviews
Prioritisation of lines of work	Capacity may be associated with the extent to which patients/family members are able to exempt themselves from the demands of everyday life to prioritise the demands of the illness/treatment workload	Patient with lung cancer: I had to retire…I said to [my boss], look, there's no way I can go back to work and then say to you every so often, 'I can't come in today,' because this and that and the other. I was, my head wasn't in a good place for going back to work. It made me lazy staying at home, to be honest with you. I didn't want to get up in the mornings [short pause] We decided between us that I would leave. (INTS-PA-019)	(35)
Perceived culpability	Capacity may be associated with felt and actual stigma where patients feel responsible for their 'self-inflicted' disease/be considered culpable by family members/clinicians/society.	Patient with COPD: It was at that point that I was then told I was suffering from COPD. It's smoking related - I presume, anyway. I remember being quite shocked, and ashamed to a degree. I think this is very much an element of people with COPD that have been smokers - self-blame, you know, and not expecting any sympathy, really. (INTS-PA-005)	(35)
Normative expectations of health behaviours	Capacity may be associated with felt and actual stigma and be reinforced by the fact that certain treatments are only available if patients enact approved health behaviours (e.g. smoking cessation, weight loss)	Respiratory specialist doctor: Now you have stopped smoking there are some good options, there are other options that are available to me alright…Have you got any questions? Patient with COPD: Er no, because every time you've explained most of it [treatment available], it's just me that's been lacking… holding everything up by smoking	(35)

Factors that shape experienced capacity	Appears in systematic reviews as	Example	Supporting systematic reviews
		Doctor: I'm not that, well I'm not in that, I'm not in that whatever. To be honest with you, that's in the past. Move forward Patient: Like I say, it was all there for me in the past. And as I say just… (OBS-PA-010)	
Quality of professional-patient communication	Capacity may be associated with the quality of professional-patient/caregiver communication	…when I'm trying to talk to them about my problem, and they'll cut you off. You know, like, 'You're not important you're wasting my time.' That's been a real problem for me. It makes you think that no one really cares, especially when it's done often. It's not like it's 1 or 2 doctors, it's a lot of them. I have gone to a lot of different doctors (293) cited in (49) (p.16).	(20, 34-36, 39, 49, 114)
Quality of professional-patient relations	Capacity may be associated with the quality of professional-patient/informal caregiver relationships	Patient with lung cancer: I think my first time of meeting [name of consultant oncologist], and I think I remember saying to him, 'I just would like you to treat me as though it was a member of your own family', and he has done. He shook my hand, and I know he's very passionate about this disease. So I would say that I had that immediately. I just felt that warmth from him. I don't know what it was. I just knew that - whereas I haven't had a lot of faith in other - like certain GPs. In the hospital I have, and I feel very, very comfortable there. (INTS-PA-010)	(20, 34-36, 49, 114)

Factors that shape experienced capacity	**Appears in systematic reviews as**	**Example**	**Supporting systematic reviews**
Relational discontinuity	Capacity may be associated with relational continuity/discontinuity with clinicians	Wife of patient with COPD: We were…Well, I was really glad when we didn't get any more appointments at [local teaching hospital] because …we thought we were seeing the consultant and we saw a lovely [junior doctor], but it's not the same. Patient with COPD: No, you hardly remember his name and you don't see him again.(INTS-PA-009)	(33-35, 114)
Caregiver support (emotional solidarity)	Capacity may be associated with caregiver support in the form of emotional solidarity (willingness to provide emotional support)	Wife of patient with COPD: One becomes aware of what one has; it has changed into a deeper relationship (164) (p.47) from (35).	(20, 34-36, 114)
Caregiver support (relational solidarity)	Capacity may be enhanced by caregiver support in the form of relational solidarity (willingness/ability to take on practical tasks, whether additional domestic tasks or treatment tasks)	Patient with COPD: My husband - there's some things I can't do, and some things I can. I do try and do everything I can…He does a lot. He does all the hoovering [laughs]… I put on whatever we're going to have for our meal at night, and we do it between us. My husband does all the vegetables and the lifting. I can't change a bed; my daughter has to do it… I can't tuck in and lift up.…I can't do my garden like I used to, and I can't kneel down, and I struggle to get up. I can't do buttons up. Sometimes I have a struggle where I have to get my husband just to help me out of bed. Things like that. We've got the pony outside that my husband sees to now… (INTS-PA-004)	(20, 34-36, 114)

Factors that shape experienced capacity	Appears in systematic reviews as	Example	Supporting systematic reviews
Limits of tolerance (Bury, 1985)	Capacity may be associated with the limits of tolerance for emotional/relational solidarity between patient/informal caregiver	Wife of patient with COPD: Yes [pause] So is there a reason he can't come shopping because he just drives me to the shop? [Patient laughs] Wife: And then I have to do all the work Respiratory specialist nurse: So why don't you be the trolley manager eh? Pop your oxygen in the trolley and push it around Patient: I do…when I go Wife: Yeah but you haven't done it for so long; you said you're out of breath and you can't do it, it's too cold and there's a load of other excuses like there's too many people in the shop etcetera. So, you know, it would be good for him to come shopping. Respiratory specialist nurse: Are we ganging up on you [patient's name]? Patient: Yeah. Don't worry me. She don't know what it's about Wife: Yeah, I do…course I do…lived with it long enough. (OBS-PA-016)	(20, 35, 36, 39, 114)
Caregiver assent/dissent	Capacity may be associated with caregiver dissent and collusion with clinicians in the allocation of culpability for past and present health behaviours	Respiratory nurse specialist: The other thing that could be a…play a part with your high carbon dioxide levels is that you are not being as active as you what you used to be so if you Patient with COPD: I'm not…I'll admit that	(35)

Factors that shape experienced capacity	Appears in systematic reviews as	Example	Supporting systematic reviews
		Nurse: Do you remember it's a bit of a vicious cycle really…so the less you do, the harder it's going to be alright?...Do you have that book that we gave you with all the exercises in?...Is it gathering cobwebs somewhere? Informal caregiver: Yeah Patient: No Informal caregiver: Yeah it is. You don't use it Patient: *I* don't, no. Where is it? Informal caregiver: You see. Where is it? He doesn't even know where it is. Patient: [laughs] under the stairs [groans] it won't be there no more [general laughter] Nurse: I get the impression [patient's name] that you just tell me what I like to hear, don't you eh? Informal caregiver: Yeah. And yet I tell you the truth (OBS-PA-016)	
Stigmatising effects of treatment	Capacity may be associated with stigmatising health technologies/treatment regimens which mark the patient as unwell	B.W. adjusts her work activities…when she is in the breathy voice phase [post-botox]: "When you have the Marilyn Monroe voice, you don't go into important situations...Even my friends who are completely on my side [say] how can we take you seriously? It's just too funny to listen to Marilyn Monroe [her identity with the breathy voice] (294) cited in (36) (p.8)	(34-36, 39, 49, 114)

Factors that shape experienced capacity	Appears in systematic reviews as	Example	Supporting systematic reviews
Isolating effects of treatment regimens/health technologies	Capacity may be associated with home based technologies which may leave patients/caregivers feeling isolated from medical help, as if their home was medicalised	Using health technologies of different kinds brought only 'temporary mastery' over disease, and required continuous attention. This led to a constant tension between managing disease and technological supports, and the other demands of everyday life. Technologies could be intrusive because of the demands that they made on patient and caregiver time and effort. Assistive technologies could also have the paradoxical effect of leaving patients and caregivers feeling isolated from clinical help and that their homes had been 'medicalised' (114) (p.11).	(34, 114)
Isolating effects of disease exacerbation (perceived risk)	Capacity may be associated with social isolation caused by avoidance of triggers for exacerbation/disease flare up	Wife of patient with COPD: I think the main thing for that very, very sadly is to isolate ourselves and that is tough, and people don't really talk about it. They say, especially with [name of patient]'s prognosis, you have to get out there and you have to live, but the problem is, in winter especially, in doing that it could actually kill you. You haven't really been out during the winter months at all, certainly this winter, and where I'm not at work anymore and we're not handling paperwork or the same materials et cetera, and I've also had to restrict my social activities during winter…I'm paranoid with hand sanitizer. You can buy stuff, whether it works or not, but it seems to have worked perhaps, Cold	(34, 35)

Factors that shape experienced capacity	Appears in systematic reviews as	Example	Supporting systematic reviews
		Guard around your nose and how you touch, so just to be very, very aware, very aware of people around you. If they have colds, you don't go and see them. That has been, I think, psychologically on both of us, extraordinarily tough. (INTS-PA-007)	
Isolating effects of symptoms	Capacity may be associated with social isolation caused by symptoms/embarrassment about visible treatment technologies	Patient with COPD: I have got the oxygen on the trolley and when I go to the supermarket as long as I'm holding on to the trolley Respiratory nurse specialist: Have you ever thought about getting a little walker or something? Patient: Um. Well I have one of them well you know. I have got one actually. Nurse: You can put your oxygen in that possibly. Patient: It used to fill up all the room in the bus. I used to feel all you know sort of Nurse: I wouldn't worry about it. You're perfectly entitled… Patient: There's all these yummy mummies with their prams and me with my walker [laughs]. Nurse: I expect they feel the same though. They probably feel that they take up a lot of room with the prams. Patient: Nah, nah. (OBS-PA-002)	(34, 35)

Factors that shape experienced capacity	Appears in systematic reviews as	Example	Supporting systematic reviews
Healthcare professional support for rationalised non adherence	Capacity may be associated with clinicians' support and sanction of patient decisions to cease, modify or reduce treatment regimens	Oncology specialist doctor: I feel really strongly that you should never do something that someone wasn't sure they wanted in the first place. If someone doesn't really want chemo and you persuade them to do it, and they end up with nasty toxicity, they will regret that decision…I think a lot of patients who seem a bit unsure, it's because in their heart they probably don't want to have the treatment, but they feel they *ought* to because society or family expects them to. I try really hard to unpick that…. I think it's really important that you're clear about what the patient's in for…It's much quicker just to give them some chemo and get them out the room, but I think to do the job right, you have to try and make sure that you're very clear about their understanding and motivations. (INTS-CL-004)	(35, 36)
Concealment of "rationalised non-adherence" (Demain et al, 2015)	Capacity may be associated with concealment from clinicians of patient decisions to cease, modify or reduce treatment regimens	Respiratory nurse specialist: Are you doing any of those exercises at home? Patient with COPD: Yes, tonnes of them Wife: No you're not. Nurse: [laughs] Informal caregiver: [gasps] God's… Patient: I get up to the toilet and go back again. That's walking. (OBS-PA-016)	(35, 36)

4.5.4 Modelling constructs

In the final stage of conceptual model building, we extracted factors that shape patient experience of the primary constructs of workload and capacity, and then modelled the relative significance and position of each of the constructs in relation to the others, creating hierarchical models of potentially modifiable and measurable factors that shape the primary constructs of workload and capacity.

Tables 11 and 12 (above) characterise each of the primary constructs (workload and capacity) with their associated potentially modifiable factors. Figures 4 and 5 detail the hierarchical relationships between the associated factors within the constructs.

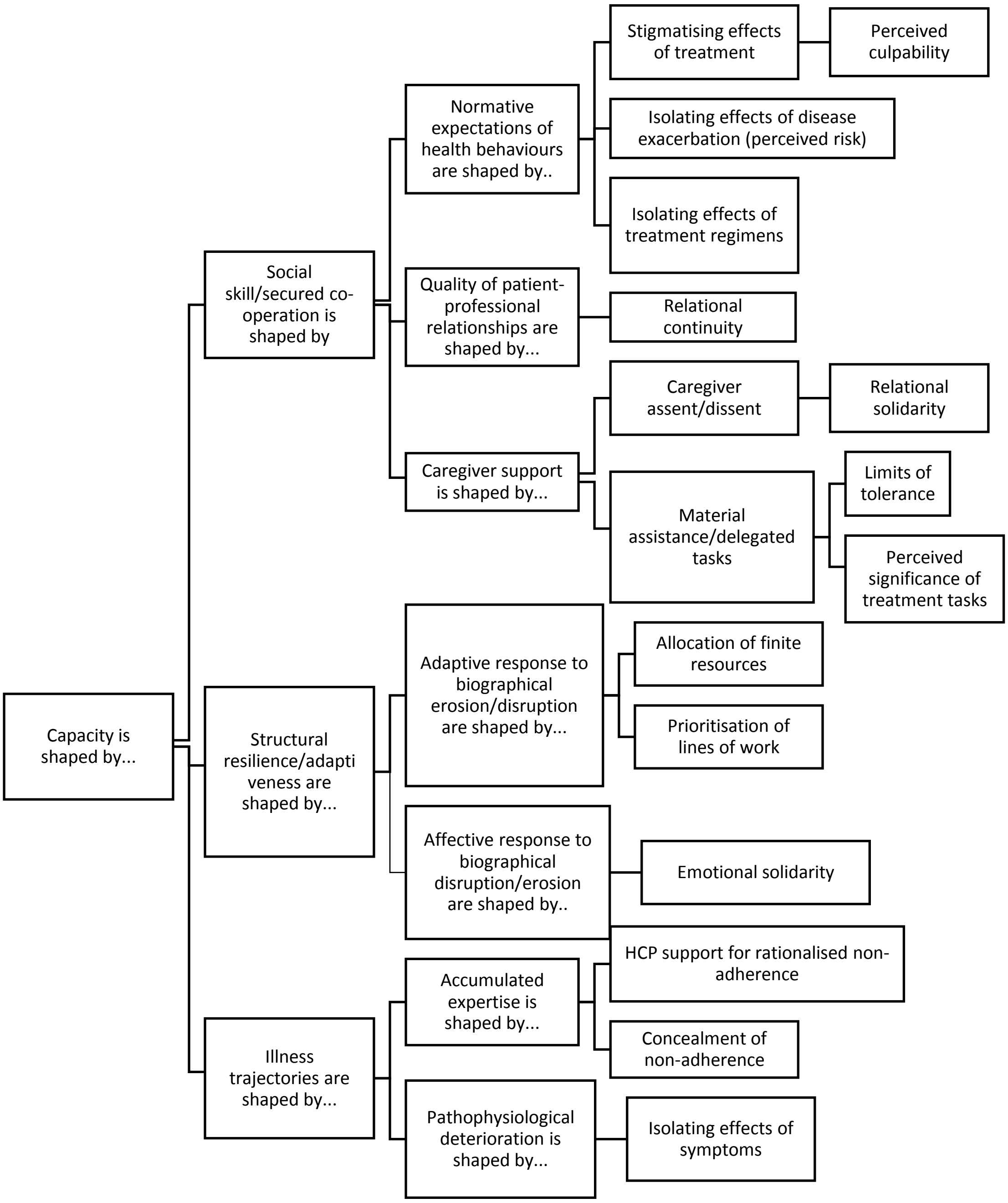


Figure 4: Hierarchical relationships between factors that shape capacity

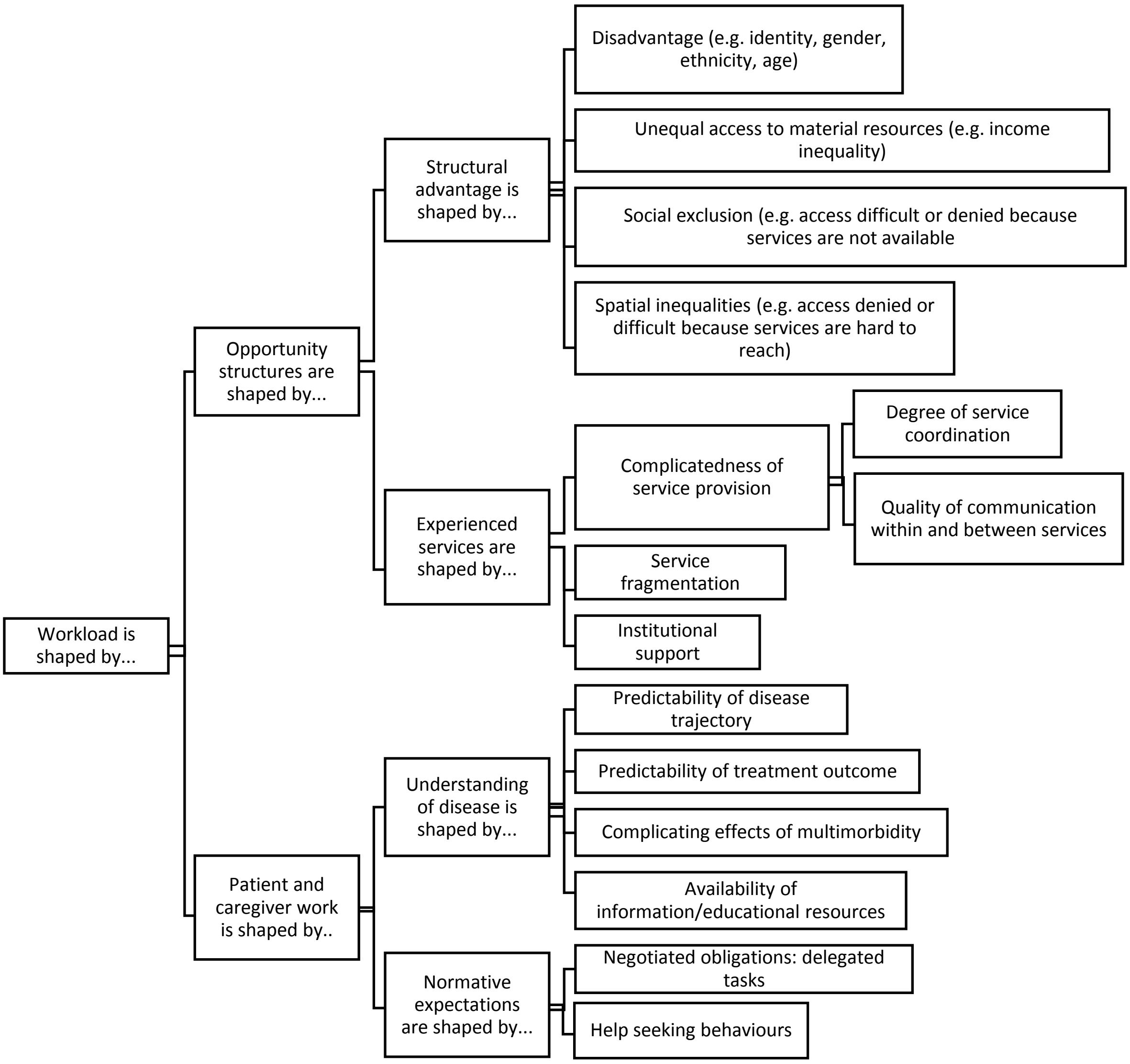


Figure 5: Hierarchical relationships between factors that shape workload

4.6 Results

The results identify and characterise the primary constructs of workload and capacity and the potentially modifiable factors associated with each. The results often compare patient experience of acute existential illnesses with commonly short trajectories such as lung cancer with chronic illnesses with patient experience of uncertain but generally prolonged trajectories such as COPD, CKD and CHF. We acknowledge that, while lung cancer typically has a short trajectory, other cancers may have prolonged trajectories and thus may be more aligned with chronic long term conditions (94).

4.6.1 Primary construct: capacity

We define capacity as it has been defined in the literature discussed above: “the practical, affective, cognitive, informational, material, physical and relational resources available for patients to mobilise” (35).

Our data demonstrates that the key factors shaping capacity are likely to be:

1. social skill
2. structural resilience
3. illness trajectory

4.6.1.1 Social skill

Our data demonstrates the *relational* nature of capacity. Capacity is not simply a set of resources instantly available to access: patients must *mobilise* capacity. This mobilisation of capacity could require patients to exercise considerable social skill (the extent to which individuals can secure cooperation (51).

A potentially modifiable factor associated with social skill was the quality of relationships between clinicians, patients and family members. Positive clinician-patient relationships between individuals, many examples of which were evident in our data, were associated with enhanced social skill. Kindness and empathy from clinicians were particularly important. Patients were more likely to be able to secure the necessary cooperation to mobilise capacity where they believed they were treated as “a person, not a number” (wife of patient with lung cancer: INTS-PA-018).

Conversely, examples of poor clinical-patient communication were pervasive in the data. These were often associated with system-level or structural factors rather than to a breakdown in communication between individual patients and clinicians (although this could occur). Where clinician-patient communication was poor, this negatively affected the quality of clinician-patient relationships leading to, for example, patients losing confidence in clinicians. In such cases, patients appeared less likely to be able to secure the necessary cooperation required to mobilise capacity.

Patients and clinicians generally discussed the mundanities of everyday disease management in the clinical encounter, rather than considering the future. Discussion of end of life issues rarely occurred. Patients with acute existential illness such as lung cancer where the threat of death from such illness had been made clear from diagnosis, were more likely to have discussions with clinicians around discontinuation of treatment and end of life issues. This appeared to enhance their social skill. In chronic diseases where trajectories could be uncertain and often prolonged, lack of discussion of end of life issues seemed to be related to what Murray et al (2005) (81) have termed “prognostic paralysis” (p.611). Prognostic paralysis occurs when clinicians avoid discussing end of life issues because of their struggle to predict accurately the likelihood of imminent death. In chronic illness, patients/family members could, therefore, lack understanding of the life-limiting nature of their disease. This appeared to diminish their social skill. Alternatively, patients could also suspect the imminence of death and express frustration at the lack of communication from clinicians about this:

> Patient with COPD: When I go and see [name of respiratory specialist doctor], we have a chat there, and I get the impression he's reserved on what he says to me. I think he says to me enough to, if you like, satisfy me but he's not giving me the blunt truth. I know the disease I've got is incurable, I know it's progressive, so if someone says to me, 'You've got a year to live,' fine, quite happy with that. I'd whoop it up a bit. That's the sort of information I want to know.
>
> **(INTS-PA-001)**

This could both diminish patients’ social skill and impact on their ability to effectively balance the priority given to their treatment workload against the priority given to other things that they deemed important in life

Relational continuity (with kind and empathetic clinicians) was also a potentially modifiable factor in the quality of clinician-patient relationships. It was apparent that patients valued being seen by clinicians whom they knew and to whom they were known. This was important both in illnesses with potentially short trajectories where patients saw clinicians frequently *and* in chronic illnesses where trajectories might be prolonged and interaction with clinicians was less frequent because of chronicity. Lack of relational continuity between patients and clinicians appeared to be common in chronic illness, particularly between patients and their general practitioners which could be associated with diminished social skill as patients felt as if they were constantly explaining the story of their illness and its treatment to new clinicians as they attempted to secure cooperation.

The other relational mainstay of capacity in the data appeared to be informal caregiver support, normally from family members, particularly spouses. In chronic conditions such as COPD, CKD or CHF, where the bulk of treatment workload was delegated by clinicians to patients to manage in the home, the demands of the treatment workload could only be met, in many cases, with informal caregiver support. Thus, informal caregivers provided an array of material support to patients. This might range from simple time commitment (for example, driving/accompanying patients to appointments) or highly technical assistance (for example, supporting patients with home dialysis). For patients to secure the necessary cooperation to mobilise capacity, it was important, therefore that the informal caregiver understood the purpose and significance of treatment tasks, especially those that were delegated to patients/family members to manage in the home.

There was a considerable amount of adaptive work required in caregiver support that was associated with capacity. Friends and family members demonstrated considerable relational solidarity – willingness to support patients in undertaking treatment tasks. Undertaking domestic and treatment tasks could be seen as an affirmation of the bond between the patient and family member. Indeed, the data shows that patients and family members could demonstrate considerable emotional solidarity (willingness to provide emotional support), in some cases forming a collective identity as if both were experiencing the illness. This could result in a collective competence that enhanced capacity.

In chronic illness where the disease trajectory could be prolonged, informal caregivers could gradually assume an ever-increasing workload, without making a conscious choice to do this. As pathophysiological deterioration impacted on patients' physical functioning, family members (particularly spouses and daughters), could assume responsibility for domestic tasks previously undertaken by patients. In addition to taking on domestic tasks, many family members supported patients with activities of daily living such as showering or getting dressed. Consequently, relationships could almost imperceptibly shift from one of equal interdependence to one of caregiver caring for dependent.

There could be considerable reluctance on the part of patients to relinquish domestic tasks to family members as the inability to undertake tasks they had performed for many years negatively impacted on their sense of self. There could be also a recognition of the potential burden that patients were inadvertently placing on the family member.

This adaptive work of negotiation of identities and division of workload within family relationships resonates with findings from Bury's (112) study of patients and family members living with rheumatoid arthritis. Particularly pertinently for the concept of capacity, Bury describes how "limits of tolerance" for this adaptive work are explored and tested within family relationships over an illness trajectory (112). Bury points out:

> "the reliance of marital relationships intensifies and yet these relationships have to be managed carefully if they are not to be overburdened with the illness and its effects"
>
> **(ibid, p.42)**

It is important to remember the potentially finite nature of capacity within family relationships. This is exemplified in a quote from a wife of a patient with COPD who appeared to have reached her "limits of tolerance" for supporting the patient with the domestic tasks of shopping.

> Wife: Yes [pause] So is there a reason he can't come shopping because he just drives me to the shop?
>
> [Patient laughs]
>
> Wife: And then I have to do all the work
>
> Respiratory nurse specialist: So why don't you be the trolley manager eh? Pop your oxygen in the trolley and push it around
>
> Patient: I do…when I go
>
> Wife: Yeah but you haven't done it for so long; you said you're out of breath and you can't do it, it's too cold and there's a load of other excuses like there's too many people in the shop etcetera. So, you know, it would be good for him to come shopping.
>
> Nurse: Are we ganging up on you [patient's name]?
>
> Patient: Yeah. Don't worry me. She don't know what it's about
>
> Wife: Yeah, I do…course I do…lived with it long enough… you could walk around [supermarket name]. You keep making me do it. It's too much for me.
>
> **(OBS-PA-016)**

Thus, capacity is not exhaustive and family members may reach their “limits of tolerance” for supporting patients.

Capacity could be diminished where diseases required reporting back to clinicians on performance against negotiated treatment tasks related to health behaviours. If a patient had been unable to adhere to the negotiated treatment task, the patient could attempt to hide this non-adherence from the clinician. It was apparent from the data that this non-adherence could be reported to the clinician by the family member. This then ruptured the collective identity of patients/family members, exposing the patient to the implicit or explicit disapproval of both the clinician and the family member:

> Wife: So sometimes when he’s sort of feeling that he can’t breathe properly, he has it [the oxygen] on 4 or 5 [litres] at home
>
> Patient with COPD: Not on 4 or 5
>
> Wife: Yeah you do
>
> Patient: [angrily] Not on 5, I’ve never gone up that high
>
> Wife: Yeah you have
>
> Respiratory nurse specialist: So… please don’t touch the concentrator at home…tell me why are you turning it up?
>
> Patient: Because I thought it helped you breathe easier
>
> Nurse: So…No
>
> Patient: And then I remembered they say the oxygen don’t help your breathing
>
> Wife: [heavy sigh] Oh God
>
> Patient: What does *she* want?
>
> Wife: You’re a nightmare, you’re a nightmare. You really are.
>
> …Nurse: I get the impression [patient’s name] that you just tell me what I like to hear, don’t you eh?
>
> Wife: Yeah. And yet I tell you the truth
>
> **(OBS-PA-016)**

This could reinforce patients' perceptions of their culpability for their disease, making them less likely to secure co-operation from family members and clinicians.

Felt stigma (where patients internalised stigma, for example, considering themselves responsible for a 'self-inflicted' disease) and actual stigma (where patients were considered culpable for their disease by others) (153) appeared to impact on the individual's ability to secure cooperation. This could be because cooperation *was* less forthcoming from others (family members/clinicians/society) because they perceived patients as culpable for their disease. Alternatively, patients themselves could be reluctant to try to secure cooperation, either because they did not believe their past health behaviour warranted it or because they believed that their attempts to secure cooperation might provoke actual stigmatisation (from family members/clinicians/society). This could be reinforced by the fact that certain treatments were only available if patients enacted approved health behaviours (for example, smoking cessation).

Another potentially modifiable factor associated with the ability to secure cooperation was that of social isolation. Patients/family members could voluntarily isolate themselves as, for example, a deliberate tactic to reduce the risk of infection and consequent exacerbations (flare ups) of disease. Patients/family members could also find themselves involuntarily isolated through the sequestering effects of treatment regimens that confined them to the home. Social isolation could limit patients/family members' ability to secure cooperation and, consequently, mobilise capacity.

4.6.1.2 Structural resilience:

The data clearly demonstrates the *dynamic* nature of capacity: patients and informal caregivers were constantly managing and adapting to the (often changing) significance and consequence of their disease and its treatments. Structural resilience has been highlighted as a key factor underpinning patients' ability to mobilise capacity ((3, 36). Structural resilience has been defined as "the potential to adapt to adversity… the extent to which members of the patient's extended network can capture, possess, and mobilise psychological and social resources to absorb and compensate for – and even thrive – in the face of biographical disruptions, adverse pathophysiological events and social processes"(3) (p.5).

Our comparative analysis of patient experiences of treatment in COPD and lung cancer demonstrated that an important distinction between the two diseases was the point of diagnosis. The diagnosis of lung cancer was experienced as a clear biographical disruption (50), a "crisis"(54) (p.144), by patients, family members and clinicians . Thus, patients with lung cancer and their family members prioritised their illness trajectories over the demands of other status passages, and, indeed, could be temporarily exempted from other social roles(271).

Conversely, in COPD the onset of symptoms was insidious and the diagnostic process fragmented. Once diagnosed, patients/family members had little understanding of the *significance* or *consequence* of the disease(112). A gradual understanding of both slowly dawned over the long and uncertain disease trajectory as pathophysiological deterioration and decline in physical functioning brought patients back into contact with the healthcare system. Rather than a biographical disruption or crisis, the experience of patients with COPD was that of a biographical *erosion* over time.

Patients' capacity is finite and has to be allocated between different "lines of work" (15). Our data demonstrated that, in biographically disruptive disease, the work of illness and treatment may be prioritised over other lines of work. In biographically erosive disease, the work of illness and treatment may be less clear and may have to be balanced against the demands of everyday life. Regardless of whether disease was biographically disruptive or erosive, the extent to which patients were able to normalise their new illness identity and treatment workload into their vision of what daily life should look like to them was strongly associated with their ability to adapt to absorb adversity.

Patients could experience negative affective states such as reduction in self-esteem and self-worth and increase in frustration, anger, fear, anxiety, worry, guilt, isolation and discomfort which could reduce their ability to absorb adversity. Negative affective states could be associated with disease diagnosis and its consequent impact on identity. Negative affective states could also stem from symptoms connected to the disease or its treatments. Poor communication from clinicians could also lead to negative affective states. Conversely, positive affective states such as optimism, confidence and hope which could arise from interaction with empathetic and kind clinicians and support from family members appeared to relate to patients' ability to absorb adversity.

4.6.1.3 Illness trajectory

Our data also shows the potentially *cumulative* nature of capacity over time. Shippee et al's CuCoM demonstrates a strong association between workload, capacity and cumulative complexity, where the volume and complexity of treatment may accumulate over an illness trajectory (21). Certainly, our data demonstrates that resources and patients/informal caregivers' abilities to mobilise them change and fluctuate over the illness trajectory which, in chronic disease, may be prolonged.

In diseases with prolonged trajectories such as COPD, CKD and CHF, patients and informal caregivers could accumulate expertise over time in managing their condition at home and navigating fragmented healthcare pathways. Indeed, many patients reported that such expertise enabled them to make decisions about ceasing, modifying or reducing treatment regimens, to ensure a better fit with their vision for daily life. Many patients did feel however that this experiential knowledge was not valued by clinicians and could attempt to conceal such "rationalised non adherence" (36)(p.1) from clinicians and even from family members. This could affect the quality of patients' relationships with clinicians which could diminish their ability to secure cooperation. In acute existential illness such as lung cancer where the disease trajectory was recognisably short, or at the end of life, rationalised non adherence appeared to be more acceptable to clinicians and was openly discussed.

Conversely, and pervasively throughout our data, pathophysiological deterioration over time, the consequent decline of physical functioning and the increasing frequency of cycles of exacerbation could diminish capacity (both the ability to secure cooperation and the ability to absorb adversity) as patients/family members struggled to meet the demands of often increasingly complex treatment regimens.

Patients' and family members' capability to mobilise capacity, therefore, may degrade over a prolonged disease trajectory whilst at the same time the demands of treatment workloads may accumulate. We go on to consider the primary construct of workload further below.

4.6.2 Primary construct: workload

We define workload as it has been defined in the literature discussed above: **"**the practical, affective, cognitive, informational, material, physical and relational tasks that patients/family members may have to carry out to undertake treatment and the *impact* of these on the individual"

Our analysis suggests that the key potentially modifiable factors shaping workload are likely to be:

1. Structural (dis)advantage
2. How services are experienced
3. Understanding of disease
4. Normative expectations of motivation to participate

4.6.2.1 Structural (dis)advantage

Treatment workload might be strongly associated with structural advantage/disadvantage. (Dis) advantages could be associated with socioeconomic factors (such as access to transport), environmental factors (such as exposure to pollution) or demographic characteristics such ethnicity, gender or age. For example, having to follow prescribed diets as part of a treatment regimen could be made more difficult by gender as this might lead to family conflict for women. In patients from ethnic minorities where, for example, their first language might differ from that of clinicians, gaining access to information/education about their condition and its treatments could be complicated.

In our data, access to healthcare appeared to have a significant association with structural advantage. In some countries, patients were only able to access healthcare if they had the financial resources to do so. Even in countries such as the United Kingdom (UK), where access to healthcare services is not (overtly) based on ability to pay, it was clear that patients might have to work hard to access healthcare treatments. Patients who had no access to private transport could find travelling to healthcare appointments challenging or the cost of public transport prohibitive. Patients who were still working could struggle to take the time off required to access treatments:

> Patient:…when I was talking to [name of respiratory physician] recently, had I been on [pulmonary rehabilitation] rehab for my condition, yes… when I looked into it…recently, yes, they do it, it's something like two hours a day [twice a week] and you do that for five weeks…so that would mean I'd have to say to my bosses, 'Do you mind if I take ten days off in the next five weeks at your expense or full pay?' or I'd have to book them as holiday, and as I don't have ten days holiday, guess what, I will not be going on this rehab thing, you know what I mean? It's something that doesn't take an Einstein, I couldn't do it even if I wanted to. Now who in their right mind decided, 'Do you know what, if somebody needs to go on this, two hours a day, twice a week for five weeks'?
>
> **(INTS-PA-012)**

Treatment workload might also be associated with access to healthcare. Dixon Woods et al (295) in their useful paper on candidacy ("the ways in which people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services"), acknowledge the "considerable work" that gaining access to healthcare services requires on the part of patients (p.7). Dixon Woods et al helpfully distinguish between "porous" (easy to access services such as Accident & Emergency departments in the UK where patients can self-refer) and services that are "less permeable" (such as those that require a referral from clinicians).

In our data, disease type could be associated with access to health services, resonating with work undertaken by McDonald and colleagues where “illness identity” was linked with eligibility for healthcare services (152). Thus, in acute existential illness such as cancer, once diagnosed, patients had immediate access to and ongoing contact with specialist clinicians. In contrast, in chronic disease with uncertain, often prolonged, trajectories such as CHF, COPD and CKD, the process of accessing healthcare itself could be hard work for patients/family members. Our data revealed that patients could be unaware that treatments for their condition existed and, indeed, could be told that no such treatments existed by clinicians in primary care. Where specialist care was accessed, unlike cancer, patients with chronic conditions did not have regular contact with specialist clinicians and a named nurse for help seeking. Indeed, in our data, patients routinely used porous services such as Accident and Emergency departments as part of help seeking for exacerbations of their disease.

Access to healthcare appeared to be complicated further by perceived culpability (a potentially modifiable factor discussed above in relation to capacity). There appeared to be a moral dimension in relation to accessing services, where implicit judgements could be made by clinicians about how entitled to treatment patients were. Patients themselves, could believe that their previous health behaviours had rendered them undeserving of treatment.

4.6.2.2 How services are experienced

Our data demonstrates a clear association between how services are experienced by patients, and treatment workload. Patients/family members with chronic conditions such as COPD, CHF and CKD, experienced unclear treatment pathways with many different components. The onus could be on patients/family members themselves to navigate these complicated, fragmented services. Services could be especially challenging for patients to navigate when they crossed intra-organisational boundaries.

Further adding to the workload caused by fragmented, complicated services, patients could experience a lack of co-ordination within and between across services, frequently allied to poor intra-professional communication. This might lead to conflicting and contradictory advice which could impact patients/family members’ negative affective states leading to frustration, distress and anger which may diminish structural resilience as we have shown above. It could also leave patients/family members with an increased workload as they struggle to understand what treatments they should pursue.

Family members, spouses in particular, could take the role of coordinating care, ensuring that patients had correct and sufficient medications and that investigations were completed in time for appointments with clinicians:

> Patient: … When we got things arranged a bit more sensibly, because we go and see the consultant every four months and the first thing she wants is an x-ray. Well, now, [name of wife] organised it so I have an x-ray three or four days before I go in. Bingo…It brings the time, the thing down, and sample, if I'm having a tough time, I'll get the sample into lab and they have a look at it. It's a bit more organised but I think that's very much a personal thing. I don't think it would happen naturally because the girls…it strikes me - and the people who manage this, the appointments are managed from a central place and there always seems to be a different lady there every time and so they're learning it all, whereas [name of wife] manages to cut through that and gets the actual phone number of the one we're dealing with.
>
> **(INTS-PA-009)**

For patients with chronic illness with prolonged uncertain trajectories, where delegated tasks comprised most of the workload, healthcare organisations appeared to be, at times, organised to deflect rather than to provide care. Patients seemed to be in the paradoxical situation of disliking hospital admission and wanting to remain at home but also, at times, yearning for institutional care as a respite from the constant pressure of managing their delegated workload at home.

In acute existential illness such as cancer, healthcare services appeared to recognise the work involved for patients/family members in coordinating care and provide capacity to support meeting the demands of this. Thus, patients valued the role of the specialist nurse as much for its *practical* importance, coordinating their treatment workload as for its emotional importance, supporting them to deal with the emotional consequences of their disease.

4.6.2.3 Understanding of disease

The meaning of disease is culturally specific (112). Indeed, the meaning of disease may change over time within a culture (for example, HIV is a less stigmatised disease than it was two decades ago (296). Thus, disease is ineluctably socioculturally constructed and sited (152).

Some diseases are better understood than others. Thus, cancer "the emperor of all maladies" (74) is better understood than many other chronic diseases such as COPD (35) or heart failure (152):

> Patient with COPD: Right, as I explained to somebody the other day, everybody has heard of the big C, cancer, if you say cancer everybody, 'Oh, terrible,' yes… if somebody says, 'Well, he's got cancer,' they all go, 'Oh, well that's fine, ah yes, that makes sense.' Maybe COPD and pulmonary disease isn't, things like that, need to be, I was going to say advertised but that's not… It needs to be made, people need to be made more aware of it.
>
> **(INTS-PA-012)**

Our data showed that poor understanding of the significance and consequence of disease could leave patients/family members ill-prepared to meet the demands of the treatment workload. This was particularly important in long term chronic disease where patients were expected to adhere to complicated, delegated medication and treatment regimens in the home, having to judge when to seek help from health services.

Importantly, our data showed that understanding of the significance and consequence of disease can be associated with *capacity* as well as workload through securing cooperation. It is difficult to garner support for a disease that no one has heard of. This was exemplified in the comments of a wife of a patient with COPD who found it easier to explain that her husband had emphysema than COPD:

> Wife of patient with COPD: The consultant walked into the room and said to him “You do realise you’ve got severe emphysema, don’t you?” And although I was taken aback, I was pleased because a**t last I had something that I could understand. And explain to others**, so that when they said to me, “What’s wrong with [name of patient]” I said, I can say “He has severe emphysema”, and **most lay people do know that term, so it makes them more sympathetic and understanding than COPD**.
>
> **(INTS-PA-009 – bolding our own)**

Thus, coming to an understanding of the significance and consequence of disease could, in itself be hard work. Patients with chronic disease such as CKD, CHF and COPD could have to work to gain information about their disease and its treatments, particularly at diagnosis but also throughout the disease trajectory. When adequate information was accessed, patients could become aware of how poorly informed they had been in the past, leading to negative affective states such as frustration and anger.

Patients could be required to process a significant volume of information. This could be complicated by structural disadvantage discussed above such as illiteracy or language barriers. Patients valued comprehensive written information that they could read at their leisure at home but, importantly, they appreciated this being supported by information given face to face by clinicians as it was in the case of patients with cancer in our data:

> Patient with lung cancer: I mean, all the people I met before I had the treatment were very reassuring. Whilst being armed with massive pamphlets, they did take pains to say, 'And if you need to email me, you can'…It wasn't just information. It was usually given to you by a smiling lady who patted your arm and said, 'Don't worry about this, it's fine. Just ring me or tell me. Have a look through that and then tell me what you think'.
>
> **(INTS-PA-017)**

Treatment workload was complicated by the unpredictability of disease trajectories in chronic conditions such as COPD, CHF and CKD, with its uncertain duration and cycles of hospital admission as exacerbation events occurred more frequently over time. Such chronic diseases seemed to require an almost dichotomous combination of careful planning of daily activities to minimise symptoms, conserve energy, and fit the workload of treatment into daily life, juxtaposed with an inability to plan for the longer term given the uncertainty of the disease trajectory.

Alongside the unpredictability of the disease trajectory, the treatment workload was made more complex by the unpredictable effects of treatment itself – for example, the possibility of technological failures such as oxygen not working.

Treatment workload could also be complicated by multi-morbidity: the cumulative effect of different treatment workloads for more than one illness. So, patients could find the sheer volume of their treatment workload overwhelming:

> Patient with COPD, myasthenia gravis and diabetes: I know you're supposed to take your tablets all separate; I have so many - well, it's like a chemist… but I take them all together and I got so fed up of swallowing tablets every time I ate anything that I argued with the nurse about the diabetic stuff and she gives me 1,000 milligrams in the morning and 1,000 milligrams in the evening, plus the insulin so that I can have a rest in the mid-day; I can go out and not worry about any tablets whatsoever, just my insulin.
>
> **(INTS-PA-013)**

This volume of workload could be intensified where medication or treatment regimens for different conditions conflicted.

4.6.2.4 Normative expectations of motivation to participate

It is apparent that there is a normative assumption on the part of health policy makers, healthcare systems and clinicians that patients will be motivated to participate in treatment tasks (285). Consequently, in chronic illness such as CHF, CKD and COPD, patients are delegated a significant workload of treatment to manage at home. Interestingly, in acute existential illness, as previously discussed above, clinicians are less likely to assume that patients are motivated to adhere to treatment regimens and, indeed, encourage patients to consider priorities outside of their disease.

The other normative assumption is that patients/family members will learn to seek help for flare ups of their condition appropriately without abusing the trust that the clinician has put in their collective competence. So, for example, where patients are given a ‘rescue pack’ in COPD, they are trusted to use this only in the case of a ‘genuine’ exacerbation. However, the judgements that patients and family members must make about what is a genuine exacerbation are hard clinical decisions that can be very challenging for patients to make. Patients are held culpable both for overusing and underutilising services – either waiting too long to acknowledge an exacerbation and seek emergency help or seeking emergency help inappropriately.

4.7 Discussion

Our analysis has built on the important work undertaken by other researchers to identify and characterise treatment workload, its impact on patients and the capacity available to patients to mobilise to meet the demands of the treatment workload alongside the demands of illness and daily life. In this paper, we have demonstrated the relational, dynamic and potentially cumulative nature of capacity, emphasising the importance of social skill in securing cooperation and mobilising capacity and of structural resilience in absorbing and adapting to biographical disruption/erosion. At the same time, we have considered the association between structural advantage, the experience of services, understanding of disease and normative expectations of motivation to participate with treatment workload.

This paper is novel in that our analysis demonstrates the importance of not conflating workload and its impact on the patient with treatment burden. Treatment burden is more than the workload of treatment and its impact on individuals and their family members. Indeed, it appears to be a complex set of interactions between the primary constructs of workload, capacity and their contingent factors.

Boehmer et al (2016) has already demonstrated how capacity is buildable – so capacity may beget capacity (115). Our analysis shows that *workload* itself may confer capacity. So, for example, the heavy workload of treatment for cancer may bring hope to patients/family members thus bolstering their structural resilience. Or, the often time-consuming workload of pulmonary rehabilitation (a twice weekly programme of exercise and education for patients with chronic respiratory disease that lasts six weeks) might support patients with understanding their disease, leaving them better able to secure the cooperation of others.

We believe that these constructs might be used to further patient care and professional understanding.

First, at an *individual* level – i.e. clinicians interacting with patients/family members.

Before delegating treatment tasks to patients to manage at home, clinicians could use these constructs to support their understanding of the extent and volume of a patients' workload – not simply of illness/treatment but that of daily life. In order to do this, as Glaser & Strauss (1971) suggest, a useful question for the clinician to ask might be "What passages is [the individual] going through today"? (54)(p.3)

Importantly, at the same time as considering workload, clinicians could use these constructs to support their understanding of the resources that exist within patients' lives to meet the demands of their workload, the social skill that patients have to mobilise these resources and the structural resilience that patients have to cope with and absorb adversity. Mair & May (2014) propose this may be expressed through a single question, "Can you really do what I am asking you to do"? (297) (p.349).

Whilst recognising the time constraints incumbent on the clinical encounter, clinicians should consider an assessment of workload and capacity at every opportunity as, as our data has shown, each are likely to fluctuate and may accumulate over a disease trajectory.

Our data has demonstrated that capacity is finite whereas workload is potentially infinite. Clinicians could also work with patients to support them with prioritisation of their "lines of work", balanced against available capacity, patients' ability to mobilise this capacity and considering patients' visions of what their life should look like. In order to do this, clinicians could work with patients to use these constructs to deliver care that is truly "person-centred". "Person-centred care" is a phrase frequently used by clinicians, healthcare organisations and healthcare policy makers but the rhetoric often does not match the reality (298, 299). Indeed, medical training directs doctors to take a reductively biomedical view of the patient as Good (1994) in his seminal set of lectures on medical knowledge and practice emphasises: "they don't want to hear the story of the person. They want to hear the edited version" (300)(p.78). Thus, doctors tend to ask patients "what is the matter with you" rather than "what matters to you" (301) . Coulter et al (2015) have usefully defined person-centred care as an "anticipatory (forward-looking), negotiated discussion or series of discussions between a patient and a health professional (perhaps with other professional or family members present) to clarify goals, options and preferences and develop an agreed plan of action based on this mutual understanding" (302)(p.7).

Second, at *system* level. The data presented in this study has shown that clinicians may be prevented from offering person-centred care by health system constraints. As McCormack (2004) argues, the *context* in which healthcare is provided has the most potential to facilitate or impede the delivery of person-centred care (303)(p.34). Our data has demonstrated that fragmented, complicated and poorly co-ordinated, siloed services that communicate inadequately with one another may add to patients' treatment workload. In the UK, the English NHS healthcare system is predicated on a hospital-based, medically dominated model organised around single diseases. Long standing organisational and cultural divisions between primary and secondary care, physical and mental health services and health and social care throw up barriers to the provision of person-centred care (304, 305). Recent policy initiatives throughout the UK have promulgated person-centred redesign of health systems, promoting a shift from a system based on competition between autonomous healthcare providers, prioritising objective performance measures (e.g. length of stay in healthcare institutions), to a more collaborative system with an increased emphasis on subjective measures such as the priorities of patients (304-306). The potentially modifiable factors presented in this paper can be used at healthcare system level to support the practical implementation of such initiatives, for example, by highlighting the importance of such factors as structural disadvantage in accessing services.

4.8 Conclusion

Our purpose in identifying, characterising and explaining workload and capacity and the key factors contingent on each is with the intent to provide a basis from which to develop an instrument to support clinicians with detecting the risk of treatment burden in people with long-term, life-limiting conditions. Preliminary studies have usefully begun to develop measures of treatment workload (18, 23, 45) and capacity (115). This work is novel and important as it demonstrates the importance of the consideration of *both* workload and capacity in the detection of treatment burden which is neither simply one nor the other but a product of interactions between the two and their associated factors.

Chapter 5 Thesis discussion

This chapter aims to restate briefly the rationale for, and objectives of, this body of work. It will explain the significance of the findings in relation to the three phases of work outlined in this thesis. First, the systematic review and interpretative synthesis presented in chapter two. Second, the cross-sectional comparative qualitative analysis set out in chapter three. Third, the conceptual modelling work presented in chapter four. It will interpret the significance of the contribution of this body of work, relating the findings to current knowledge and highlighting its novel contribution to knowledge and understanding of burden of treatment. It will consider the relevance of these findings to healthcare practice and policy, discuss the strengths and limitations of this body of work and suggest areas for further research.

5.1 Rationale

This thesis aimed to answer the research question 'What is Burden of Treatment and how is it experienced by patients living with chronic obstructive pulmonary disease (COPD) or lung cancer?' Treatment burden has been conceptualised as "disruptions in care, self-care and outcomes" (21) (p.1042). Treatment burden may occur when workload , "the affective, cognitive, informational, material, physical and relational tasks" (35) that exist in people's lives, outweighs capacity, "the affective, cognitive, informational, material, physical and relational" (35) resources available to patients to mobilise to meet the demands of this workload (3, 21). Detection of treatment burden is important both at individual patient level and at population level. At patient level, treatment burden may lead to an individual's poor adherence to prescribed treatments and self-management regimens, resulting in adverse clinical outcomes such as higher mortality and worse health-related quality of life (3, 17-20, 22, 26). At population level, treatment burden may lead to an inefficient use of healthcare resources (21, 22, 26).

To recapitulate, the objectives of this body of work were as follows:

1. To identify, characterise and explain patients' experiences of workload and capacity in people living with COPD or lung cancer
2. To interrogate and refine the concept of burden of treatment itself, specifically focusing on the constructs of diagnosis, illness identity, workload and capacity
3. To identify and characterise potentially modifiable factors associated with workload and capacity, either condition specific or applicable to both COPD and lung cancer

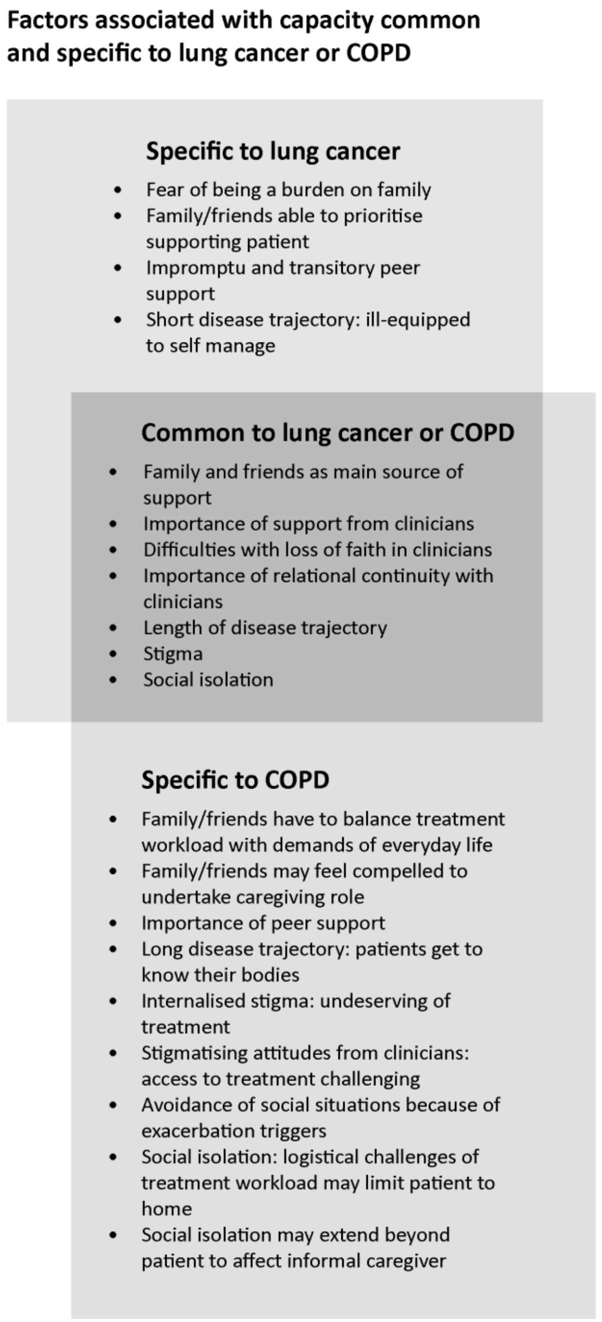
4. To identify and characterise if and how treatment burden is manifest in the clinical encounter for patients with COPD and lung cancer
5. To build an empirically derived conceptual model to explain common and specific features of burden of treatment with recourse to COPD and lung cancer
6. To use the empirically derived conceptual model to identify targets for supportive interventions which might be introduced into routine clinical practice to ameliorate treatment burden

5.2 Explanation of the significance and novelty of findings

This thesis took as its starting point Shippee et al's (2012) cumulative complexity model in which the authors contended that a workload which exceeds capacity might be the primary driver of treatment burden (21). May et al's (2014) burden of treatment theory has also strongly influenced this work's understanding of the relationship between workload and capacity, particularly in relation to how social skill and structural resilience may be associated with capacity. Whilst these conceptual models/theories provided useful theoretical concepts to explore, both were based on narrative reviews of the literature and therefore required empirical analysis. The studies presented in chapters two and three, therefore, aimed to address thesis objectives 1-4. They identified and characterised patients' experiences of the primary constructs of 'workload' and 'capacity' in relation to treatment burden, comparing and contrasting similarities and difference in each in order to explore variation across conditions (COPD or lung cancer), time points along the illness trajectory and healthcare situations.

5.2.1 Development of taxonomy of common and specific features of workload and capacity in COPD or lung cancer

Chapter two (paper one), comprising a systematic review and synthesis of the international qualitative literature on patient and informal caregiver interactions with health and social care, developed a taxonomy identifying and characterising common and specific features of 'workload' and 'capacity' in COPD and/or lung cancer (see Table 4) . To the best of my knowledge, this paper was the first to compare explicitly patients' experiences of treatment burden in malignant and non-malignant respiratory disease and the first to develop a taxonomy of treatment burden in respiratory disease. Figures 6 and 7 (below) set out the features of the key treatment burden constructs of 'workload' and 'capacity' found to be common to both conditions or specific to either COPD or lung cancer.



Factors associated with capacity common and specific to lung cancer or COPD

Specific to lung cancer

- Fear of being a burden on family
- Family/friends able to prioritise supporting patient
- Impromptu and transitory peer support
- Short disease trajectory: ill-equipped to self manage

Common to lung cancer or COPD

- Family and friends as main source of support
- Importance of support from clinicians
- Difficulties with loss of faith in clinicians
- Importance of relational continuity with clinicians
- Length of disease trajectory
- Stigma
- Social isolation

Specific to COPD

- Family/friends have to balance treatment workload with demands of everyday life
- Family/friends may feel compelled to undertake caregiving role
- Importance of peer support
- Long disease trajectory: patients get to know their bodies
- Internalised stigma: undeserving of treatment
- Stigmatising attitudes from clinicians: access to treatment challenging
- Avoidance of social situations because of exacerbation triggers
- Social isolation: logistical challenges of treatment workload may limit patient to home
- Social isolation may extend beyond patient to affect informal caregiver

Figure 6: Factors associated with capacity common and specific to lung cancer or COPD

Factors associated with workload common and specific to lung cancer or COPD

Specific to lung cancer

- Shock of diagnosis
- Obvious illness identity
- Short disease trajectory
- Treatment workload as priority
- Practical demands of treatment as relief
- Treatment as hope
- Immediacy of access to healthcare
- Specialist healthcare professionals with specific knowledge of lung cancer
- Structured treatment pathway in secondary care
- Few delegated tasks
- High quality information available about condition
- Patients may deliberately choose not to be fully informed

Common to lung cancer or COPD

- Diagnosis/illness identity
- Attitude towards treatment
- Treatment options
- Access to/navigation of healthcare systems/ organisations
- Practical/informational workload of treatment
- Conflicting information leads to patient distress

Specific to COPD

- Imperceptibility of diagnosis
- Unclear illness identity
- Long/uncertain disease trajectory
- Treatment workload balanced against daily life
- Lack of information about treatment options
- Difficulties accessing healthcare
- Generalist healthcare professionals lacking knowledge of COPD
- Fragmented treatment pathway across primary and secondary care
- Many delegated tasks at home
- Typically ill-informed about condition

Figure 7: Factors associated with workload common and specific to lung cancer or COPD

This study found that, in lung cancer, the normative assumption of healthcare professionals, patients, family members and society was that the disease exerted agency over patients. Therefore, although the workload of treatment in hospital was frequently gruelling and intensive, patients were not expected to direct and manage it. Instead, capacity to support the demands of treatment (from healthcare professionals and from family and friends) was made available. Conversely, in COPD, the normative assumption from healthcare professionals, patients, family members and society was that patients were able to exert agency over the disease. Therefore, patients were expected to direct and manage their own treatment workload at home. Capacity to support the demands of treatment (from healthcare professionals and from family and friends) was less readily available and patients had to work to mobilise it.

This study also highlighted the importance of the understanding of patients' balancing of their treatment workload against the demands of other status passages. This finding was clinically relevant to lung cancer as it illuminated how patients could prioritise the treatment workload over other lines of work in their daily life. Patients with lung cancer might thus continue to pursue treatment options even when the utility of these were limited. This finding was also clinically relevant to COPD as it demonstrated how a delegated workload of treatment could be an exhausting, rather than an empowering experience for patients, to the extent that some patients even experienced institutionally provided care as a respite from the burden of self-management.

5.2.2 Comparative analysis of the lived experience of treatment of patients with lung cancer or COPD

In chapter three (paper two), the taxonomy was interrogated and refined through a comparative analysis of the lived experiences of treatment of patients with COPD or lung cancer.

In addition to confirming the majority of the elements of the existing taxonomy (see Table 10 above), new constructs added to the taxonomy were as follows:

Features associated with workload specific to COPD:

1. Diagnostic ambiguity
2. Workload of changing health behaviours at home
3. Clinicians performance manage patients against delegated tasks
4. Informal caregivers report failure of patients to perform against delegated tasks to clinicians
5. Patients may voluntarily or involuntarily assume treatment tasks

Features associated with capacity specific to COPD:

1. Delegated workload of tasks for informal caregiver
2. Informal caregiver must undertake domestic duties previously undertaken by patient
3. Knowledge and skills gained from specialist care are vital
4. Inflexibility of treatment experience

Features associated with capacity specific to lung cancer:

1. Specialist clinicians encourage patients to have priorities other than treatment
2. Flexible and responsive treatment experience

There were features of ‘workload’ and ‘capacity’ identified and characterised in the systematic review and interpretative synthesis, but not identified in the comparative analysis. First, the sense of limbo that patients with lung cancer experienced once they had completed treatment. This was an expected finding as the patients included in the comparative analysis were those who were *undergoing* treatment rather than those who had *completed* treatment. Second, patients’ experience of stigma and social isolation. In the comparative analysis, patients reported how lung cancer could be seen as contagious and how this might be associated with a contraction of their social circle. Aside from this, there was no discussion of stigma or social isolation in lung cancer implicitly or explicitly either during the interviews or observations. This may have been because the interview schedule did not explicitly cover questions on stigma or social isolation. However, the interview schedule for patients with COPD did not cover either of these issues. Yet, it was apparent in both interviews and observations that patients experienced significant felt and actual stigma internally from themselves and externally from healthcare professionals and from society at large. This was strongly associated with capacity in terms of patients’ social skill (their ability to secure cooperation) (51) and structural resilience (their ability to adapt to adversity) (3). Social isolation was prevalent amongst patients with COPD (and their informal caregivers) and this too was strongly associated with capacity.

5.2.3 The impact of diagnosis and illness identity on treatment burden

From this interrogation and refinement of the taxonomy, a richer understanding of how patients’ experiences of diagnosis and subsequent illness identity impacted on ‘workload’, ‘capacity’ and consequently treatment burden has emerged. This is explicated in detail below through comparison of a biographically disruptive with a biographically erosive illness.

5.2.3.1 Illness as biographically disruptive

As previously discussed above, Bury (1982) characterised the experience of being diagnosed with a chronic illness as biographically disruptive, requiring the diagnosed individual to “re-think fundamentally their biography and self-concept" (50). The work presented in chapters two and three above has shown that, indeed, in an illness such as lung cancer, the experience of diagnosis and subsequent illness identity may be that of biographical disruption. Patients understood the existential threat of their illness and the fact that it is likely to have a short trajectory – i.e. that they may die imminently. In "status passage" (54) terms, the diagnosis of lung cancer was seen as a "crisis" and patients were thus able to prioritise their treatment workload over other "lines of work". As Glaser & Strauss rather beautifully characterised it, "crises tend to "flood" the lives of the passagee so that virtually all other passages may have to be temporarily "frozen" or even permanently abandoned"(54) (p.144). This experience of diagnosis/illness identity as biographical disruption was associated with patients' experiences both of 'workload' and 'capacity'.

Treatment workload, whilst ongoing, might become the primary focus of life for patients with lung cancer. As Glaser & Strauss argued, "Tactics…used to slow the downward passage may dramatically affect other status passages, sometimes being even more potent in their competitiveness than the downward passage itself. Thus, regimens for…disease may interfere more with time and energy needed for other endeavours than even the worsening symptoms of the disease" (54)(p.145).

Glaser & Strauss emphasised how a crisis may extend out from beyond an individual's passages to affect the passages of those close to them. Thus, the capacity (in terms of family and friends) of patients with lung cancer might be enhanced, as those close to them recognised the existential threat and likely short trajectory of the illness, and temporarily suspended the demands of their other passages to funnel resources into dealing with the crisis. Likewise, capacity (in terms of healthcare resources) was almost immediately available to patients with lung cancer, again because of health systems and healthcare professionals' recognition of the existential threat and likely short trajectory of the illness. Thus, patients with a biographically disruptive disease such as lung cancer were less likely to require social skill to mobilise capacity as the meaning and significance of the disease was clear not only to patients themselves but to friends, family, society and the healthcare system.

Treatment workload for patients with lung cancer was characterised by tasks that were done to patients by healthcare professionals in hospitals, predominantly in secondary care, with a relatively clear and structured treatment pathway. Where tasks were delegated to patients/informal caregivers to undertake at home, there was an obvious route for help seeking, generally supported by healthcare capacity (in the shape of specialist nursing staff) to do so. The workload was heavy and intense, clearly recognisable as a conventional treatment, often with side effects that marked patients as unwell. The workload was, however, generally temporally limited, ‘cycles’ of treatment with potentially curative or, more commonly, life-prolonging effects. As treatments might be directly linked to a cure or a prolongation of life, despite the volume and intensity of the treatment workload, patients’ attitudes towards treatment might not be one of treatment as burden but, conversely treatment as hope.

5.2.3.2 Illness as biographically erosive

In contrast, in COPD, the diagnostic process was fragmented; patients might not be formally diagnosed or be aware of their diagnosis for many years. Even when formally diagnosed, the term ‘COPD’ might be confusing for patients, family members and even non-specialist healthcare professionals as it covered a range of respiratory pathologies, present to a greater or lesser extent in individuals (267). Allied to this diagnostic ambiguity was a lack of public understanding of the disease, despite its high global incidence, most of the general public had never heard of COPD (78) Thus, the meaning and significance of the disease and its likely trajectory might not be clear to patients, informal caregivers and sometimes even non-specialist healthcare professionals. The work presented in chapters two and three has shown, therefore, that, in COPD, diagnosis and illness identity was not experienced by patients as a biographically disruptive crisis that could be pinpointed to one moment, but rather as a slow, inexorable process of biographical erosion over time. A juxtaposition of the theoretical lens of Glaser and Strauss’s theory of status passage (54) against Bury’s concept of a diagnosis of illness as biographically disruptive (50), allowed for the deeper characterisation of the construct of diagnosis/illness identity as biographically *erosive*. Glaser & Strauss postulated “there are many status passages of whose existence passagees are unaware…it is only revealed to the passagee as he [sic] goes along. Thus, he has to discover the passage…for himself, sometimes quite without the help of others” (54) (p.83). Thus, patients with biographically erosive disease such as COPD might, first, lack awareness of the existence of their illness trajectory. Second, patients might only gradually come to an understanding of the meaning and significance over its often long and frequently uncertain disease trajectory. As Glaser & Strauss argue, “information or knowledge of a passage allows control over its shape” (54)(p.83) (shape being a combination of a passage’s direction and temporality). Without knowledge of and information about their illness trajectory, patients with COPD were unable, first, to prioritise their treatment workload over other status passages and, second, to identify and mobilise resources to manage it. Unlike patients with lung cancer, patients with COPD had to work hard to mobilise healthcare capacity. Indeed, patients reported being told that there were no treatment options available for COPD. Thus, patients might not have access to a treatment workload for many years until pathophysiological deterioration and subsequent decline in physical function obliged them to re-engage with the healthcare system or they identified treatment options through their own research or from the experience of peers.

Patients could thus be obliged to exercise considerable social skill to access healthcare capacity. Once identified and accessed, most treatment tasks were delegated by healthcare professionals to patients/informal caregivers to be undertaken at home. The bulk of this delegated workload of treatment involved changing health behaviours such as smoking cessation, weight management and increasing physical activity. While healthcare professionals held normative assumptions that patients with COPD were motivated to adopt and enact this delegated workload of health behaviours, it was apparent that the meaning and significance of this treatment was not clear to patients in the same way that more conventional treatment workloads, such as adhering to complex medication regimens, might be. Indeed, a health behaviour workload might be experienced by patients as, in itself, biographically erosive as it could involve major lifestyle redesign and effort with a lifetime commitment to treatment. However, the treatment held out no hope of a cure and the life prolonging impacts of health behaviours appeared difficult to quantify. Moreover, a health behaviour workload was one that was generally delegated to patients to manage at home as, indeed, were most treatment tasks for patients living with biographically erosive disease such as COPD. Thus, patients and family members or friends supporting them were obliged to assume responsibility for a range of complex delegated tasks which might involve making clinical decisions (for example deciding whether to help seek from healthcare services in the event of a flare up of the condition).

Capacity in the shape of family and friends’ support for the delegated workload of treatment tasks at home was not immediately available to be mobilised in the same way that it was with a biographically disruptive illness like lung cancer. First, as it was with patients themselves, the existence of the illness trajectory was not clear to family and friends. Second, once the existence of the illness trajectory has been established, its meaning and significance was not fully understood by family and friends. This meant that the purpose of the treatment workload could be unclear. Furthermore, where a treatment workload was changing health behaviours rather than conventionally understood treatments (compared to, for example, chemotherapy), family and friends, again like patients, could lack understanding of the importance of this treatment workload. Thus, family and friends might not prioritise support for the patients’ treatment workload but instead balanced the demands of the treatment workload against the demands of other lines of work.

There appeared to be some moral judgements on the part of family and friends about the culpability of patients in, first, inflicting COPD on themselves through smoking and, second, in failing to perform against delegated tasks. This manifested itself in non-participant observations of the clinical encounter, where family and friends reported patients’ failure to perform against delegated tasks, adopting or maintaining health behaviours such as smoking or exercise, to healthcare professionals. The interactions between illness identity, workload and capacity and their associated factors are set out in figures 8 and 9.

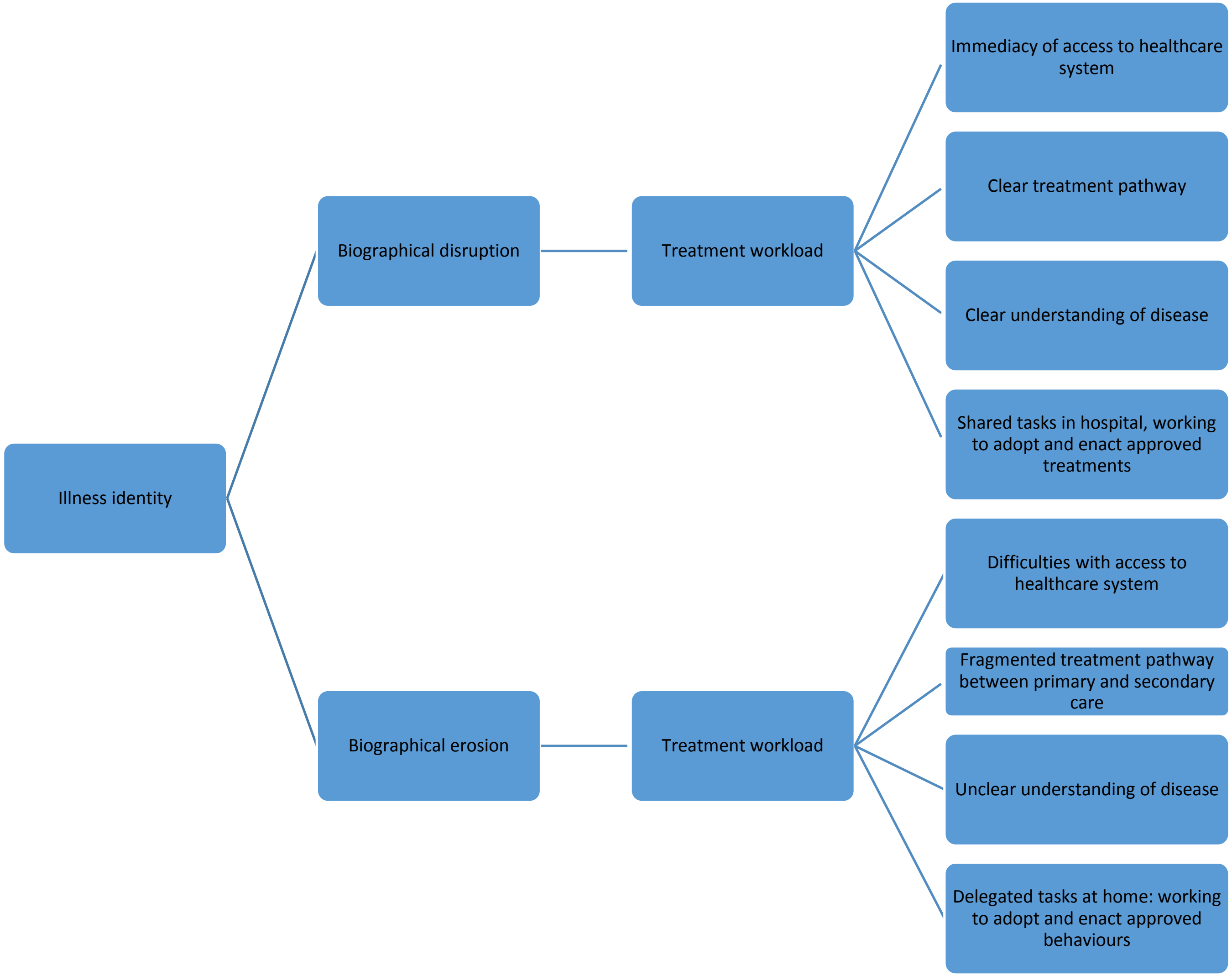


Figure 8: Illness identity and workload

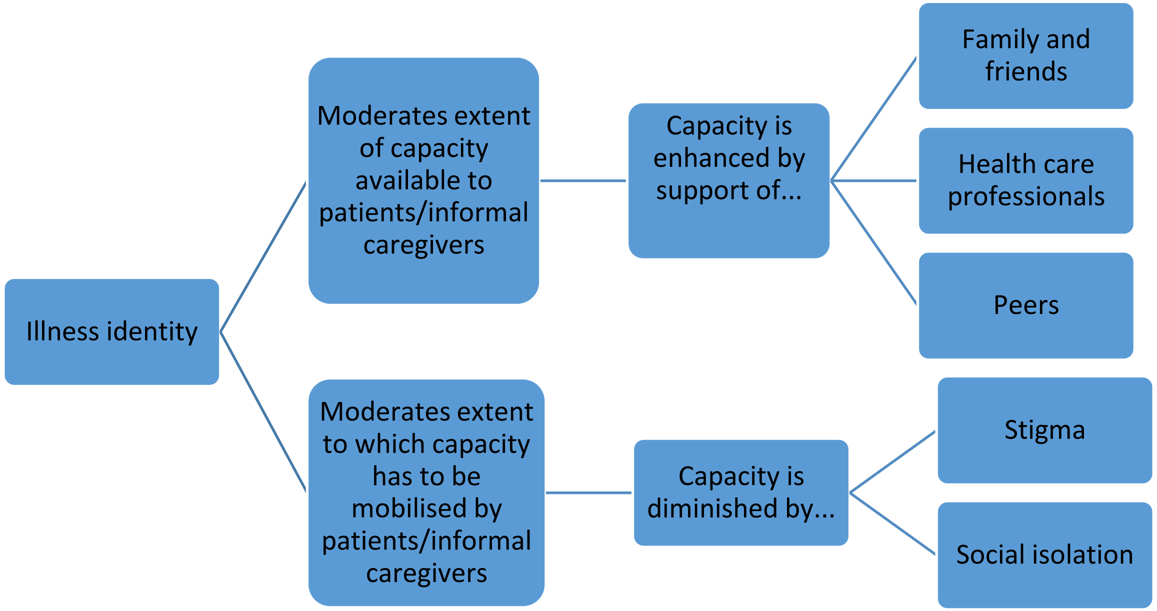


Figure 9: Illness identity and capacity

5.2.4 Conceptual modelling work: interactions between workload and capacity and associated factors that may lead to treatment burden at individual patient level

The work set out in chapter four extends the analysis undertaken in chapters two and three which sought to identify and characterise common and specific features of patients' experience of 'workload' and 'capacity' in COPD or lung cancer. This was done through the systematic, abductive combining of empirical and theoretical propositions developed as a result of the earlier work. These propositions were interrogated and refined against the findings of other systematic reviews identifying and characterising 'workload' and 'capacity' in disease. In addition to identifying and characterising the constructs of 'workload' and 'capacity', the work reported in chapter four maps the hierarchical relationships between the constructs and their associated potentially modifiable and measurable factors, explaining how these might interact to create treatment burden. The work presented in chapter four has, therefore,

1. Used the theories of status passage, burden of treatment, biographical disruption and the cumulative complexity model to support the development of an empirically tested conceptual model of treatment burden through a focus on the constructs of 'workload' and 'capacity'
2. Identified and characterised potentially modifiable and measurable factors associated with treatment burden across diseases

Thus, chapter four addresses thesis objectives 2, 3, 5 and 6.

As argued previously, this thesis differs from much of the literature in its careful delineation of treatment workload as separate from treatment burden. Importantly, the conceptual model set out in chapter four has built on the work from the two earlier studies presented in chapters two and three, demonstrating that the relationship between workload and capacity is not necessarily a linear one. Boehmer and colleagues (2016) in their systematic review of capacity have also demonstrated this, illustrating how capacity may build capacity (49). The novel finding of this thesis is that treatment *workload* itself may confer capacity and cannot therefore be directly equated with treatment burden.

This is particularly pertinent when examining the one study identified that has, to date, characterised treatment burden in lung cancer. This quantitative retrospective cohort study of Medicare patients with lung cancer concluded that these patients experienced substantial treatment burden (43). The authors defined this treatment burden in terms of volume. First, the number of days patients were in contact with the healthcare system. Second, the number of physicians involved in a patients' care. Third, the number of medications prescribed. Resonating with the findings of this thesis, the study found that lung cancer patients spent considerable time interacting with the healthcare system (1 in 3 days during the first 60 days of treatment). However, a simple equation of treatment workload with treatment burden does not align with the findings from this thesis. This thesis has explicated how the attitude of patients with lung cancer towards their treatment workload was one of hope; relief from the existential threat of cancer and therefore the workload, although heavy, was not necessarily viewed as burdensome. It has also demonstrated how patients might appreciate and value access to and relational continuity with specialist healthcare professionals, choosing to *add* to their workload in order to maintain this relational continuity. Presley et al's study (2017) usefully added, therefore, to the characterisation of treatment workload in lung cancer but did not explain treatment *burden*. This demonstrates the importance of the use of qualitative methods in the understanding and characterisation of treatment burden, a limitation that the authors in the study discussed above themselves acknowledged (43).

There has been one Australian qualitative interview study of treatment burden in COPD (31). This study's findings resonated with the findings of this thesis in two ways. First, participants found the nature of the treatment workload – tasks that involved changing or maintaining health behaviours – particularly challenging. Second, patients had to rely on sometimes absent family members in order to meet the demands of this treatment workload. However, this study again equated treatment burden with workload and its impact on patients. Thus, although its characterisations of workload were useful, it does not *explain* treatment burden.

In the UK, Gallacher and colleagues have undertaken an important series of studies identifying and characterising treatment burden, first in heart failure (19) and then in stroke (20, 22) which have informed the design and direction of this body of work. Gallacher's final study developed a conceptual model of treatment burden (22), although it differed from the conceptual model of treatment burden in illness presented in chapter four of this thesis as it was stroke-specific. In this conceptual model, Gallacher identified treatment burden as, first, a consequence of the healthcare workload of thinking about, organising, doing and reflecting on the management of stroke and, second, the "endurance of care deficiencies" (ibid, p.3) (features of health/social care that did not meet patients' requirements or expectations). Importantly, Gallacher also identified potentially modifiable factors associated with capacity: personal attributes, support network, financial status, life workload, environments. Although these potentially modifiable factors have been drawn from stroke-specific work, they resonate with the potentially modifiable factors that characterise capacity in disease delineated in the conceptual model presented in chapter four. Whilst Gallacher initially seems to equate treatment workload with treatment burden (she defines treatment burden as “the workload of healthcare for patients and the effects on this on well-being”, (22)(p.1)), in actuality, her conceptual model usefully traces the complex interactions between healthcare workload and patient capacity. So, treatment burden may arise

> As a consequence of healthcare workload and/or care deficiencies, which can both influence and be influenced by patient capacity. This quality and configuration of health and social care services can influence healthcare workload, care deficiencies and patients’ capacity (the latter is also influenced by factors external to healthcare systems)
>
> **((22) p. 12)**

Again, this echoes findings from the conceptual modelling work set out in chapter four which demonstrated how fragmented and poorly coordinated healthcare provision might be associated with workload and how the extent to which patients might have to prioritise status passages not associated with healthcare might affect capacity.

5.3 Relevance of findings to health policy and practice

As a nurse working within the English NHS system, this body of work was undertaken with the intent of translating findings into recommendations with relevance for health policy and provision, and healthcare professionals. I have organised, therefore, potentially modifiable factors associated with workload and capacity into those that might be influenced by health policy and provision, and those that might be influenced by healthcare professionals (see tables 13 and 14). Some factors might, of course, be influenced by **both** healthcare policy and provision and healthcare professionals and, therefore, might be repeated.

Table 13: Potentially modifiable factors associated with workload

HEALTH POLICY AND PROVISION	**HEALTHCARE PROFESSIONALS**
• Disadvantage • Unequal access to material resources • Social exclusion • Spatial inequalities • Complicatedness of services • Service fragmentation • Degree of service co-ordination • Quality of intra-organisational communication • Institutional support • Access to information • Quality of information • Access to educational resources for patients/caregivers • Normative expectations of motivation to participate • Complicating effects of multi-morbidities • Support for help seeking behaviours	• Patient/informal caregiver understanding of disease • Patient/informal caregiver understanding of (un)predictability of disease trajectory • Patient/informal caregiver understanding of (un)predictability of treatment outcomes • Complicating effects of multi-morbidities • Access to information • Quality of information • Access to educational resources for patients/caregivers • Normative expectations of motivation to participate • Recognition of and support for delegated tasks • Support for help-seeking behaviours

Table 14: Potentially modifiable factors associated with capacity

HEALTH POLICY AND PROVISION	**HEALTHCARE PROFESSIONALS**
• Perceived culpability • Stigmatising/isolating effects of treatment/disease exacerbation/symptoms • Support for allocation of finite resources • Recognition of role of caregiver	• Perceived culpability • Illness trajectory • Accumulated expertise • Pathophysiological deterioration • Understanding of adaptive/affective responses to biographical disruption/erosion • Patient centred prioritisation: 1) recognition of priorities other than treatment 2) prioritisation with patients of status passages 3) allocation of finite resources (capacity) in discussion with patients • Quality of patient-professional communication • Quality of patient-professional relations • Relational (dis)continuity • Support for rationalised non-adherence • Recognition of role of caregiver 1) recognition of emotional/relational solidarity 2) recognition of limits of tolerance 3) caregiver assent/dissent

I have selected five areas with the most immediate salience to health policy, provision and healthcare professional practice to discuss in more detail.

5.3.1 Recognition by healthcare professionals of the work of treatment for patients

This thesis began by setting out the long history of sociological understanding of the work of patient-hood, with an emphasis on the work of treatment. This understanding of treatment as work is not always well translated to the clinical setting.

The series of studies presented in chapters two to four of this thesis have shown that, in a biographically disruptive illness such as cancer, the bulk of the work of conventional treatments (e.g. radiotherapy, chemotherapy) was obvious and visible to both the patient, family member and healthcare professional. Indeed, treatment tasks were often shared between patients, family members and healthcare professionals or carried out by patients and healthcare professionals in tandem in hospital. In contrast, in a biographically erosive disease such as COPD, treatment tasks were frequently delegated to patients to undertake at home. Much of the workload of delegated tasks might be, therefore, invisible to healthcare professionals (9, 307). Thus, healthcare professionals might not appreciate the volume and impact of the delegated treatment tasks undertaken by patients (21, 308).

The results set out in chapter three showed how, in chronic illness, outpatient appointments provided an opportunity for healthcare professionals to monitor the results of patients' performance against their delegated tasks. In addition to this monitoring, healthcare professionals could use outpatient appointments as an opportunity to use the constructs developed in this body of work to make a formal assessment of potentially modifiable factors of 'workload' and 'capacity'. Most importantly, healthcare professionals should recognise that a delegated workload of healthcare behaviours might be experienced by patients living with chronic illness as hard, relentless, lifelong work.

It is also important for healthcare professionals working with patients with chronic illness to recognise the importance of the role of the informal caregiver. This body of work has shown that, frequently, informal caregivers play a vital role in the provision of capacity (material assistance and emotional and relational solidarity) to support the delegated workload of treatment tasks at home and the mobilisation of capacity (healthcare resources) when help seeking. It is apparent that informal caregivers might have to make complex clinical judgements about help-seeking for patients. Both the provision and mobilisation of capacity might prove overwhelming for informal caregivers, particularly over a long disease trajectory as treatment regimens become more complex and patients' pathophysiological deterioration and consequent decline in physical function means that informal caregivers have to undertake domestic tasks previously undertaken by the patient.

Healthcare professionals could, therefore, use the conceptual model set out in chapter four to explore 1) the nature and volume of treatment tasks they have delegated to individuals 2) the resources individuals have to carry out these treatment tasks and the extent to which they have to work to mobilise them 3) the amount of work the informal caregiver has to provide and their ability to provide it.

5.3.2 Complicating effects of multi-morbidities

Globally, healthcare professionals are trained as specialists to delegate work to patients in line with disease -specific clinical guidelines, rather than considering how treatment workloads might accumulate or, indeed, sometimes conflict across more than one condition. As the number of people living with multi-morbidity is increasing rapidly (272), it is important for healthcare professionals to consider the nature and volume of the treatment tasks that not only they, but other healthcare professionals might have delegated to patients. A recent study has quantified the potential for accumulation of treatment workload in multi-morbidity, finding that, in patients with six chronic conditions, patients might take 18 medications each day, visit a healthcare professional 6.6 times in a month and spend a mean (SD) of up to 80.7 (35.8) hours a month in health-related activities (309).

Consideration of the accumulation of workload across conditions is important not only for healthcare professionals but for health policy in the development of clinical guidelines. Dobler and colleagues have usefully highlighted how clinical practice guidelines might not give adequate consideration to the patient work involved in adopting and enacting recommendations for treatment (308). They concluded that guidelines should "explicitly state the treatment burden associated with enacting different recommendations (the quantifiable workload as well as the potential effect on a patient's life)" (ibid, p. 2). Whilst this is a useful starting point, it is important for policy makers to consider not only the treatment workload associated with specific clinical guidelines but *across* clinical guidelines, particularly considering conditions with common co-morbidities (for example COPD and heart failure may often co-exist) (310).

5.3.3 Provision of information/understanding of disease

The hierarchical conceptual model delineated in chapter four explicitly associated the potentially modifiable factor of ‘understanding of disease’ with workload. However, ‘understanding of disease’ could equally be associated with capacity. It is difficult to identify, access and mobilise resources for a disease that one does not understand. Returning to the theoretical lens of status passage, allows us to understand how understanding of, first, the existence and, second, the possible trajectory of an illness allows the patient control over its shape – its direction and, to some extent, its temporality. Glaser & Strauss conclude “passages with relatively unknown directions and temporal properties are difficult to control” (54)(p.59).

In this body of work availability of, and access to, informational/educational resources about disease and the quality of these resources have been associated with the understanding of disease and the hard work of understanding a biographically erosive disease such as COPD has been characterised in detail. In the English NHS, the National Institute for Health and Clinical Excellence (NICE) has recently reissued its clinical guideline on the diagnosis and management of COPD (311). This new guideline emphasises the importance of the provision of information about COPD not only at diagnosis but at multiple points throughout the disease trajectory, indeed at every review appointment. In line with findings from this thesis which emphasised the volume of resources that family members provide for the delegated tasks of treatment, it also recommends that information about COPD should be given to family members.

There is a recognition that information provision may be challenging for clinicians, particularly around discussing end of life where the unpredictability of disease trajectories may lead to “prognostic paralysis”(81). However, findings from this thesis have demonstrated that an understanding of disease and particularly its likely trajectory - even when the exact trajectory is unclear - assisted patients with the prioritisation of their treatment workload against the workload of other status passages and the allocation of finite capacity.

Healthcare professionals could, therefore, use the conceptual model presented in chapter four to help them consider the following

1) Provision of timely, appropriate information tailored to the individual
2) Provision of written information with the opportunity for discussion with specialist health care professionals (and peers with the same disease if the patient wants)
3) Including informal caregivers in the provision of information (specifically, in the case of COPD, consideration should be given to inviting caregivers to attend the educational components of pulmonary rehabilitation courses)

5.3.4 Patient centred care

This thesis has shown how an illness trajectory does not take place in a vacuum. Indeed, an illness trajectory may be only one of multiple status passages that the individual is traversing. Glaser & Strauss (1971) suggested that a sociologist using status passage theory should ask themselves the question 'What status passages is the individual going through today'? (54) In the same way, it is important for the healthcare professional to recognise that the illness trajectory and its treatment workload is only one of many potential status passages that vary in significance and priority to an individual. Each status passage might have its own workload which might fluctuate over time. For example, individuals might have a diagnosis of disease, but they may also be a parent, a child, have a profession – perhaps they may even be undertaking a PhD. Healthcare professionals should, therefore, recognise that patients might have priorities other than treatment. Specialist healthcare professionals seemed to recognise this in relation to cancer where the workload of treatment was obvious and where the duration of the illness trajectory was likely to be short, ending in death. However, it is equally imperative for healthcare professionals to recognise this in life-limiting, chronic disease where the duration of the illness trajectory was uncertain but potentially long.

Importantly, healthcare professionals should support prioritisation of what is important to patients in the context of their lives rather than what is important to healthcare professionals. Thus, healthcare professionals should aim to deliver "minimally disruptive medicine" (2) that is truly "person-centred". Coulter et al defined person-centred care as an:

> "anticipatory (forward-looking) negotiated discussion or series of discussions between a patient and a health professional (perhaps with other professional or family members present) to clarify goals, options and preferences and develop an agreed plan of action based on this mutual understanding"
>
> **(302)(p.7).**

Healthcare professionals could use the potentially modifiable factors developed in this body of work to support patients with prioritisation of their workloads across status passages, balanced against patients' access to and the availability of capacity and patients' abilities to mobilise this capacity.

5.3.5 The design of healthcare systems

The design of health care systems and organisations, developed around specialist responses to acute care needs (297, 312) might be a potentially modifiable factor in both workload and capacity. Patients described how fragmented, poorly coordinated services and organisations and healthcare professionals which operated independently of one another might be associated with both ‘workload’ and ‘capacity’. This thesis has demonstrated how a fundamental shift in healthcare design is required, so that healthcare systems not only provide for patients with acute conditions who need episodic, short-term care but also supply the life-long, holistic care required for those with life-limiting conditions (312, 313).

Patients with cancer described the importance of the *practical* as well as the emotional support of their clinical nurse specialist. This named individual, with whom they met regularly, was easily contactable and, in addition to providing clinical advice, was able to co-ordinate medical appointments and treatment within and between healthcare organisations. Health care systems should consider the provision of comparable capacity to patients living with long-term life-limiting conditions so that ‘empowerment’ of patients to self-manage is not simply patients left to manage without sufficient support from healthcare systems (314).

5.4 Strengths and limitations

Strengths and limitations of each of the studies that make up the thesis have been discussed in previous chapters. This section will make some general comments about strengths and limitations.

The first study presented in chapter two, a qualitative systematic review and synthesis developed a taxonomy of ‘workload’ and ‘capacity’ in COPD and lung cancer from patient and informal caregivers experience of a range of international healthcare settings. This macro-level approach to the identification and characterisation of workload and capacity was then complemented by the second study set out in chapter three, a micro-level identification and characterisation of patients’ lived experience of workload and capacity in COPD and lung cancer through interviews and observations of patient-healthcare professional encounters in the English NHS. The conceptual modelling work reported in chapter four enabled the explanation of the interactions between workload and capacity that might create burden and was confirmed and strengthened by comparisons of findings with other systematic reviews exploring patients’ experiences of workload and capacity across a number of conditions. The systematic, abductive approach to the identification and characterisation of variation and generalisation and the combining of empirical and theoretical materials is a strength of this body of work. The iterative and recursive nature of an abductive approach has enabled the weaving of the three phases of this body of work into a harmonious whole.

My own clinical as well as research interests have influenced this thesis. This could be seen by some as a limitation, however, I worked closely with my supervisors through study design, data collection and analysis to consider my findings reflexively in order to turn this subjectivity into a strength rather than a weakness. Moreover, I attempted to mitigate the melding of my clinical and research identities by being careful to avoid recruiting patients with whom I had worked clinically in the past. I also did not present myself to patients as a healthcare professional either in the observations or in the interviews (although I did not conceal this fact if directly asked as I was on several occasions). Finally, I kept a reflexive journal in which I recorded and challenged my own bias, views and experiences throughout the development of this thesis (255).

The comparative qualitative analysis took place in a high-income country, the UK. As Sav and colleagues caution, it might thus provide only partial evidence for treatment burden in low-and-middle income countries (8). The risk of this has been mitigated through its integration with the results of the international systematic review described in chapter three and subsequent systematic review work undertaken with Roberti and colleagues which was deliberately extended to include insured and uninsured patients' experiences of treatment burden in low- and middle-income countries (34).

5.5 Areas for further research

5.5.1 The measurement of treatment burden

Sav et al's useful scoping review on the measurement of treatment burden in chronic disease highlighted the current lack of consensus on the best method of recognising and quantifying treatment burden among patients (8). Sav and colleagues argued that this lack of an agreed measure impeded the efforts of researchers and clinicians to comprehend and thus intervene to reduce treatment burden at an individual patient level (8). Measures of treatment burden do exist. Tran and associates (2012, 2014) have produced the Treatment Burden Questionnaire (TBQ) initially in French and later translated into English (45, 48). The TBQ predominantly assessed the impact of the material workload of treatment: 1) taking medications 2) undertaking laboratory tests and other examinations (e.g. x-ray) 3) self-monitoring 4) attending medical appointments 5) the organisational and administrative work of treatment 6) the financial work of treatment 7) the work of health behaviours (specifically diet and exercise). It also assessed domains that might be associated with capacity 1) the difficulties patients had in their relationships with healthcare providers 2) how healthcare impacted patients' relationships with others 3) how the need for regular healthcare reminded patients of their health problems.

In the USA, Eton and colleagues have undertaken a series of studies (2012, 2013, 2015, 2017) which have produced the rigorous and lengthy 48 item Patient Experience with Treatment and Self-Management (PETS) measure of perceived treatment burden (18, 23, 37, 40, 315). This contains nine domains, again mainly focusing on the impact of the material workload of treatment: 1) medical information 2) taking medications 3) medical appointments 4) monitoring health 5) medical and healthcare expenses 6) difficulty with healthcare services. Two domains could be associated with capacity (1) how a patients' self-care interfered with their role and social activity limitations (2) how a patients' self-care affected their physical and mental exhaustion.

A third measure of treatment burden has been developed by researchers in the UK (46) , based on the work done by Eton et al in the USA. This specifically focused on treatment burden in multi-morbidity. This, too, emphasised the impact of the material workload of treatment, focusing on 1) taking, collecting and paying for medications 2) self-monitoring 3) arranging and organising healthcare 4) accessing healthcare 5) obtaining information about the condition 6) changing health behaviours. It contains one domain which could be associated with capacity 1) having to rely on the help of family and friends. As is demonstrated from the measurements of treatment burden described above, these measures prioritised the assessment of treatment workload over the assessment of capacity. The body of work described in this thesis has shown the importance of the consideration of *both* workload and capacity.

In the USA, Boehmer's (2016) systematic review of patient capacity, provided a useful starting point for the consideration of patient capacity, illuminating the importance of the following domains: 1) biography 2) resources 3) environment 4) balancing patient and life work 5) social functioning (49). From this systematic review, Boehmer and colleagues have developed a helpful, practical discussion aid, the ICAN tool (316). This is designed around three questions:

1) What are you doing when you're not sitting here with me?
2) Where do you find the most joy in your life?
3) What's on your mind today?

It also asks patients to consider whether areas of their life (family and friends, work, house and neighbourhood, finances, free time, faith, being active, rest, emotional life, senses and memory, eating well) are a source of satisfaction or burden (or both). It asks patients to list the things that doctors have asked them to do to care for their health and whether these are a help or a burden (or both). Boehmer et al's ICAN discussion aid is, therefore, a useful basis from which to support patients and clinicians in the consideration of capacity in the clinical encounter. However, it does not provide a tool with which to measure capacity.

The conceptual model presented in this body of work is novel and important in that, for the first time it presents a list of potentially modifiable factors that describe the basis of *both* ‘workload’ and ‘capacity’. The findings from the three phases of this body of work have shown the importance of the consideration of both constructs in the detection of treatment burden. These potentially modifiable factors describe the basis of possible survey items that might be developed into an instrument to detect the risk of treatments overburdening patients with long-term, life-limiting disease.

5.6 Conclusion

This thesis has used complementary qualitative methods to identify, characterise and explain burden of treatment with recourse to COPD and lung cancer. Its detailed examination of variation in ‘workload’ and ‘capacity’ in these two diseases has extended our understanding of the concept of treatment burden from one defined by treatment workload, to a more complex and situational characterisation of treatment burden as occurring as a result of interactions between workload, capacity, illness identity and their associated factors.

The taxonomy of treatment burden in COPD or lung cancer developed through a review of the international literature, and interrogated and confirmed by a comparative qualitative analysis, has been extended into a conceptual model outlining potentially modifiable factors associated with workload and capacity that could be used in the detection and consideration of treatment burden in illness at an individual patient level. The findings from this thesis underline the importance of the integration of treatment burden considerations into healthcare policy and provision and routine clinical practice.

Appendix A Search strategy

MEDLINE SEARCH STRATEGY. OVID INTERFACE.

CHF/CKD/COPD:

1 Heart Failure/

2 heart failure, diastolic/ or heart failure, systolic/

3 ((heart$1 or cardiac or cardial or myocardial) adj3 failure$1).ti,ab,kf.

4 ((heart$1 or cardiac or cardial or myocardial) adj3 decompensat$).ti,ab,kf.

5 ((heart$1 or cardiac or cardial or myocardial) adj3 incompetenc$).ti,ab,kf.

6 ((heart$1 or cardiac or cardial or myocardial) adj3 insufficienc$).ti,ab,kf.

7 ((heart$1 or cardiac or cardial or myocardial) adj3 (standstill or stand-still)).ti,ab,kf.

8 (CHF or CHFs).ti,ab,kf.

9 or/1-8

10 exp Renal Insufficiency, Chronic/

11 Renal Insufficiency/

12 exp Renal Replacement Therapy/

13 Hemodialysis Units, Hospital/

14 (chronic kidney or chronic renal or chronic nephropath$).ti,ab,kf.

15 (kidney failure$1 or renal failure$1).ti,ab,kf.

16 (renal insufficienc$ or kidney insufficienc$).ti,ab,kf.

17 (dialysis or predialysis).ti,ab,kf.

18 (hemodialysis or haemodialysis).ti,ab,kf.

19 (hemofiltration or haemofiltration).ti,ab,kf.

20 (hemodiafiltration or haemodiafiltration).ti,ab,kf.

21 (end-stage renal or end-stage kidney or endstage renal or endstage kidney).ti,ab,kf

22 (stage 5 and (renal disease$1 or kidney disease$1)).ti,ab,kf.

23 (kidney transplant$ or renal transplant$ or kidney graft$ or renal graft$ or kidney replacement$1 or renal replacement$1).ti,ab,kf.

24 (CKF or CKD or CRF or CRD).ti,ab,kf.

25 (ESKD or ESRD or ESKF or ESRF).ti,ab,kf.

26 (CAPD or CCPD or APD).ti,ab,kf.

27 or/10-26

28 exp Pulmonary Disease, Chronic Obstructive/

29 (obstruct$ adj3 (pulmonary or lung$1 or airway$1 or airflow$1 or bronch$ or respirat$)).ti,ab,kf.

30 (chronic$ adj3 bronchiti$).ti,ab,kf.

31 emphysem$.ti,ab,kf.

32 (COPD or COAD or COBD or AECB).ti,ab,kf.

33 or/28-32

34 9 or 27 or 33

35 exp qualitative research/

36 qualitativ$.ti,ab,kf.

37 interviews as topic/

38 interview$.ti,ab,kf.

39 focus groups/

40 focus group$1.ti,ab,kf.

41 grounded theory/ or (grounded theor$ or grounded study or grounded studies or grounded research or grounded analys$).ti,ab,kf.

42 phenomenol$.ti,ab,kf.

43 (ethnograph$ or ethnonurs$ or ethno-graph$ or ethno-nurs$).ti,ab,kf.

44 (story or stories or storytelling or narrative$1 or narration$1).ti,ab,kf.

45 (open-ended or open question$ or text$).ti,ab,kf.

46 Narration/ or personal narratives/ or personal narratives as topic/

47 (discourse$ analys$ or discurs$ analys$).ti,ab,kf.

48 content$ analys$.ti,ab,kf.

49 ethnological.ti,ab,kf.

50 purposive sampl$.ti,ab,kf.

51 (constant comparative or constant comparison$1).ti,ab,kf.

52 theoretical sampl$.ti,ab,kf.

53 (theme$ or thematic$).ti,ab,kf.

54 (emic or etic or hermeneutic$ or heuristic$ or semiotic$).ti,ab,kf.

55 data saturat$.ti,ab,kf.

56 participant observ$.ti,ab,kf.

57 exp Humanism/ or (humanistic$ or existential$ or experiential$ or paradigm$).ti,ab,kf.

58 Postmodernism/ or (social construct$ or postmodern$ or post-modern$ or poststructural$ or post-structural$ or feminis$ or constructivis$).ti,ab,kf.

59 (action research or cooperative inquir$ or co-operative inquir$).ti,ab,kf.

60 human science.ti,ab,kf.

61 biographical method$.ti,ab,kf.

62 life world.ti,ab,kf.

63 theoretical saturation.ti,ab,kf.

64 group discussion$1.ti,ab,kf.

65 direct observation$.ti,ab,kf.

66 mixed method$.ti,ab,kf.

67 (observational method$ or observational approach$).ti,ab,kf.

68 key informant$1.ti,ab,kf.

69 (field study or field studies or field research$ or field work$ or fieldwork$).ti,ab,kf.

70 (semi-structured or semistructured or unstructured or un-structured or informal or in-depth or indepth).ti,ab,kf.

71 "face-to-face".ti,ab,kf.

72 ((guide or structured) adj5 (discussion$1 or questionnaire$1)).ti,ab,kf.

73 (heidegger$ or colaizzi$ or speigelberg$ or van manen$ or van kaam$ or merleau ponty$ or husserl$ or giorgi$ or foucault$ or corbin$ or glaser$).ti,ab,kf.

74 or/35-73

75 Consumer Behavior/

76 attitude/ or exp attitude to health/ or Attitude to Death/

77 personal satisfaction/

78 exp Emotions/

79 Stress, psychological/

80 exp Patients/px

81 Caregivers/px

82 professional-patient relations/ or nurse-patient relations/ or physician-patient relations/

83 professional-family relations/

84 Empathy/

85 Feedback/

86 ((patient$1 or client$1 or user$1 or consumer$1 or personal or carer$1 or caregiver$1 or care-giver$ or family$1 or families) and (experienc$ or perspective$1 or perception$1 or opinion$1 or account or accounts or attitude$1 or view or views or viewpoint$1 or satisf$ or unsatisf$ or dissatisf$ or disatisf$ or belief$1 or believ$)).ti.

87 ((patient$1 or client$1 or user$1 or consumer$1 or personal or carer$1 or caregiver$1 or care-giver$ or family$1 or families) adj3 (experienc$ or perspective$1 or perception$1 or opinion$1 or account or accounts or attitude$1 or view or views or viewpoint$1 or satisf$ or unsatisf$ or dissatisf$ or disatisf$ or belief$1 or believ$)).ab,kf.

88 ((patient$1 or client$1 or user$1 or consumer$1 or personal or carer$1 or caregiver$1 or care-giver$ or family$1 or families) and (emotion$ or feeling$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet$ or anxious$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat$ or stress$ or distress$ or embarrass$ or empath$ or accept$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother$ or unbother$ or pleased or displeased$ or concern$ or burden$ or hassl$ or convenien$ or inconvenien$ or confus$ or hope or hopeless or hopeful or trust or trusts or mistrust$ or distrust$ or entrust$ or trusting or trusted or confiden$ or unconfiden$)).ti.

89 ((patient$1 or client$1 or user$1 or consumer$1 or personal or carer$1 or caregiver$1 or care-giver$ or family$1 or families) adj3 (emotion$ or feeling$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet$ or anxious$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat$ or stress$ or distress$ or embarrass$ or empath$ or accept$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother$ or unbother$ or pleased or displeased$ or concern$ or burden$ or hassl$ or convenien$ or inconvenien$ or confus$ or hope or hopeless or hopeful or trust or trusts or mistrust$ or distrust$ or entrust$ or trusting or trusted or confiden$ or unconfiden$)).ab,kf.

90 (life experience$1 or lived experience$1 or actual experience$1 or real experience$1).ti,ab,kf.

91 or/75-90

92 34 and 74 and 91

93 ((heart$1 or cardiac or cardial or myocardial) adj3 (failure$1 or decompensation or incompetenc$ or insufficienc$ or standstill or stand-still)).ti.

94 (CHF or CHFs).ti.

95 (kidney or renal or nephropath$ or dialysis or predialysis or hemodialysis or haemodialysis or hemofiltration or haemofiltration or hemodiafiltration or haemodiafiltration or CKF or CKD or CRF or CRD or ESKD or ESRD or ESKF or ESRF or CAPD or CCPD or APD).ti.

96 (obstruct$ adj3 (pulmonary or lung$1 or airway$1 or airflow$1 or bronch$ or respirat$)).ti.

97 (chronic$ adj3 bronchiti$).ti.

98 emphysem$.ti.

99 (COPD or COAD or COBD or AECB).ti.

100 or/93-99

101 qualitativ$.ti. or qualitative research/

102 ((patient$1 or client$1 or user$1 or consumer$1 or personal or carer$1 or caregiver$1 or care-giver$ or family$1 or families) and experiences).ti.

103 ((patient$1 or client$1 or user$1 or consumer$1 or personal or carer$1 or caregiver$1 or care-giver$ or family$1 or families) adj2 experienc$).ti.

104 100 and (101 or 102 or 103)

105 92 or 104

106 exp animals/ not humans/

107 (news or comment or editorial or letter or case reports or randomized controlled trial).pt.

108 case report.ti.

109 105 not (106 or 107 or 108)

110 limit 109 to (english language and yr="2006 -Current")

111 remove duplicates from 110

Lung cancer:

1. exp Lung Neoplasms/

2. Carcinoma, Non-Small-Cell Lung/

3. Small Cell Lung Carcinoma/

4. (lung adj2 cancer$).ti,ab,kf.

5. 1 or 2 or 3 or 4

6. exp Qualitative Research/

7. qualitativ$.ti,ab,kf.

8. Interviews as Topic/

9. interview$.ti,ab,kf.

10. Focus Groups/

11. focus group$1.ti,ab,kf.

12. Grounded Theory/

13. (grounded theor$ or grounded study or grounded studies or grounded research or grounded analys$).ti,ab,kf.

14. phenomenol$.ti,ab,kf.

15. (ethnograph$ or ethnonurs$ or ethno-graph$ or ethno-nurs$).ti,ab,kf.

16. (story or stories or storytelling or narrative$1).ti,ab,kf.

17. (open-ended or open question$ or text$).ti,ab,kf.

18. Narration/

19. Personal Narratives/

20. Personal Narratives as Topic/

21. (discourse$ analys$ or discurs$ analys$).ti,ab,kf.

22. content$ analys$.ti,ab,kf.

23. ethnological.ti,ab,kf.

24. Purposive sampl$.ti,ab,kf.

25. (constant comparative or constant comparison$1).ti,ab,kf.

26. theoretical sampl$.ti,ab,kf.

27. (theme$ or thematic$).ti,ab,kf.

28. (emic or etic or hermeneutic$ or heuristic$ or semiotic$).ti,ab,kf.

29. data saturat$.ti,ab,kf.

30. participant observ$.ti,ab,kf.

31. exp Humanism/

32. (humanistic$ or existential$ or experiential$ or paradigm$).ti,ab,kf.

33. Postmodernism/

34. (social construct$ or postmodern$ or post-modern$ or poststructural$ or post-structural$ or feminis$ or constructivis$).ti,ab,kf.

35. (action research or cooperative inquir$ or co-operative inquir$).ti,ab,kf.

36. human science.ti,ab,kf.

37. biographical methods$.ti,ab,kf.

38. life world.ti,ab,kf.

39. theoretical saturation.ti,ab,kf.

40. mixed method$.ti,ab,kf.

41. (observational method$ or observational approach$).ti,ab,kf.

42. key informant$1.ti,ab,kf.

43. (field study or field studies or field research$ or field work$ or fieldwork$).ti,ab,kf.

44. (semi-structured or semistructured or unstructured or un-structured or informal or in-depth or indepth).ti,ab,kf.

45. "face-to-face".ti,ab,kf.

46. ((guide or structured) adj5 (discussion$1 or questionnaire$1)).ti,ab,kf.

47. (heidegger$ or colaizzi$ or speigelberg$ or van manen$ or van kaam$ or merleau ponty$ or husserl$ or giorgi$ or foucault$ or corbin$ or glaser$).ti,ab,kf.

48. 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47

49. Consumer Behavior/

50. Attitude/

51. exp Attitude to Health/

52. Attitude to Death/

53. Personal Satisfaction/

54. exp Emotions/

55. Stress, Psychological/

56. exp Patients/px [Psychology]

57. Caregivers/px [Psychology]

58. Professional-Patient Relations/

59. Nurse-Patient Relations/

60. Physician-Patient Relations/

61. Professional-Family Relations/

62. Empathy/

63. Feedback/

64. ((patient$1 or client$1 or user$1 or consumer$1 or personal or carer$1 or caregiver$1 or family$1 or families) and (experienc$ or perspective$1 or perception$1 or opinion$1 or account or accounts or attitude$1 or view or views or viewpoint$1 or satisf$ or unsatisf$ or dissatisf$ or disatisf$ or belief$1 or believ$)).ti.

65. ((patient$1 or client$1 or user$1 or consumer$1 or personal or carer$1 or caregiver$1 or family$1 or families) adj3 (experienc$ or perspective$1 or perception$1 or opinion$1 or account or accounts or attitude$1 or view or views or viewpoint$1 or satisf$ or unsatisf$ or dissatisf$ or disatisf$ or belief$1 or believ$)).ab,kf.

66. ((patient$1 or client$1 or user$1 or consumer$1 or personal or carer$1 or caregiver$1 or family$1 or families) and (emotion$ or feeling$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet$ or anxious$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat$ or stress$ or distress$ or embarrass$ or empath$ or accept$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother$ or unbother$ or pleased or displeased$ or concern$ or burden$ or hassl$ or convenien$ or inconvenien$ or confus$ or hope or hopeless or hopeful or trust or trusts or mistrust$ or distrust$ or entrust$ or trusting or trusted or confiden$ or unconfiden$)).ti.

67. ((patient$1 or client$1 or user$1 or consumer$1 or personal or carer$1 or caregiver$1 or care-giver$ or family$1 or families) adj3 (emotion$ or feeling$1 or happy or happiness or unhappy or unhappiness or sad or sadness or anger or angry or anxiet$ or anxious$ or worry or worries or worried or worrying or troubled or troubling or troubles or troublesome or trouble-some or frustrat$ or stress$ or distress$ or embarrass$ or empath$ or accept$ or alone or lonely or loneliness or fear or fears or fearing or feared or afraid or scary or scared or bother$ or unbother$ or pleased or displeased$ or concern$ or burden$ or hassl$ or convenien$ or inconvenien$ or confus$ or hope or hopeless or hopeful or trust or trusts or mistrust$ or distrust$ or entrust$ or trusting or trusted or confiden$ or unconfiden$)).ab,kf.

68. (life experience$1 or lived experience$1 or actual experience$1 or real experience$1).ti,ab,kf.

69. 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68

70. 5 and 48 and 69

71. qualitativ$.ti.

72. Qualitative Research/

73. ((patient$1 or client$1 or user$1 or consumer$1 or personal or carer$1 or caregiver$1 or care-giver$ or family$1 or families) and experiences).ti.

74. ((patient$1 or client$1 or user$1 or consumer$1 or personal or carer$1 or caregiver$1 or care-giver$ or family$1 or families) adj2 experienc$).ti.

75. 71 or 72 or 73 or 74

76. 5 and 75

77. 70 or 76

78. exp animals/ not humans/

79. (news or comment or editorial or letter or case reports or randomized controlled trial).pt.

80. case-report.ti.

81. 77 not (78 or 79 or 80)

82. limit 81 to (english language and yr="2006 -Current")

Appendix B Modified RATS (Relevance, appropriateness, transparency, soundness) guidelines (121)

Quality assessment tool (modified RATS)

Reference number/ Reviewer initials	Criteria	Detail	Yes/No
	Relevance	• Is the research question clearly stated? • Is the question generated from an analysis of the literature?	
	Appropriateness of method	• Is the qualitative method(s) stated most effective way of addressing the research question? • Is it stated why this method was used?	
	Transparency of research procedures	• Is the sampling procedure explained? • Are the criteria for the selection of participants stated? • Was the collection of data systematic and comprehensive? • Is the role of the researchers addressed? • Are ethical issues addressed?	

	Soundness of interpretive approach	• Is the analytical approach a reasonable approach and judged to be appropriate for the study?	
	Presentation of findings and common features of poor research	• Are the interpretations clearly outlined and supported by empirical evidence? • Were the interpretations checked? • Are the findings embedded in a theoretical or conceptual framework? • Is the way that the results add to existing knowledge stated? • Are limitations stated? • Is the article well written? • Is there an overuse of jargon? • Do the interpretations seem appropriate? Are they self-evident? • Is there an adequate discussion of consent – thin detail often indicates poor ethics.	

Appendix C Characteristics of Studies

Study	Year	Country	Qualitative method	Index condition	Setting	How sampled?	Sample	Age of sample	Gender of sample	How data analysed?	Study details
Adams et al #157	2006	UK, Netherlands, Denmark	Interviews	COPD	Community	Convenience	23 patients	38-84	16M, 7F	Descriptive (thematic analysis)	To explore the notion of COPD exacerbations from the viewpoint of patients who had recently suffered an exacerbation.
Arnold, E. #165	2011	UK	Interviews	COPD	Community	Purposive	27 patients	54-85	14M, 13F	Theory building (grounded theory)	To obtain in-depth information

											about perceptions and use of prescribed ambulatory oxygen systems from patients with COPD to inform ambulatory oxygen design, prescription and management.
Arnold, E. #166	2006	UK	Interviews	COPD	Pulmonary rehabilitation (hospital based)	Participants screened against eligibility criteria. All	20 patients	45-85	9M, 11F	Theory building (grounded theory)	To explore the experiences of COPD patients

						eligible patients invited to participate. Participants recruited until no new themes emerged.					invited to join a pulmonary rehabilitation programme.
Boyle, Anne H.#9	2009	USA	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	10 wives	57-71	10F	Theory informed (phenomenological-hermeneutic approach)	To describe and understand the meaning of the experience of living with a spouse who has COPD
Caress, A.#170	2010	UK	Interviews	COPD	Acute hospital	Participants screened against eligibility criteria. Those	14 patients, 12 family	Patients = 60-80. Family member	Patients = 8M, 6F. Family	Descriptive (content analysis)	To generate in-depth insights into patients' and

						eligible who agreed to participate included.	members	s not stated	members = 3M, 9F		family members' understanding of the causation, progression and prevention of COPD and the role of health promotion with this population
Clancy, Karen #13	2009	UK	Serial interviews	COPD	Acute hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate	9 patients, 7 care-givers	Patients = 57-78. Care-givers = 50-78	Patients = 6M, 3F. Care-givers = 2M, 5F	Theory informed (phenomenological-hermeneutic approach)	To explore the existential experiences of patients with COPD who had been prescribed

						included. Informal care-givers nominated by patients.					long-term oxygen therapy and their carers
Clarke, A #14	2010	UK	Interviews	COPD	Community	Purposive (maximum variation)	23 patients	50-80	14M, 9F	Theory building (grounded theory)	To explore patients' views of an early supported discharge service for COPD
Cooke, M #15	2012	UK	Focus groups	COPD	Community	Purposive	8 HCPs, 30 patients, 2 care-givers	Patients = 48-73. Care-givers and HCPs not stated	Patients = 16M, 15F. Care-givers = 2F. HCPs not stated	Descriptive (thematic analysis)	To define, compare and order 'assessed needs and defined outcomes' of

											professional providers of COPD services with patients' 'prioritised needs and defined outcomes' and relate these to service provision
Curry, R. #172	2006	UK	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	11 patients	Not stated	Not stated	Descriptive (thematic framework approach)	To explore patients' views of introduction of a new nurse-led urgent care team (UCT)

											for patients with COPD
Dickenson, J.#19	2009	UK	Interviews	COPD	Community	Participants screened against eligibility criteria.	12 patients	Not stated	Not stated	Descriptive (framework approach)	To explore the COPD patient's perception of their dietary habits and nutritional status and to identify their perceptions of dietary health and its impact on general quality of life.
Ehrlich, Carolyn #22	2010	Australia	Interviews	COPD	Community	Theoretical sampling	9 patients	56-77	4M, 5F	Theory building (grounded theory)	To report how people with COPD gather,

											interpret and apply health affecting information
Ek, K.#23	2014	Sweden	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible, who agreed to participate included.	13 family members	Not stated	7M, 6F	Descriptive (content analysis)	To retrospectively describe the final year of life for patients with advanced COPD with a focus on death and dying from the perspective of relatives.

Ek, K.#24	2011	Sweden	Serial interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	4 patients	66-75	1M, 3F	Theory informed (phenomenological-hermeneutic approach)	To describe the experience of living with advanced COPD and long-term oxygen therapy when living alone
Ek, K.#25	2008	Sweden	Interviews	COPD	Hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	8 patients	48-79	3M, 5F	Theory informed (phenomenological approach)	To describe the essential structure of the lived experience of living with severe COPD during the palliative

											phase of the disease
Ek, K.#26	2011	Sweden	Serial interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	4 couples (4 patients, 4 spouses)	67-74	4M, 4F	Theory informed (phenomenological-hermeneutic approach)	To examine couples' experiences of living together when one partner has advanced COPD
Ellison, L.#27	2012	UK	Interviews	COPD	Community	Convenience and purposive	14 patients	49-79	7M, 7F	Descriptive (constant comparison and framework approach)	To understand the mental health needs of people living with COPD

Fischer, M. J #31	2007	Netherlands	Interviews	COPD	Pulmonary rehabilitation (outpatient)	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	12 patients	34-77	8M, 4F	Theory informed (interpretative phenomenological analysis)	To examine patients' pretreatment beliefs and goals regarding pulmonary rehabilitation
Fraser, D. D.#34	2006	USA	Interviews	COPD	Community	Purposive	10 patients	59-86	5M, 5F	Theory informed (phenomenological-hermeneutic approach)	To understand how COPD affects the lives of patients.
Gale, N. K.#36	2015	UK	Interviews	COPD	Community	Purposive	20 patients, 4 carers, 15 HCPs	Patients = 52-83. Carers not stated.	Patients = M = 8, F = 12. Carers and HCPs not stated.	Theory building (grounded theory)	To explore experiences of domiciliary non-invasive ventilation in COPD, to

								HCPs = 26-54			understand decision-making processes and improve future palliative care
Goodridge, D #41	2011	Canada	Interviews	COPD and bronchiectasis	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	7 patients	57-88	2M, 5F	Descriptive (interpretive description)	To explore the impact of living with advanced chronic respiratory illness in a rural area
Gullick, J #45	2008	Australia	Serial Interviews	COPD	Community	Convenience	15 patients, 14 family members	Patients = 55-77. Family members = 29-82	Patients = 9M, 6F. Family members not stated	Theory informed (phenomenological-hermeneutic approach)	To explore the experience of the person who lives

											within a body with COPD
Guo, S.E. #161	2014	Canada	Interviews and focus groups	COPD	Pulmonary rehabilitation (outpatient)	Patients screened against eligibility criteria. Those eligible who agreed to participate included. HCPs sampled purposively.	25 patients, 7 HCPs	Patients = 53-84. HCPs not stated.	Patients = 13M, 12F. HCPs not stated.	Descriptive (thematic analysis)	To describe the experiences of patients who are in a pulmonary rehabilitation (PR) programme and explore the perceptions of patients and HCPs about what improves effective PR

Appendix C

Gysels #48	2008	UK	Interviews and participant observation	COPD	Community and outpatient clinics	Purposive	18 patients	52-78	7M, 11F	Theory building (grounded theory)	To explore the experience of breathlessness in patients with COPD through patients' accounts of their interactions with services
Gysels #178	2010	UK	Interviews and participant observation	COPD	Community and outpatient clinics	Purposive	18 patients	Median 69/70	7M, 11F	Descriptive (narrative analysis)	To investigate how the experience of breathlessness in COPD influences patients' attitudes toward the

											end of life and their quality of life
Habraken #49	2008	Netherlands	Interviews	COPD	Outpatient clinics and respiratory centre	Purposive	11 patients	61-83	8M, 3F	Descriptive (thematic analysis)	To gain insight into why patients with end-stage COPD tend not to express a wish for help
Halding #50	2012	Norway	Serial interviews	COPD	Pulmonary rehabilitation (outpatient)	Purposive (maximum variation)	18 patients	52-81	13M, 5F	Descriptive (thematic analysis)	To explore the experience of patients with COPD in terms of their transitions in health during and after

											pulmonary rehabilitation
Hall #53	2010	Canada	Interviews	COPD	Acute hospital	Patients screened against eligibility criteria.	6 patients	Mean age 69	4M, 2F	Descriptive (exploratory descriptive)	To describe the perceptions of people living with severe COPD with respect to the end of life
Harris #55	2008	UK	Interviews	COPD	Community	Purposive	16 patients	Mean age 66.8	12M, 4F	Theory building (grounded theory)	To assess patients' concerns about accepting an offer of pulmonary rehabilitation

Hasson #58	2009	Canada	Interviews	COPD	Community	Care-givers screened against eligibility criteria. Those eligible who agreed to participate included.	9 care-givers	25-65	2M, 7F	Descriptive (content analysis)	To explore the experiences of palliative care that bereaved carers had while providing care to a dying loved one with COPD
Hasson #57	2008	UK	Interviews	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	13 patients	45-65	10M, 3F	Descriptive (content analysis)	To explore the potential for palliative care among people living with COPD

Hayle #59	2013	UK	Interviews	COPD	Specialist palliative care	Participants recruited against eligibility criteria. Those eligible who agreed to participate included.	8 patients	63-77	5M, 3F	Theory informed (phenomenological-hermeneutic approach)	To evaluate the experiences of patients with COPD who accessed palliative care
Hellem #61	2012	Norway	Interviews and focus groups	COPD	Pulmonary rehabilitation (outpatient)	Purposive	11 patients	53-68	3M, 8F	Theory informed (phenomenological approach)	To elucidate how patients with COPD who successfully maintain a long term exercise programme understand concordance with

											maintenance exercise and see potential solutions
Hogg, L. #62	2012	UK	Focus groups	COPD	Pulmonary rehabilitation (outpatient)	Purposive	16 patients	Patients divided into two groups. Group 1 = 71 (mean). Group 2 = 67 (mean)	9M, 7F	Theory building (grounded theory)	To understand the views and perceptions of patients with COPD regarding maintaining an active lifestyle following a course of pulmonary rehabilitation

Hopley, #63	2009	New Zealand	Interviews	COPD	Community	Purposive	9 patients	50-80	Not stated	Descriptive (general inductive approach)	To understand the challenges people living with COPD in rural areas face in accessing specialist health care services
Hynes, G #65	2012	Ireland	Interviews	COPD	Community	Patients identified care-givers. All invited to participate. Owing to small numbers, further recruitment in patient support groups and	11 care-givers	20-79	2M, 9F	Descriptive (thematic analysis)	To explore the experiences of informal caregivers providing care in the home to a family member with COPD

						advertisements in media.					
Jackson, #66	2012	Canada	Case study	COPD	Community	Convenience	4 patients	57-81	3F, 1M	Descriptive (thematic analysis)	To understand older patients with COPD experiences of their journeys through the health system
Jonsdottir #71	2007	Iceland	Serial interviews	COPD	Community	Convenience	7 patients	40-65	7F	Theory informed (interpretive phenomenology)	To explore the experience of women with advanced COPD of repeatedly relapsing to smoking

Appendix C

Kanervisto #72	2007	Finland	Interviews	COPD	Hospital	Participants selected by clinicians	5 patients, 4 spouses	Not stated	Patients = 3M, 2F. Spouses = 3F, 1M	Descriptive (deductive content analysis)	To describe the coping of the families of people with advanced COPD
Kauffman, #73	2014	USA	Focus groups	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	18 patients	49-75	12M, 6F	Descriptive (thematic analysis)	To describe the subjective sleep complaints of patients with COPD along with their attributions as to the cause of these symptoms and their treatment

											preferences for insomnia
Keating #74	2011	Australia	Interviews	COPD	Pulmonary rehabilitation (outpatient)	Patients screened against eligibility criteria. Those eligible who agreed to participate included.	37 patients	53-86	18M, 19F	Descriptive (thematic analysis)	To understand what prevents people with COPD from attending and completing pulmonary rehabilitation
Kerr #75	2010	UK	Interviews	COPD	Pulmonary rehabilitation (outpatient)	All patients attending pulmonary rehabilitation invited to participate. Those who agreed to	9 patients	62-80	6M, 3F	Theory building (grounded theory)	To understand from an occupational perspective how patients live with COPD

						participate accepted on study.					
Kvangarsnes #77	2013	Norway	Interviews	COPD	Acute hospital	Purposive	10 patients	45-85	5M, 5F	Descriptive (narrative analysis)	To explore patient perceptions of COPD exacerbation and experiences of their relations with health personnel during care and treatment
Lewis #79	2014	UK	Interviews	COPD	Pulmonary rehabilitation (community)	Convenience	25 patients	42-90	Not stated	Theory informed (interpretative phenomenological approach)	To explore the lived experience of COPD patients

											referred to pulmonary rehabilitation programmes prior to participation
Lewis #80	2010	UK	Focus group	COPD	Community	Purposive	6 patients	61-83	1M, 5F	Descriptive (thematic analysis)	To explore the attitudes of people with COPD to exercise and reasons for non-concordance with exercise maintenance post pulmonary rehabilitation

Lindgren #81	2014	Norway	Interviews	COPD	Community	Purposive	8 patients	60-74	3M, 5F	Theory informed (phenomenological-hermeneutic approach)	To illuminate patients' lived experiences of being diagnosed with COPD
Lindqvist #82	2013	Sweden	Serial interviews	COPD	Community	Purposive	21 spouses	53-84	21F	Theory informed (phenomenography)	To describe the conceptions of daily life in women living with a man suffering from COPD in different stages
Lindqvist #83	2010	Sweden	Serial interviews	COPD	Acute hospital	Open sampling initially then theoretical sampling in	23 patients	52-82	10M, 13F	Theory building (grounded theory)	To illuminate the main concern of patients with

						order to saturate emerging categories					COPD and how they handle their everyday life
Lindqvist #159	2013	Sweden	Serial interviews	COPD	Community	Purposive	19 spouses	55-85	19M	Theory informed (phenomenography)	To describe the conceptions of daily life in men living with a woman suffering from COPD in different stages
Lomborg, K.#86	2008	Denmark	Participant observation and interviews	COPD	Acute hospital	Patients screened against eligibility criteria and consecutively included.	12 patients, 4 HCPs	Patients = >30. HCPs not stated	Not stated	Theory building (grounded theory)	To explore COPD patients' and nurses' expectations, goals and

						Further sampling selective and theoretical.					approaches to assisted personal body care.
Lundh, L. #87	2012	Sweden	Interviews	COPD	Community	Participants screened against eligibility criteria and recruited consecutively.	14 patients	47-83	7M, 7F	Theory building (grounded theory)	To investigate why some patients with COPD have difficulty quitting smoking and to develop a theoretical model that describes their perspectives on these difficulties.

Luz, E. L #88	2013	Portugal	Interviews	COPD	Community	Convenience and theoretical sampling	22 patients	26-72	17M, 5F	Theory building (grounded theory)	To understand how people live with COPD
MacPherson, A. #89	2013	UK	Interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who agreed to participate included.	10 patients	58-86	9M, 1F	Theory building (grounded theory)	To explore the views of people with severe COPD about advance care planning
Mathar, H. #90	2015	Denmark	Interviews	COPD	Community	Purposive	6 patients	67-83	3M, 3F	Descriptive (text condensation method)	To understand the experiences and preferences of COPD

											patients in relation to discharge from hospital with televideo consultations
McMillan Boyles, C #93	2011	Canada	Interviews	COPD	Community	Purposive	15 patients	>50	Not stated	Descriptive (narrative analysis)	To develop an understanding of the meaning of disability for individuals living with COPD
Meis, J #94	2014	Netherlands	Interviews and focus groups	COPD	Pulmonary rehabilitation (inpatient)	Patients screened against eligibility criteria. Those eligible who agreed to	13 patients, 14 HCPs	Patients = 54 -78. HCPs = 24-52	Patients = 8M, 5F. HCPs = 3M, 11F	Theory informed (descriptive phenomenological approach)	To assess COPD patients' experiences during an inpatient

						participate included. HCPs randomly invited to participate.					pulmonary rehabilitation program
Moore, #96	2012	UK	Interviews	COPD	Pulmonary rehabilitation (community)	Random sampling of three groups meeting different eligibility criteria. Patients recruited until data saturation had been achieved.	24 patients	47-84	14M, 10F	Descriptive (framework approach)	To assess the obstacles to participation in pulmonary rehabilitation among COPD patients in a community based pulmonary rehabilitation programme and associated general practices

Mousing #97	2012	Denmark	Interviews and focus groups	COPD	Community	Interviews: participants screened against eligibility criteria and then consecutively recruited until recruitment target met. Focus group: all participants attending patient education sessions invited to participate.	11 patients	51-75	3M, 8F	Descriptive (thematic analysis)	To explore how group patient education influences the self-care of patients with COPD
Nykvist #100	2014	Sweden	Interviews	COPD	Community	Patients screened against eligibility criteria. Those	6 patients	Not stated	6F	Descriptive (narrative analysis)	To describe how a group of smoking women with

						eligible who agreed to participate included.					COPD experienced their everyday life and their relationship to smoking
Panos #107	2013	USA	Focus groups	COPD	Community	Participants were selected by systematic sampling against eligibility criteria and consecutively recruited until recruitment target met.	42 patients	48-88	42M	Descriptive (thematic analysis)	To determine the perceptions of veterans with COPD about their disease, its effects on their lives and their interactions with the Veterans' Healthcare

											Administration
Philip #108	2012	Australia	Interviews and focus groups	COPD	Acute hospital	Patients screened against eligibility criteria. Patients recruited consecutively until data saturation had been achieved. HCPs sampled purposively.	10 patients, 31 HCPs	Patients = 55-76. HCPs = 23-61	Patients = 6M, 4F. HCPs not stated	Descriptive (thematic analysis)	To explore the views of patients with COPD and HCPs focusing upon information needs and treatment preferences
Philip #109	2014	Australia	Interviews	COPD	Community	Care-givers identified by patient or physician. Those who agreed to participate	19 care-givers	28-83	9M, 10F	Descriptive (thematic analysis)	To understand the experiences and needs of family carers

						included in study.					of people with severe COPD
Pinnock #110	2011	UK	Serial interviews and focus groups	COPD	Community	Purposive	21 patients, 13 care-givers, 18 HCPs	Patients = 50-83. Care-givers and HCPs not stated.	Patients = 14M, 7F. Care-givers and HCPs not stated.	Descriptive (thematic narrative analysis)	To understand the perspectives of patients with severe COPD as their illness progresses, and of their informal and professional carers
Reinke #112	2008	USA	Serial interviews	COPD or cancer	Community	HCPs: Drs screened against eligibility criteria,	55 patients, 56 HCPs,	Patients = 67.3 (mean), relatives	Patients = 22M, 33F. Relatives = 18M, 18F.	Theory building (grounded theory)	To examine participants' perspectives on the

						classified into specialty categories and then randomly selected. Nurses identified by patients or drs. Patients: identified by HCPs against eligibility criteria. Relatives: identified by patients.	36 relatives	= 60.3 (mean), HCPs = 47 (mean)	HCPs = 22M, 34F		experiences of key transitions in the context of living with advanced COPD or cancer
Schroedl #117	2014	USA	Interviews	COPD	Acute hospital	Purposive	20 patients	52-83	9M, 11F	Descriptive (thematic analysis)	To understand the unmet health care needs among

											patients to help determine which aspects of palliative care are most beneficial
Seamark #119	2012	UK	Interviews	COPD	Community	Patients screened against eligibility criteria. All eligible patient invited to participate.	16 patients	58-83	12M, 4F	Descriptive (content analysis and constant comparison)	To examine whether an admission to hospital for an exacerbation of COPD is an opportunity for advance care planning (ACP) and to understand, from a pt perspective,

											the optimum circumstance for ACP
Sheridan #121	2011	New Zealand	Interviews	COPD	Community	Pragmatic (8 patients initially interviewed, further participants from a certain ethnic group recruited in order to explore theme further)	29 patients	50-89	15M, 14F	Descriptive (thematic analysis)	To explore how patients with COPD experience helplessness
Shipman #122	2009	UK	Interviews	COPD	Community	Patients screened against eligibility criteria. Those eligible who agreed to participate	16 patients	54-86	9M, 7F	Descriptive (framework approach)	To explore factors that influence the use of general practice services by people with

						included. 4 patients excluded post interview as did not meet eligibility criteria.					advanced COPD
Shum #123	2014	Canada	Interviews and focus groups	COPD	Community	Convenience	30 patients, 16 care-givers	Not stated	Not stated	Descriptive (thematic analysis)	To investigate how patients with COPD from new immigrant communities received and utilised information about their condition and its management

Simpson #125	2010	Canada	Interviews	COPD	Community	Purposive	14 care-givers	46-89	3M, 11F	Descriptive (interpretive description)	To understand the extent and nature of 'burden' experienced by informal care-givers in advanced COPD
Simpson #156	2012	Canada	Serial dialogue	COPD	Community	Participants screened against eligibility criteria.	8 patients, 8 care-givers	Patients = 53-76. Care-givers not stated.	Patients = 4M, 4F. Care-givers = 3M, 5F	Descriptive (interpretive description)	To understand what is required for meaningful and effective advance care planning in the context of

											advanced COPD
Small #191	2012	UK	Interviews and focus groups	COPD	Community	Patients screened against eligibility criteria then randomly selected and invited to participate. Those eligible who agreed to participate included. Staff recruited from primary and secondary care with range of staff characteristically involved in COPD	21 patients, 39 HCPs	Patients = 57-78. HCPs = 25-63	Split site study. Only one set of patients/HCPs reported on. Patients = 7M, 6F. HCPs = 6M = 6; F = 14	Descriptive (thematic analysis)	To report patients, family members and HCPs' experiences of COPD

						care (drs and nurses)					
Sorensen #128	2013	Denmark	Participant observation, interviews	COPD	Acute hospital	Participants screened against eligibility criteria. Those eligible who agreed to participate included. Recruitment continued until conceptual density achieved.	21 patients (obs) 11 patients (ints)	43-81	11M, 10 F	Theory building (grounded theory)	To present a theoretical account of the pattern of behaviour in patients with acute respiratory failure owing to COPD while undergoing non-invasive ventilation
Sossai #129	2011	Australia	Interviews	COPD	Community	Purposive	8 patients	50-85	5M, 3F	Descriptive (thematic analysis)	To explore the experience of living with COPD

Spence #130	2008	UK	Interviews	COPD	Community	Purposive	7 care-givers	55-65	1M, 6F	Descriptive (content analysis similar to constant comparison)	To explore the specific care needs of informal care-givers of patients with advanced COPD
Strang #133	2013	Sweden	Interviews	COPD	Community	Purposive (maximum variation)	31 patients	48-85	15M, 16F	Descriptive (thematic content analysis)	To explore perceptions of anxiety and the alleviation strategies that are adopted by patients with COPD
Thorpe #137	2014	Australia	Interviews	COPD	Hospital	Purposive	28 patients	Mean age 71.86	22M, 6F	Descriptive (content analysis)	To explore the barriers to and enablers of

											participation in physical activity following hospitalisation for COPD
Torheim #138	2010	Norway	Interviews and focus groups	COPD	Acute hospital	Purposive	5 patients, 8 nurses	Patients = 45-78. Nurses not stated.	Patients = 2M, 3F. Nurses not stated.	Theory informed (phenomenological approach)	To explore the experiences of mask treatment in patients with acute exacerbations of COPD
Torheim #139	2014	Norway	Interviews	COPD	Acute hospital	Strategic (recruited to meet eligibility criteria)	10 patients	45-85	5M, 5F	Theory informed (phenomenological approach: meaning condensation)	To gain insight how patients with advanced COPD experience

											care in the acute phase (specifically in the intensive care unit)
Willgoss #145	2012	UK	Interviews	COPD	Community	Purposive (nonprobabilistic)	14 patients	Mean age 62.3	5M, 9F	Descriptive (thematic network analysis)	To elicit and describe the first-hand experiences of anxiety in community patients with stable COPD
Williams #147	2010	UK	Interviews	COPD	Pulmonary rehabilitation (outpatient)	Participants screened against eligibility criteria. Those eligible who agreed to	9 patients	54-84	6M, 3F	Theory building (grounded theory)	To explore how pulmonary rehabilitation affects the experience of activity and

						participate included.					breathlessness of people with COPD
Williams #146	2007	UK	Interviews	COPD	Community	Purposive	6 patients	64-83	4M, 2F	Descriptive (thematic analysis)	To investigate what is most important to people living with COPD
Williams #148	2011	UK	Interviews	COPD	Community	Purposive and theoretical sampling	18 patients	54-84	12M, 6F	Theory building (grounded theory)	To understand how people with COPD experience activity
Wilson #150	2008	Canada	Serial interviews	COPD	Community	Participants screened against eligibility criteria. Those eligible who	12 patients	Not stated	Not stated	Descriptive (constant comparison approach)	To determine the care needs of seniors living at home with

						agreed to participate included.					advanced COPD
Wilson #152	2007	UK	Focus groups	COPD	Community	Purposive	32 patients, 8 HCPs	Patients = 56-82. HCPs not stated.	Patients = 25M, 7F. HCPs not stated	Theory building (grounded theory)	To ascertain what should be included in the educational component of pulmonary rehabilitation
Wodsku #153	2014	Denmark	Interviews and focus groups	COPD	Community	Purposive	34 patients, 8 relatives	Patients = 48-87; Relatives = not stated	Patients = 15M, 9F. Relatives = 3M, 5F	Descriptive (content analysis)	To examine the experiences of COPD patients and their relatives of integrated care

Appendix D Study protocol for comparative analysis (chapter 3)

Study Protocol

What is the Burden of Treatment in Chronic Obstructive Pulmonary Disease (COPD) and Lung Cancer and how is it experienced by patients and their informal caregivers?

The 'BEACON Lung' study "**B**urden of Tr**EA**tment in **C**hronic **O**bstructive Pulmonary Disease and Lung Ca**N**cer"

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Funder	Health Foundation	
Funding Reference Number	HS119	
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Any Other Number		
Version Number and date	4	22/12/2017
Key protocol contributors	Professor Carl May Professor Alison Richardson	C.R.May@soton.ac.uk Alison.Richardson@soton.ac.uk

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the study sponsor

Signature

Name

Position Date

Chief Investigator

Name

Position Date

Background to study

Burden of illness and its consequent symptoms have been well-defined (Sav et al, 2013a). However, the burden associated with treating and managing that illness, referred to here as "burden of treatment", is an emerging concept which is yet to be fully defined (Demain et al, 2015). Treatment burden is not the unavoidable workload that illness inevitably confers on patients and their informal caregivers (Corbin and Strauss, 1985) but a potentially *modifiable* workload which treatment for that illness may bring (May et al, 2014). This is both the practical workload *and* the physical, cognitive, behavioural and psychosocial impact of treatments on the patient and their caregiver (Demain et al, 2015; Sav et al, 2013b; Gallacher et al, 2013b). The literature also discusses the concept of "capacity", defined as the resources and limitations that affect patients' capability to carry out the work of chronic illness (Shippee et al, 2012). Capacity may be viewed at an individual level (i.e. the patient) or collective level (i.e. the patients' social network) (Vassilev et al, 2015). Both individual and collective capacity may be affected by a variety of multi-dimensional factors, from socio-economic factors such as ethnicity and poverty, to the social skill necessary to ensure the engagement of stakeholders (May et al, 2014; Shippee et al, 2012; Gallacher et al, 2011, 2013a; Sav et al, 2013b; Demain et al, 2015). A workload that exceeds capacity, might, in some cases, be the primary driver of disruption to care, self-care and outcomes for patients (Shippee et al, 2012; May et al, 2014). Neither workload nor capacity are static but are likely to fluctuate over time as illness progresses, functional capacity declines and patients' social networks change (Shippee et al, 2012; May et al, 2014) or, indeed, as the patient is able to accept, adapt and normalise their condition into their daily life (Sav et al, 2013b; Demain et al, 2015).

Minimally disruptive medicine

Medical training directs doctors to take a reductively biological view of the patient, as Good (1994) in his seminal set of lectures on medical knowledge and practice emphasises: "they don't want to hear the story of the patient. They want to hear the edited version" (p.78). Thus, doctors tend to ask patients "what is the matter with you" rather than "what matters to you" (De Longh et al, 2015). The literature (May et al, 2009, 2014; Eton et al, 2012, 2015; Gallacher et al, 2013a) emphasises the importance of adequately equipping clinicians with tools to detect burden of treatment, and training to ameliorate burden in order to provide "minimally disruptive medicine" (May et al, 2009). This is an approach to health-care that takes into account patient priorities, multi-morbidity and the impact of treatment workload on the patient and carer (May et al, 2009).

I have chosen to look at Burden of Treatment in respiratory disease because of my background as a respiratory nurse specialist. COPD and lung cancer are the most common cause of respiratory-related mortality in the United Kingdom (UK), excluding pneumonia (British Thoracic Society, 2006). Both diseases are commonly caused by smoking, thus patients may have both or either disease (Raviv et al, 2011) which can be accompanied by a 'self-inflicted' stigma (Chambers et al, 2012; Berger et al, 2011). Patients are likely to have in common the potentially debilitating symptom of breathlessness (Bausewein et al, 2010; Gysels & Higginson, 2011). There is a growing body of literature, especially in palliative care, comparing the two diseases (Weingaertner et al, 2014; Bausewein et al, 2010; Gore, 2000).

COPD typically has a protracted trajectory of periods of long-term limitation, punctuated by recurrent episodes of respiratory worsening known as "exacerbations" (Pinnock et al, 2011). Prognosis is uncertain – patients with mild to moderate COPD may live for many years after diagnosis whereas other patients with severe COPD may die shortly after diagnosis (GOLD, 2017). Conversely, lung cancer typically has a rapid trajectory of steady progression with a clear terminal phase (Murray, 2005). The prognosis for lung cancer is poor; only 1 in 10 patients live for more than 5 years after diagnosis (The National Institute for Health and Care Excellence (NICE), 2011). The main treatments for the management of lung cancer in England are hospital-based. Patients attend specialist units in hospitals, usually as outpatients, to receive radiotherapy or systemic anti-cancer treatment. Alternatively, they may undergo surgical treatment as an inpatient in a hospital (NICE, 2011). In contrast, the emphasis on treatment for COPD tends to be on "self-management" (management of the condition by patients and informal caregivers in the home) (NICE, 2010). Despite the similarities of stigma, symptoms and risk factors described above, burden of treatment is likely, therefore, to be experienced very differently by patients living with these two common respiratory conditions.

Furthermore, the research evidence suggests that there is greater healthcare support, especially palliative care, available for patients with cancer than patients with chronic long-term conditions such as COPD (Gore, 2000; Elkington, 2005). Thus, patients with COPD may experience treatment burden differently to patients with lung cancer because of the support processes available to patients living with each condition.

Rationale:

The literature on burden of treatment consists of empirically grounded theoretical models (May et al 2009, 2014; Shippee et al, 2012), systematic reviews (Gallacher et al, 2013a and b; Eton et al 2013, Sav et al, 2013b, Demain et al, 2015; Jani et al, 2013, May et al, 2016; Boehmer et al, 2016) and secondary data analysis (Gallacher, 2011). However, there is a paucity of primary empirical qualitative research explicitly exploring the experiences of treatment burden in patients. Primary empirical qualitative research on burden of treatment includes research in Australia, France and America on a range of chronic conditions (Fried and Bradley, 2013; Sav et al, 2013a; Eton et al, 2012; Tran et al, 2012). It also includes end-stage renal disease in the UK (Karamandiou et al, 2013; Johnston and Noble, 2012) and various life-limiting, non-malignant conditions (Jordan et al, 2006; Baylor et al, 2007; George et al, 2010) in the UK and America. There has been little primary qualitative research carried out on burden of treatment in COPD, certainly none in the UK. Likewise, there has been no primary qualitative research on patients' experiences of treatment burden in lung cancer in the UK or elsewhere. This gap in evidence demonstrates a need for research into patient experiences of treatment in lung cancer and COPD in order to identify and characterise burden.

Study aims and objectives:

The aim of the study is to identify, characterise and explain common and specific features in the experiences of treatment burden with recourse to patients living with either lung cancer or COPD.

- To identify, characterise and explain what treatment burden is to patients and to clinicians (Study phases one, two and three)
- To identify and characterise modifiable areas of burden, either condition specific or applicable to both conditions (Study phases one, two and three)
- To identify, characterise and explain how treatment burden is manifest in outpatient settings (Study phases two and three)
- To identify if and how clinicians assess and take treatment burden into account in their interactions with patients and care-givers (Study phase two)
- To build an empirically derived middle range theory to explain common and specific features of burden of treatment with recourse to COPD and lung cancer (Study phase three, building on study phases one and two)
- To use the empirically derived middle range theory to identify targets for supportive interventions which might be introduced into routine clinical practice (Study phase three, building on study phases one and two)

I aim to identify potentially modifiable areas of treatment burden for patients living with COPD or lung cancer or their caregivers where supportive interventions might be introduced into routine clinical practice. Further research will be required to develop supportive interventions for the areas identified.

Study design

Qualitative

I have chosen to use qualitative methods in order to address the study aim and objectives. Qualitative research is intended to aid understanding of “social phenomena in natural…settings, giving due emphasis to the meanings, experiences and views of all the participants” (Mays & Pope, 1995, p.43). Qualitative research may also reveal links between concepts and behaviours and aid the development or refinement of theory (Bradley, 2007).

I am using Bradley et al’s three steps of “taxonomy, themes and theory” (2007) which aim to give health service researchers a framework through which to structure qualitative research which is undertaken with the express aim of developing theory.

Through a systematic review and meta-synthesis of the qualitative literature, I will build a taxonomy that identifies and characterises common and specific features of burden of treatment with recourse to COPD and lung cancer (objectives (1) and (2)). The first stages of data collection for the empirical study (which this protocol describes), will be guided by the taxonomy (objectives (1), (2), (3) and (4)). I will revisit the taxonomy following empirical data collection, to explore and develop common and specific features of burden of treatment. Thus, both the qualitative meta-synthesis and the empirical study will iteratively contribute to theory-building (objectives (5) and (6)).

Taxonomy

As the first step in my sequential, qualitative research, I have undertaken conceptual modelling work, with colleagues, to develop a coding framework underpinned by robust, empirically derived, middle-range theories including burden of treatment theory (May et al, 2014), the cumulative complexity model (Shippee, 2012) and status passage theory (Glaser & Strauss, 1971). I have applied this coding framework to a qualitative meta-synthesis of literature on patient and caregiver experiences of interactions with health and social care. I aim to develop a **taxonomy** of burden of treatment for patients and their caregivers living with COPD and lung cancer from this qualitative meta-synthesis. A taxonomy allows the description of a set of discrete domains and dimensions, enabling the researcher to dissect complex concepts into their fundamental components. It is an important first step in comparing multifaceted, complex phenomena (Bradley et al, 2007). I will use the taxonomy generated from the qualitative meta-synthesis as a ‘building block’ for the empirical study described in this protocol. Thus, I will compare components identified in the taxonomy with components identified in the empirical study, aiming to identify unifying and recurrent components across the taxonomy and empirical study.

I have used preliminary findings from the qualitative meta-synthesis to inform the interview schedule for the qualitative interviews in the empirical study. This will be an ongoing process as the taxonomy develops.

Themes

The work set out in this protocol describes the second step in my research: an empirical study using multiple qualitative methods, drawing on ethnographic approaches (Wolcott, 1997). I will use non-participant observation of outpatient clinics and semi-structured interviews with patients and clinicians. I will carry out these two qualitative data collection methods in parallel. I have chosen these two qualitative methods as a number of studies have shown differences between how patients behave in the clinical encounter and how they articulate their thoughts and feelings in a different context (Stimson and Webb, 1975; Strong, 1979). Strong points out in his seminal study, ‘The Ceremonial Order of the Clinic’, “there is no necessary relationship between what patients do in medical consultation and what they say they do in another context" (Strong, 1979, p. 225). This is not a necessarily intentional difference, people attend to the things that concern them most and therefore interview data generally lacks routine daily details (Strong, 1979). Murphy (2001) has applied this to healthcare professionals where, through the realities of daily work, they stop noticing the mundane elements of their practice and the constraints that the setting may impose on their practice. Finally, Hammersley more generally describes observation and interviewing as complementary techniques:

> To rely on what people *say* about what they believe and do without also observing what they do, is to neglect the relationship between attitudes and behaviour; just as to rely on observation without also talking with people in order to understand their perspectives is to risk misinterpreting their actions.
>
> (1992, pp11-12)

In order to address fully my research aim, therefore, it is important to have complementary methods of data collection: observation focussing on conversation, interaction and behaviour in a specific context and interviews focussing on the presentation of participants' thoughts and feelings in an alternative context.

I will use the coding framework described above to integrate the taxonomy developed from the qualitative meta-synthesis with data from my empirical study in order to generate **themes**. Bradley et al (2007) define themes as "recurrent unifying…statements about the subject of inquiry [which] characterise experiences of individual participants by general insights from the whole of the data" (p.1761).

Theory

Finally, I will aim to integrate the themes generated from the data collected in the qualitative meta-synthesis and the empirical study into a robust, empirically derived middle range **theory** to explain burden of treatment in lung cancer and COPD. Theory is often seen as arcane and abstract, with little applicability to 'real-life' (Polit & Beck, 2016; Davidoff, 2015). Consequently, the development of empirically grounded theory may be an overlooked step; yet, theory may be very useful for health services research (Davidoff, 2015; May 2016). Theory can be developed through linking sets of logically interconnected propositions from which uniformities may be identified to explain the phenomena of interest (Merton, 1949; Bradley et al, 2007). Middle-range theory is applicable to discrete conceptual ranges, sitting between frequently generated minor working hypotheses and all-encompassing efforts to explain systematically the observed uniformities of society (Merton, 1949). Middle range theory may be particularly helpful, therefore, in generalising learning in health services improvement so that interventions can be replicated in different contexts (Davidoff, 2015). The intention behind the generation of middle range theory in my research is to find common and specific features of burden of treatment, which are modifiable, and to identify targets for supportive interventions, which might be introduced into routine clinical practice

Methods of data collection

As discussed above, there will be two methods of data collection in this empirical study.

- Non participant observation of outpatient clinics (lung cancer or COPD)
- Semi-structured interviews of patients living with lung cancer or COPD and clinicians treating lung cancer or COPD

Non participant observation

Observation in qualitative research is the process of systematically watching, listening and making detailed records of people and events in order to investigate behaviours and interactions in natural settings (Mays & Pope, 1995; Murphy, 2001; Bloomer, 2012). The researcher acts as the “research instrument” by “entering the field”, describing, and analysing what he or she observes (Mays & Pope, 1995). Observation or participant observation is sometimes used as a synonym for ethnography (Denzin, 1978 cited in Lathlean, 1995). Ethnography is the description and interpretation of a group or culture (Fetterman, 1998; Polit & Beck, 2016). In an ethnography, the researcher immerses themselves in a group or culture, ‘getting inside’ the way in which the group or culture views the world (Hammersley, 1992; Fetterman, 1998). However, I have chosen to use *non-participant* observation, an ethnographic *approach* to data collection, rather than undertaking an ethnography (Wolcott, 1997). I am not studying a culture; I am aiming to observe and document behaviours, interactions and practice of individuals belonging to two particular groups (patients and health care professionals) in the specific context of the outpatient hospital setting. Non-participant observation allows the researcher to observe independently, being able to step in and out of the group under observation without becoming a member (Bloomer, 2012). The involvement of the researcher in observation sits on a continuum, ranging from non-participation (complete observer) to complete participation (full participant) observation (Gold 1958; Spradley, 1980; Adler & Adler, 1987). My identity as a nurse means that I am, to an extent, a member of one of the groups (health care professionals). This 'insider' status may be an advantage: it allows me to access participants and to understand the essentials of what is going on (Lathlean, 1995; Allen, 2004). However, 'insider' status may also be a disadvantage. Although I have chosen to use non-participant observation, I need to be aware that my 'insider' status and previous experience may lead to assumptions where, because of my familiarity with the clinical encounter, I take things for granted, missing salient detail obvious to a complete outsider (Lathlean, 1995; Bonner & Tolhurst, 2002). Gold's continuum of complete participant to complete observer discussed above has been criticised as having limited value when understanding the researcher's role in fieldwork, as he does not consider how this relates to the researcher's positioning as an insider/outsider (Allen, 2004). It is important for me to be aware that my participant/non participant, insider/outsider status will fluctuate throughout the research process, changing with different groups and different individuals (Allen, 2004). It will be important, therefore, for me to think reflexively on my practice as a clinician-researcher and my insider/outsider identity. I will discuss this concept of reflexivity further below.

I will undertake-non participant observation of outpatient consultations between health care professionals and patients with lung cancer and/or COPD. For patients with lung cancer, I will observe consultations with patients being cared for by an oncologist and having various forms of treatment. For COPD patients, I will focus on patients who have been referred to specialist care because of complex needs. Consultations will be audio-recorded because I want to capture conversations verbatim. Consultations will be transcribed verbatim apart from where the participant is named or there is any other potentially participant identifiable information. I will transcribe consultations myself rather than sending these to a University transcriber, as I believe this will be a useful part of the analytical process. I will also take written field notes using a structured data collection form. I will record details of patients' age, sex, co-morbidities, stage of disease (COPD or lung cancer), employment status, social network and treatment/management plans. I will take this information from patients' medical records once formal written consent has been received so that I am sure that patients understand that I will be accessing their medical notes and for what purpose. Where informal caregivers attend with the patient, I will record details of their sex and relationship to the patient. I will record clinicians' age, sex, specialty, profession and length of time in practice.

Entering the field

Appendix D

Once I have received the necessary ethical approvals and honorary contracts for each site, I will "enter the field" (Mays & Pope, 1995). This will be a period of approximately 4-6 weeks where I will undertake a number of activities before I begin formal data collection. These may include, but will not be limited to, such activities as attending outpatient clinics, clinical meetings and meeting clinical staff. During this time, I will be clear with the clinical team about my study aim and methods. "Entering the field" allows me to familiarise myself with the setting and the people in the setting to get used to my presence (Murphy, 2001). It allows me to build trust and rapport with the clinical team whom I will be observing (Murphy & Dingwall, 2007). Finally, in order to gain access to the relevant outpatient clinics, not being a member of the NHS Trusts concerned and not known to the clinicians, I have had to be completely clear with the clinical team about the purpose of my research. As they are not 'blinded' to the purposes of the study, it may be that their behaviour in clinic is changed. Evidence demonstrates the so-called "Hawthorne effect" where the presence of the researcher affects the research subjects and setting in such a way to change behaviour (Pope & Mays, 1995). However, evidence also demonstrates that it is possible to counter the "Hawthorne effect" simply by being present for a prolonged period of time (Goffman, 2014). I believe that clinicians are so used to having people present in their clinics (they often have junior staff or students), that they will simply accept my presence after a while and interact with patients as they would normally.

Interviews

Interviews are the most common method of data collection in qualitative research and have a long history: Beatrice Webb in the 19th century described interviews as "conversations with a purpose" (cited in Holloway, 2009). Holloway (2009) suggests that interviews are a direct conduit to the reality of human experience; that, through interviewing, the researcher discovers how participants feel, perceive or think. However, Dingwall (1997) considers the interview more critically, suggesting it is an "artefact", created by "the self-presentation of the respondent and whatever interactional cues have been given off by the interviewer about the acceptability or otherwise of what is being interviewed" (p.59). Holstein & Gubrium (1997) agree arguing, "both parties to the interview are necessarily and ineluctably active" (p.114). Thus, it will be important for me to consider the interview as an encounter in a specific social context and to be aware that access to participant experience is mediated by this context. As with the non-participant observation method, therefore, it will be important for me to consider my data collection, analysis and interpretation reflexively. I will consider this further below.

I will undertake semi-structured interviews of patients with COPD and/or lung cancer and the clinicians who are treating and managing them in secondary care. Interviews will be semi-structured and follow interview guides informed by literature on topic guide formulation (Kvale, 1996) and by the taxonomy building in the qualitative meta-synthesis. In keeping with the principles of qualitative research, the interview schedules are a guide to the types of the questions that I am likely to ask in the interview and not a list of questions, all of which I will ask, in a particular order. The development of the interview schedules is an iterative process. Thus, the interview schedules will be refined and extended as data emerges from the qualitative meta-synthesis or from the empirical data collection (observations or interviews). Interviews will be audio-recorded, and transcribed verbatim apart from where the participant is named or there is any other potentially participant identifiable information. . In the unlikely event that a participant declines to be recorded, I will take notes of the interview, which I will transcribe electronically after the interview. It is anticipated the interviews will last no longer than 60 minutes, however, it has been shown that participating in qualitative interviews can be an emotional and cathartic process, enabling participants to feel that they are helping others (Carter, 2008). It will be important, therefore, not to cut the interview prematurely short if a participant is finding it a useful process. I will make reflective notes at the end of each interview, documenting how the interview went and key issues raised by participants. Prior to each subsequent interview, I will review my field notes in order to ensure that I follow up any novel insights raised by a previous interview. Anonymised interview data transcription will be undertaken by a transcriber with experience of transcribing qualitative health-related studies and who has worked with the University of Southampton on previous occasions. As part of the consent process, I will ask participant if they wish to receive a copy of the interview transcript to review for accuracy. Participants will be given two weeks to suggest any corrections to their transcript, after which time it will be assumed they are happy with the transcript as it stands.

Reflexivity

Reflexivity has been defined as “attending systematically and continually to the context of knowledge construction – and, in particular, to the researcher’s effect on the collection, analysis and interpretation of data” (Polit & Beck, 2016, p.561). As argued above, the researcher *is* the research instrument in qualitative research and thus their values and social/professional identity may affect the research process (Polit & Beck, 2016; Allen, 2004). As such, it is important that reflexivity should be considered throughout the research process with clear decision making that the researcher (and others) can scrutinise (Hand, 2003). Manias and Street (2001) have demonstrated how reflexive practice obliged them to acknowledge their own ‘taken for granted’ values and to consider how these influenced their judgements of participants.

Appendix D

The most common strategy for maintaining reflexivity is to keep a journal in which to record and challenge the researcher's bias, views and experiences during data collection, analysis and interpretation (Polit & Beck, 2016). With my supervisors, I will consider my own assumptions and perspectives before commencing the research. I will keep the reflexive journal throughout the data collection, analysis and interpretation phases of the study.

Participant identification, recruitment and sampling

Inclusion criteria

Patients

Over the age of 18

Diagnosis of COPD or lung cancer

Receiving specialist treatment (COPD: specialist respiratory care; lung cancer: oncology)

Able to give informed consent

Able to speak English

Clinicians

Must be health care professionals (e.g. a doctor, nurse, health care assistant, physiotherapist or psychologist) currently providing specialist treatment and management for patients with a diagnosis of COPD or lung cancer in secondary care

Exclusion criteria

Patients

Under the age of 18

Unable to give informed consent

Without a diagnosis of COPD or lung cancer

Not receiving specialist care

Unable to speak English

Deemed unfit to participate in study by their health care professionals owing to medical condition (physical or psychological)

Clinicians

Not a health care professional currently providing specialist treatment and management for patients with a diagnosis of COPD or lung cancer

Working in primary care

Access to participants: recruitment strategies

Observations

Clinicians

As part of “entering the field” (described in section 5.1.1 above) I will meet with the members of the clinical team who will be attending outpatient clinics. I will take every opportunity to inform them about the study at a series of informal and formal meetings within their normal working hours. I will give each member of the clinical team a participant information sheet which they will have at least 24 hours to consider before l make arrangements to take informed written consent. Informed written consent from members of the clinical team will be in place prior to undertaking observations. As Murphy & Dingwall (2007) point out, negotiating consent is likely to be an ongoing process as relationships between the researcher and those observed develops. As rapport and trust develops between the researcher and those observed, it is likely that those being observed will be more open with the researcher and it is important to be as clear as possible about what is under direct observation as part of the process and conversations that are had with the researcher as a colleague. Finally, consent may be withdrawn if those observed feel the researcher has observed practice that deviates from what might be expected (Murphy & Dingwall, 2007). In order to ensure consent is explicit and ongoing, I will reaffirm consent verbally with clinicians every time I observe clinics.

Patients

A health care professional will review the clinic lists in order to ensure that all patients are suitable to participate in research (some patients may be deemed ineligible because of physical or psychological frailty or because they lack the mental capacity to participate). Once the clinic lists have been reviewed, the clinical team will post a study introduction letter on Trust headed notepaper, participant information sheet and copy of the consent form to eligible patients attending outpatient clinics. For lung cancer participants attending oncology clinics at **[name of Trust redacted]**, the clinical team may instead give the study introduction letter, participant information sheet and copy of the consent form to eligible patients attending outpatient clinics. Patients will still have at least 24 hours to consider the information Where letters are posted, I will work closely with the clinical and administrative teams at each site to ensure that letters are posted only to patients attending outpatient clinics at which I will be present. This is to avoid patients being burdened with information sheets for clinics which are then not observed. There will also be posters displayed in the waiting areas of the outpatient clinics, explaining that a researcher will be observing consultations. Patients living with respiratory disease have reviewed the participant information sheets and posters to ensure that the information given is appropriate and intelligible.

Patients will have the opportunity to contact me prior to the outpatient clinic if they wish. If patients contact me to discuss the study prior to their clinic appointment and are happy to participate, I will take formal written consent over the telephone and ask them to bring their consent form with them to their clinic appointment. However, this will not be a condition of participation in the study. Once the patient has arrived at clinic, a member of the clinic team will ask eligible patients for consent for me to approach them to discuss the study. If the patient agrees that I may approach them, I will introduce myself and seek oral consent to observe their consultation with the clinician. If the patient verbally declines to participate, I will not observe that consultation. If time permits, I will seek formal written consent prior to the consultation. However, if this would interfere with the clinic processes, making the process in the clinic unwieldy, I will seek formal written consent once a consultation is finished, I will seek written consent from the patient. Consent is likely to be taken in a quiet area of the waiting room; it will not be in the outpatient clinic room itself, as this will delay the clinic. If the patient declines to provide written consent after the consultation or changes their mind once the consultation is over, I will dispose of the field notes and audio recording of the relevant observation.

I will seek explicit consent from the patient participants to access their medical records for the purpose of collecting demographic information which will enable me to describe the characteristics of participants in my results. If a participant wishes to receive a summary of the results of the study, I will seek permission to note their address from the medical records.

Care-givers

Where a caregiver attends with the patient, I will seek oral consent from the caregiver as well as the patient to observe the consultation with the clinician. In the unlikely event of a patient consenting but a caregiver declining to participate, I will not observe that consultation.

Interviews

Patients

I will undertake interviews with patients with lung cancer receiving treatment from an oncologist and patients with COPD requiring specialist input. These patients will not be patients whom I have observed. This decision has been arrived at following discussion with my supervisor, an experienced qualitative researcher. In his experience, if patients are interviewed after observation, they may think that the researcher will be able to recall exactly what happened in the period of observation. Thus, patients who are observed and then interviewed may feel that their 'performance' in the observation has been judged and found to be substandard, requiring further exploration in interview (May, 2016). The clinical team will identify patients against the inclusion/exclusion criteria outlined in section 6.1 above. The clinical/administrative team will have a list of participants who have participated in the observation component of the study and will therefore not send or give a letter of invitation for the interview component of the study to patients who have participated in the observation component of the study. I will explain to the clinical and administrative teams that the same principles of confidentiality apply to this list, as would patients' medical records. A participant information sheet will be posted out to potential participants on Trust headed notepaper explaining the study. For lung cancer participants attending oncology clinics at **[name of Trust redacted]**, the clinical team may instead give the participant information sheet to eligible patients attending outpatient clinics. This will include a freepost envelope. Patients will have the option to return a slip by freepost giving consent for me to contact them, to email me or to telephone me. Once I have received consent from the patient to contact them, I will telephone the patient and discuss the study with them, ensuring that they have every opportunity to clarify any points they do not understand and ask for more information if they wish. I will complete a demographic information form over the telephone in order to ensure maximum variation sampling (see section 9.3 below). This form will only be used for collection of demographic information by telephone prior to interview. If the patient meets the sampling strategy and is happy to be interviewed, I will arrange an interview at a date, time and venue convenient for the patient. I will telephone the patient the day before the interview to remind them of our agreement and to ascertain the presence of any dangerous animals. I will take written consent on the day of the interview, which will be at least 24 hours after the patient has received the participant information sheet. The patient will have a further opportunity to ask questions about the study on the day of the interview. Reimbursement for time will not be offered, however, should the patient incur costs such as parking charges, these will be reimbursed.

I will verbally advise patients who have participated in the interview component of the study that they are ineligible for the observation component of the study and advise them to disregard any study literature for the observation component of the study should it be sent to them in error.

Clinicians

I will approach all the clinicians participating in the observation component in the study for their consent to participate in the interview arm of the study. I will interview clinicians once the observation component of the study is complete except in the case of clinicians who are leaving the Trust (for example, junior doctors). I will give the clinician a participant information sheet. At this point, they will have the opportunity to ask any questions that they may have about their interview. I will arrange an interview at a date, time and venue convenient for the clinician. I will take written consent on the day of the interview, which will be at least 24 hours after the clinician has received the participant information sheet. The clinician will have a further opportunity to ask questions about the study on the day of the interview. Reimbursement for time will not be offered; however, in the unlikely event that the clinician incurs costs such as parking charges, these will be reimbursed. The clinician will also be offered a certificate of evidence of participation in research to put towards professional revalidation.

Setting

I will undertake the study in COPD and lung cancer outpatient clinics in two NHS Trusts (**[name of Trust redacted]**). For observations, consent and data collection will take place at the NHS Trust. For interviews, participants will be able to choose the location in order to maintain equity between researcher and research participant (Goodyear-Smith et al, 2009).

I have selected the hospital sites pragmatically because they treat and manage patients with a diagnosis of lung cancer or COPD and are geographically close to the University of Southampton.

I have a clinical background as a respiratory nurse, specialising in COPD. I have links with both hospitals: I worked as a staff nurse on a respiratory ward in **[name of Trust redacted]** from 2008 – 2011 and I have attended meetings on COPD related issues with colleagues from**[name of Trust redacted]**. These links have enabled me to gain access to clinicians at each hospital site. I have met with clinicians in each specialty and discussed the study with them. However, I have not worked clinically with COPD outpatients or lung cancer patients at either Trust. I am, therefore, likely to be able to access study participants but am unlikely to meet patients with whom I have worked in a clinical capacity. As discussed in section 5.3 above, the distinction between my ‘outsider’ status as a researcher independent of the clinical team I am observing and ‘insider’ status as a nurse, a person like the clinical team I am observing may be hard to maintain. In the unlikely event that I do encounter patients with whom I have worked clinically, I will not include these patients in the study in order to preserve the distinction between my insider (nurse) and outsider (researcher) status as far as possible (while recognising that these will inevitably blur at times).

Sampling (size and strategy)

Observations

There are no clear guidelines on how long is enough in terms of qualitative observation. What is clear is that observation needs to take place over a prolonged period (Spradley, 1980; Polit & Beck, 2016). A minimum of six months has been suggested (Fetterman, 1998). Thus, for pragmatic reasons (I am undertaking a full-time PhD study and have limited time and resources), I will observe one COPD and one lung cancer clinic every week for six months.

There are between 8-15 patients booked for each clinic. However, attempting to observe all 8-15 consultations is unrealistic. Qualitative data collection is an exhausting process that requires deep concentration and commitment (Polit & Beck, 2016). In order to have a manageable workload and time to take formal written consent between consultations, I estimate that I will observe approximately four consultations per clinic per week (i.e. up to eight consultations per week).

Interviews

The grounded theory concept of 'saturation' – sampling to a point where no new information is generated (Polit & Beck, 2016) – has become a fundamental guiding principle for determining sample size in qualitative research (Hennink, 2016). It is generally related to interviews rather than observation (Morse, 1995, 2015; Mason, 2010; Hennink, 2016). However, it is a concept that is difficult to define and is often poorly described in qualitative studies (Morse, 1995; Mason, 2010; Hennink, 2016). There are various criteria to consider in determining sampling size in qualitative research. For example, the diversity of the study population, the scope of the research question, the skills and experience of the researcher, the complexity or sensitivity of the phenomena being studied and the quality of the data (Morse, 1995; Mason, 2010; Polit & Beck, 2016; Hennink, 2016). Determining sample size is important, however. First, ethically, unnecessary research should not be carried out which will require time and commitment from often already burdened participants. Second, pragmatically, limited resources (and ethics committees) require an estimate of workload (Mason, 2010). Hennink's useful study (2016), whilst recognising the numerous variables that affect saturation, suggests that it may be achieved between 8-16 interviews. I have decided, therefore to interview a purposive sample of patients: up to 12 patients with COPD and up to 12 patients with lung cancer.

As discussed in section 7.3 above, I will ask clinicians to screen patients against inclusion/exclusion criteria for interview. Should recruitment prove problematic, I will use ‘snowballing’ as a supplementary recruitment strategy. This is where participants in the study identify others with experience in the area of interest (Atkinson & Flint, 2001). Thus, I would ask participants to suggest other patients who might be interested in participating in the study. The participants would pass on my contact details and the patients would get in contact with me. I acknowledge that the use of ‘snowballing’ risks lessening the diversity of sample views. However, it can be useful in the recruitment of seldom heard groups (Atkinson & Flint, 2001).

9.3 Strategy:

I will use maximum variation sampling to select patients of different ages, sexes and socioeconomic backgrounds. Selecting participants with diverse perspectives should allow me to enhance and challenge my emerging themes (Polit & Beck, 2016). It should also ensure that any common themes that arise, given the diverse range of participants, should be of particular utility in capturing uniformities to explain the phenomena of interest and, hence, develop theory (Polit & Beck, 2016).

I will interview a convenience sample of up to five clinicians for each disease (COPD and lung cancer) as there are likely to be no more than five clinicians involved with the outpatient clinics. I will interview all the clinicians who consent.

As previously stated, I will not invite patients who have previously been observed to interview.

Data analysis

I will analyse data using directed qualitative content analysis (Hsieh & Shannon, 2005). Qualitative content analysis allows the identification of recurrent themes and patterns between themes (Polit & Beck, 2016). A key feature of content analysis is that it provides a way to condense a large amount of text into meaning units – the “smallest segment of a text that contains a recognisable piece of information” (Polit & Beck, 2016, p. 537). I will use *directed* qualitative content analysis as opposed to conventional content analysis as my research question is based on existing theories (the conceptual modelling work that developed the coding framework discussed in section 4.2 above). Directed qualitative content analysis allows the researcher to work deductively, conceptually extending existing theories (Hsieh & Shannon, 2005).

I will use the coding framework to support the process of integration of the data from the interviews and observations, in addition to returning to and refining the taxonomy developed through the qualitative meta-synthesis. I will use the study steering group (clinicians, patients and caregivers) to help me consider the multiple perspectives (patients and clinicians) in the data.

Ethical considerations

11.1 Investigator responsibilities

I will carry out this study in accordance with the principles of the Good Clinical Practice (GCP) guidelines. I have completed full GCP training in 2012, with updates in March 2014 and December 2016. I have also completed a course on qualitative interviewing run by the University of Oxford. My supervisor, Professor Carl May, is an experienced qualitative researcher and he, along with my other supervisor Professor Alison Richardson, will be providing me with frequent opportunities for reflection and feedback throughout the data collection process.

I have sought and received an enhanced Criminal Records Bureau check. I will ensure that I have a research passport before carrying out any research.

11.2 Ethical permissions:

I will seek ethical permission through the University of Southampton and through the HRA.

11.3 Informed consent

As the principal investigator, I am responsible for obtaining informed consent before any protocol specific procedures are undertaken. The decision of a participant to take part in research is voluntary and should be based on a clear understanding of what is involved. I will ensure this by adequate provision of oral and written information and explanation of study particulars (study introduction letter, participant information sheet, and consent form). I will provide the oral information to the participants and this will cover all the elements specified by the study particulars. Potential participants will be given an appropriate amount of time (e.g. at least 24 hours) to consider the study information and requirements before deciding to take part.

In all cases where written informed consent has been sought, consent will be taken in duplicate with one consent form given to the participant and the other retained in the site file. If there is doubt over the participant’s capacity to give informed consent, I will not recruit the participant to the study

11.4 Withdrawal procedures

Participants are free to withdraw from the study at any time without giving any reason. Data collected from participants who have withdrawn from the study will not be used in the data analysis, where they withdraw prior to the process of analysis starting. Information on how to withdraw from the study is given in the participant information sheet.

Professional considerations

I will observe clinical consultations only; I will not play a part in the care delivered or the conservations during consultations. In the unlikely event of an emergency arising as a registered nurse my professional code obliges me to “offer help if an emergency arises in my practice setting or anywhere else” (Nursing and Midwifery Council (NMC), 2015 p.12). I will, if it proves necessary in these circumstances, offer help to the clinical team and participate in the delivery of care within the limits of my knowledge and competence. In the unlikely event that I observe poor practice, as a registered nurse I am bound to comply with the NMC Code of Conduct (2015) to raise or escalate concerns if a patient is at risk. I will discuss this with my supervisors before taking any action.

Data management

Voice recordings will be transferred from the audio device to a university computer at the earliest opportunity (within hours of the interview taking place) and stored on a password protected system on a university computer supported by the University of Southampton’s IT department. Once transcribed, voice recordings will be destroyed. Only my supervisors and I will have access to the data, which is securely stored on the University’s hard drive and password protected (in accordance with University policy). Written field notes will be kept on my person when in use. When not in use, they will be stored in a locked file. I will type up written field notes at the earliest opportunity and these will be stored on a password-protected system on a university computer supported by the University of Southampton’s IT department.

Sections of data will be shared with the study steering group. This comprises clinicians (not in study sites) who work with patients living with COPD or lung cancer and patients/care-givers living with COPD or lung cancer. Any participant identifiable information will be redacted from these data.

I will keep a list of names of all participants with their allocated study number or pseudonym on a computer database. This will be in a password-protected file on a password-protected computer. I will be the only person able to access this. This will not contain any other personal data and will be stored separately from the anonymised research data. I will use the information to ensure all research data are coded correctly. I will store participants’ contact details (to contact them for the interview, if they decide that they want to review the interview transcript and/or receive a summary of the research results) in a separate password protected file on a password-protected computer. This will not be linked to the list of names of participants. They will be identified by their allocated study number or pseudonym not by name. Again, I will be the only person able to access this. Personal data will be stored for 3 months after the study has finished and then destroyed. Records of the study will be archived by the Faculty of Health Sciences Archivist and kept for 10 years (in accordance with University policy).

Confidentiality

I will give participants a unique identifier to protect their identity and ensure confidentiality. The unique identifier will identify whether the data are taken from observations (OBS) or interviews (INTS). It will also identify whether the participant is a patient (PA) or clinician (CL). The other part of the identifier will be allocated sequentially, e.g. the first patient to be interviewed will be "INTS-PA-001", the first clinician to be observed will be "OBS-CL-001".

Where extracts of text are used as quotes from interviews, these too will be coded with the corresponding identifier. Demographic data will be stored in a password-protected file on a password-protected computer separately to the anonymised data transcripts. Whilst it should be relatively simple to maintain linked anonymity for patients, it is acknowledged that maintaining the anonymity of participants in qualitative studies can be problematic, particularly where the participant is a specialist in a field (for example, a consultant doctor) and other colleagues are aware of the study being conducted (van den Hoonard, 2003). This will be fully discussed with the consenting participants and explicit in the participant information sheets. In order to minimise this risk, NHS sites will not be named in any public facing study documentation.

Safety considerations

Serious adverse events

In the unlikely event of a serious adverse event (an adverse event that results in death, is life-threatening, requires hospitalisation or prolongation of hospitalisation, results in persistent or significant disability or incapacity), this will be documented in the Investigator Site file and reviewed by my supervisors and I. It will be reported to the sponsor/hosting R&D department as soon as possible.

Participant safety: harms and benefits

There are potential disadvantages/risks associated with this study.

Taking part in this study will mean patients may experience some inconvenience or fatigue. Interviews are likely to be around 30-45 minutes for most people. I am a qualified respiratory nurse with over 10 years' experience of caring for patients. I have the necessary skills to be able to detect fatigue, stop the interview and to signpost the patient to the appropriate clinician/service if required. It is unlikely that clinicians or informal caregivers will experience fatigue, however, my main concern with these groups is adding to an already busy workload. I will mitigate this risk by fitting in with their schedules flexibly and minimising the time required where possible.

As with any qualitative study there is potential for interviewees to experience discomfort when sharing personal views. There is a risk that discussing patients' treatment workload, capacity to manage this workload and burden may provoke strong emotions such as sadness. However, evidence from previous qualitative studies, show that patients may find an opportunity to discuss issues with an outsider beneficial and cathartic (Carter, 2008). Patients may find it beneficial to feel that they are helping others. I will be sensitive to this risk when conducting the interviews and aim to listen to patients and caregivers empathetically and compassionately, rather than simply collecting data. If I believe that patients have experienced strong emotions and I have concerns for their wellbeing, I will signpost them back to their clinical teams.

Some patients may feel uncomfortable knowing the consultation is being recorded. This may mean they do not say all that they would like to the healthcare professional. There is also a small chance that the healthcare professional may also respond differently to questions patients ask them due to their being recorded. To try to reduce the impact of recording, I have chosen to use an audio-recorder rather than a video, as it is smaller and less intrusive.

The presence of a researcher may make healthcare professionals uncomfortable at first until they get used to me being present. Previous studies have shown that healthcare professionals quickly get used to a researcher being present. Healthcare professionals may feel uncomfortable discussing sensitive issues with patients in my presence. I will remind them at the beginning of every observation period that they are free to ask me to leave the consultation or to turn off the tape recorder at any point should they feel uncomfortable with my presence without having to give a reason.

Taking part will mean both healthcare professionals and patients giving some of their time to the study. This is difficult to quantify exactly but is unlikely to be more than 10 minutes. I understand the need to avoid delays in a busy outpatient clinic and will work hard to ensure that the impact on healthcare professionals is minimal.

Although “burden of treatment” is a phrase increasingly commonly understood in clinical and academic circles, I believe that it is an unhelpful term to use with patients. Burden is an emotive term and may lead patients to assume they have an issue where none exists or where, previously, the patient did not view this as problematic. Using the phrase “burden of treatment” when communicating with patients, therefore, has the potential in itself to add to patients’ burden. To minimise this issue, I will discuss the study’s purpose as understanding the experience of patients undergoing treatment in communicating with patients both orally and through the study literature rather than using the phrase “burden of treatment”.

There are no direct benefits to participants in this study and participants will be clearly informed of this. However, participants may indirectly benefit from the knowledge that findings from the study will be used to inform and hopefully to improve care for others.

15.3 Researcher safety

For cases where the participant requests a face-to-face interview at their home, I will adhere to the University of Southampton’s safety policy for lone working and will carry a safety device with me. Previous evidence has shown that even veteran nurses may experience considerable emotional impact from carrying out qualitative interviews (Pellatt, 2003). In order to minimise this risk, I will debrief with my supervisors at regular periods after interviews.

Dissemination

I aim to publish the findings in peer reviewed open-access journals and present at relevant conferences. Findings will also be disseminated through the Wessex CLAHRC website and through the Health Foundation (the study funder). I will ask all participants in the study whether they wish to receive a copy of the results of the study in lay language. This would be prior to any publication. I would need to be sensitive to the fact that, given some patients may have a short time to live when I see them in clinic; I may need to check with the clinical team before sending out the lay summary in order to ensure patients have not died.

Patient and public involvement

Patients and caregivers have been involved at all stages in the research process. They have reviewed and commented on the study protocol and materials. With the study steering group, they will be involved in reviewing sections of the data to challenge and enrich data analysis. They will also be involved in developing the lay summary and disseminating the results of the study to interested lay groups (e.g. in the case of COPD patients, the Breath Easy groups run through the British Lung Foundation).

Appendix D

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Appendix E Interview Schedule (patient)

Interview schedule

In keeping with the principles of qualitative research, this is a guide to the types of questions that are likely to be asked in the interview and not a list of questions, all of which will be asked, in a particular order. Where clarification or probing is required, participants may be asked questions not in the interview schedule to elicit further information. For example, you mentioned x. Could you tell me a little more about that.

Moreover, as the taxonomy building from the qualitative meta-synthesis and data collection from the observation component of the study develop, questions may be refined and extended to explore and test uniformities observed.

Can you tell me about your health condition?

Can you tell me about your diagnosis?

Could you describe a typical week in terms of the treatments that you are undergoing for your health condition?

Do you monitor your condition on your own (e.g., check your blood pressure)? What type of monitoring do you do and how often?

Have you had to learn anything new (e.g., new skills) in order to care for yourself?

Do your treatments or self-care affect your work, or your social and family life? If yes, can you give me examples?

Have you made any changes to the way you live as a result of your health condition or treatment for your health condition?

How big a part of your life would you say is made up of activities you do to manage your health and illnesses?

How often do you see your doctor about your health condition? What happens? Is this enough?

Appendix E

Please tell me about the information you receive from your health care professionals about your treatment (Prompts: Is it sufficient? From whom do you receive it? From whom do you wish to receive it?)

How has your care been since you were diagnosed? Can you tell me what has been good about the care you received? What has been less positive?

In caring for your health, do you get support from other people apart from your doctor or nurse (for example family or friends)? Who? What kinds of things do they do to help you?

Has helping with your healthcare made any difference to your relationship with those people? If so, how?

Have you ever joined a patient support group or spoken to other people with your condition?

Are there any things that make the management of your health condition easier? (That you do, that your family or friends do, that doctors/nurses/the healthcare system do?)

Are there any things that make the management of your health condition more difficult?

What do you think people who make decisions in the NHS need to know about patient experiences?

Is there any advice you would give to a health care professional (e.g. nurse or doctor) about supporting patients like you with their treatment?

Is there anything else that you would like to tell me about today regarding your health condition and the treatment you receive for it?

Appendix F Interview Schedule (clinician)

Interview schedule – health care professionals

In keeping with the principles of qualitative research, this is a guide to the types of questions that are likely to be asked in the interview and not a list of questions, all of which will be asked, in a particular order. Where clarification or probing is required, participants may be asked questions not in the interview schedule to elicit further information. For example, you mentioned x. Could you tell me a little more about that.

Moreover, as the taxonomy building from the qualitative meta-synthesis and data collection from the observation component of the study develop, questions may be refined and extended to explore and test uniformities observed.

Can you tell me about your approach to a clinical consultation – preparation and the consultation itself?

Do you discuss options for treatment with patients? If yes, can you give me an example?

What factors do you take into account when considering treatment options? (E.g. evidence base, patients' likelihood of compliance)

Who do you think generally makes the final decision on treatment options – you or the patient? Why do you think that is?

Do you assess whether or not a patient is able to adhere to treatment? If yes, how?

Is there something that you think makes a patient's experience of treatment better? Can you give examples?

Is there something that you think makes a patient's experience of treatment harder? Can you give examples?

Do you think informal carers (relatives/friends) should play a role in supporting patients with their treatment? If yes, what kind of a role?

Appendix F

What advice would you give to a junior doctor starting out on their approach to a clinical consultation?

Appendix G Observation record

Record sheet for observations:

Date:

Please circle:

Time: AM PM

Day: Monday Tuesday Wednesday Thursday Friday

<u>Lead Health Care Professional</u>

Age:

Gender: Male Female

Specialty:

Profession: Doctor Nurse Physiotherapist Other (please specify)____________

Length of time in practice: ≤5 years 6-10 years 10-15 years 15-20 years >20 years

<u>Other Health Care Professionals participating in consultation</u>

Age:

Gender: Male Female

Specialty:

Profession: Doctor Nurse Physiotherapist Other (please specify)____________

Length of time in practice: ≤5 years 6-10 years 10-15 years 15-20 years >20 years

<u>Patient:</u>

Age:

Gender: Male Female

Condition:

Appendix G

Stage of condition:

Co-morbidities:

Employment status: Employed Unemployed Retired

Social network:

Management/treatment plans

Informal care giver (if present)

Gender: Male Female

Relationship to patient: Spouse/partner Child Sibling Friend Other (please specify)___________

Consider:

Posture/Movements/Gesture

Facial expression

Positioning

Voice: pitch, tone, intensity, silences, fluency

Involuntary responses: blush, tremor

Demeanour: preoccupation, embarrassment, engagement

Congruence: between appearance and words

Appendix H Taxonomy of treatment burden (systematic review and empirical study integrated) with associated exemplar quotes

LUNG CANCER	**Exemplar quote**	**COPD**	**Exemplar quote**
Diagnosis as shock	Patient: I don't know, because I think at first I didn't want to believe, and I couldn't believe that I'd had this [diagnosis of lung cancer], and I was *absolutely*, and I'm going to be honest, I was terrified. And I don't think…it's almost like I was in a different world, to be quite honest. Even though people were stood in front of me, or sat in front of me talking, I just was *unable* to take anything in... I felt as though I was in a different - I don't know, even though we	Diagnosis imperceptible	Patient: Actually I don't really [know who gave me the diagnosis of COPD] - oh, I think the nurse suspected it to start with. Researcher: At the GP surgery? Patient: Yes, because I'd always been struggling…she thought this a while back but it was only when I went with this chest infection that they got really worried…I think it was there [at the hospital admission following the chest infection] that it was more

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	were all in the same room, it was almost like were in parallel worlds (INTS-PA-010)		brought up as COPD because of the breathing aspect (INTS-PA-013)
Obvious illness identity with socio-cultural resonance (therefore understood by patient/informal caregiver/HCP)	Wife of patient: …That was a shock that time then, being told he had cancer. Patient: …I had an appointment with some, I think that was somebody else down there and I walked into the room and I remember the specialist nurse. I walked into the room with him and the doctor and she said, 'We can't cure your cancer,' she said, 'But we can treat it,' and so we never had no inclination that I had cancer at that point, of course my daughter was with me and we were all upset, it was a bit of a shock…It was a bit of a shock to say it… (INTS-PA-018)	Unclear illness identity, without socio-cultural resonance (therefore poorly understood by patient/informal caregiver/HCP)	Patient: Right, as I explained to somebody the other day, everybody has heard of the big C, cancer, if you say cancer everybody, 'Oh, terrible,' yes… if somebody says, 'Well, he's got cancer,' they all go, 'Oh, well that's fine, ah yes, that makes sense.' Maybe COPD and pulmonary disease isn't, things like that, need to be, I was going to say advertised but that's not… It needs to be made, people need to be made more aware of it. (INTS-PA-012) Wife of patient: Well, I have never really understood, for a long time, what COPD meant. I knew it was chronic obstructive

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			pulmonary disease but that doesn't really tell you very much" (INTS-PA-009).
Short disease trajectory (clear to patient and informal caregiver)	Patient: I was told [of my diagnosis of lung cancer] …Of course, it hit me [sound of clicking fingers] and it was all going round…She [the lung cancer nurse specialist] came - the doctor told me and she stayed with me, and I said, 'Well, is it operable?', 'No', 'Is it curable?', 'No', 'Well, how long have I got?', 'Oh, it could be days, it could be weeks', and that really…and of course, well, they say your life flashes before you. Everything, I thought my God, I'm not going to get out of here, I'm not going to see my sons and that carry on, and everything just whirled. That night, I didn't sleep much at all. (INTS-PA-020)	Long and uncertain disease trajectory (unclear to patient and informal caregiver)	Patient: I know the disease I've got is incurable, I know it's progressive, so if someone says to me, 'You've got a year to live,' fine, quite happy with that. I'd whoop it up a bit. That's the sort of information I want to know. I think the problem is, why they don't do that is because they can't give you a treatment to dangle in front of you to say, 'Well, if you do this, it might go from a year to three years.' I think that's where the problem is… (INTS-PA-001)
		Diagnostic ambiguity	Wife of patient: The consultant walked into the room and said to him "You do realise you've got severe emphysema, don't you?"

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			And although I was taken aback, I was pleased because at last I had something that I could understand. And explain to others, so that when they said to me, “What’s wrong with [name of patient]” I said, I can say “He has severe emphysema”, and most lay people do know that term, so it makes them more sympathetic and understanding than COPD. (INTS-PA-009)
Demands of treatment workload as overriding life priority (for both patient and informal caregiver)	Patient: my husband and my son, bless them, had to make sure I got there [to treatment] every day and got home every day…My husband changed shifts so that he was working nights instead of days so that he could take me during the day (INTS-PA-019)	Demands of treatment workload balanced with domestic/professional/ sentimental demands of everyday life (for both patient and informal caregiver)	Patient:…when I was talking to [name of respiratory physician] recently, had I been on [pulmonary rehabilitation] rehab for my condition, yes…when I first did it it wasn't so bad, it was done once a week every week, I think it was half past five at [name of local community hospital]. What I actually got my then boss, my then director to agree was I would slope off at four o'clock, my Mrs would

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			pick me up, I'd be at [name of local community hospital] by five o'clock. One day a week for the, I think it was an eight or ten-week period, that's what I would do. Now when I looked into it next and when I've looked into it again recently, yes, they do it, it's something like two hours a day [twice a week] and you do that for five weeks…so that would mean I'd have to say to my bosses, 'Do you mind if I take ten days off in the next five weeks at your expense or full pay?' or I'd have to book them as holiday, and as I don't have ten days holiday, guess what, I will not be going on this rehab thing, you know what I mean? It's something that doesn't take an Einstein, I couldn't do it even if I wanted to. Now who in their right mind decided, 'Do you know what, if somebody needs to go on this

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			two hours a day, twice a week for five weeks'? (INTS-PA-012)
Practical demands of treatment workload as a relief from the existential threat of cancer	SYSTEMATIC REVIEW ONLY	Practical demands of treatment workload as hard work	Patient: Was this in [local district general hospital]? Last time I was up in [local district general hospital] yeah and he sent me home while I was still ill. But er I went to that um you know two a week exercise thing. Specialist respiratory nurse: Oh right? At [name of pulmonary rehabilitation centre] Pt: Yeah and I went [two days of the week classes held] Specialist respiratory nurse: Yes, that was with us. Yes, OK Patient: And I wasn’t well in any of them. Specialist respiratory nurse: No, you weren’t. Patient: No [laughs]. And I was gasping…

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			Specialist respiratory nurse: But you still came didn't you? Patient: Yes. Specialist respiratory nurse: You did very well. Patient: I missed three. One was a hospital visit and two was I just didn't fancy the idea of you putting me through the torture (OBS-PA-002)
Treatment as hope	Patient:...I was taken aback a bit about - he [specialist oncology doctor] give me some treatment which made me rough, but I didn't mind. I didn't want it, but put up with it because that's the way it is. He said, 'We'll stop that.' I said, 'Well, you know,' and he said, 'Well, I'm not sure that it's doing any good anyway.' Yes, but, I just feel that I	Institutionalised care as respite from unrelenting demands of self-management	Patient: …we were in the garden and obviously it was August, it was summer, and I was out there sawing a piece of wood and the following couple of days my shoulders had started to ache and I put it down to the fact, 'Oh I've just done something sawing a piece of wood,' strange as that seems. Obviously, that was masking what was

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	should have carried on with that treatment a bit more because there was more pieces to it. I never got it. He changed it to something else. So, I don't know. My biggest fear is that it comes to the end, and he says, 'I've done all that I can,' and it hasn't done a great deal of good, do you know what I mean? (INTS-PA-016)		actually happening here and it suddenly caught me out, I suddenly realised it wasn't the shoulder at all, it was my lungs and I got caught. Obviously, I was admitted. I felt, even though I was being admitted, I actually felt okay, you know, like, 'Oh, well I've got to go in. They're going to fix me.' Obviously, they said it was a little bit worse than that and it was lucky that I went in when I did go in because otherwise it could've become even a bigger problem (INTS-PA-002)
Sense of 'limbo' once treatment completed	SYSTEMATIC REVIEW ONLY		
Reluctance to stop treatment despite debilitating pathophysiological side effects	Specialist oncology doctor: So obviously a treatment like this, it's a new treatment and it's different to what you had before. As I've told you, I wouldn't anticipate it being any more difficult than anything we've done previously but erm you know I appreciate you're feeling slightly apprehensive and the		

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	bottom line with these sorts of treatments is you only know how you are going to get on with it once you've tried it Patient: Yes, that's what I said to my granddaughter Specialist oncology doctor: And I suppose the reality is that, you know, in the last few months we've been trying to find something to do Patient: Yeah, that's right Specialist oncology doctor: because we'd run out of options and then this was a new option that's been made available to us. Patient: That's it (OBS-PA-029)		
Treatment for family rather than for patient	Patient: They said it was lung cancer and of course I never wanted to, I always said I		

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	wouldn't take chemo but when I told my daughters they, 'How could you say that? What about us? What about your grandchildren?' I said, 'Well, I'll see. (INTS-PA-011)		
Lack of options: treatment or death	Patient: Well, there wasn't anywhere else to go. I could have said no to [name of consultant giving radiotherapy], when he originally suggested it, and said, 'You have to come to [name of local teaching hospital] for it'. I thought, oh, no. I knew if I didn't have it, I'm my own worst enemy. When something like that is offered to you, there's a reason, it's an expensive procedure, they don't give it to you for nothing. (INTS-PA-019)	Lack of treatment options (lack of information or feeling that 'nothing can be done' from HCPs)	Patient: I was sent to have this x-ray and they diagnosed emphysema. Following that, for many years, nothing really happened. I just carried on as if I wasn't told anything, it didn't make any difference to me. I just carried on working, and so on and so on. (INTS-PA-001)

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
Decision to cede control over choice of treatment options to trusted HCPs	Specialist oncology doctor: So if you went up to full dose, you'd have enough for 14 days but knowing you, you'd probably want to increment it I would have thought? Patient: Well I was going to ask your advice. I thought I was going to have to go up to the top and give it a blast because that's what is necessary but I don't think that my system can cope with it Specialist oncology doctor: Oh, I don't know. You never know do you? Why don't you go up to 3 and 3? Or three in the morning, two at night for a couple of days? Then 3 and 3, then 4 and 3, then 4 and 4? Patient: So how would you like me to…? Specialist oncology doctor: However you would like to do it. As quickly as *you* think you could do it		

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	Patient: I'm not good at decisions so you need to tell me. Specialist oncology doctor: [sighs, laughs] Patient: If you give a suggestion and if I can't do it, I'll… Specialist oncology doctor: Every other day, go up another dose Patient: And you want me to go up to the top? Specialist oncology doctor: [short pause] Yeah, I think you need to. (OBS-PA-033)		
Immediacy of availability of specialist healthcare	Patient: I have lung cancer. So I saw [name of respiratory physician], and she arranged for me to see [name of thoracic surgeon] at [name of local teaching hospital], who was a surgeon, and everything seemed to move	Work (for patients and informal caregivers) of accessing healthcare	Patient: The GP…recommended that I did [pulmonary rehabilitation], and nothing happened, and this did happen occasionally at the surgery…but I was then turned down, several times, because of the state of my

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	very, very fast….once they'd discovered what it was…So I said to [respiratory physician] at the time, knowing what the NHS was like with operations, et cetera, 'How long will it be before I see him?' and she said, 'If you haven't seen him within two weeks of today's date, ring my secretary', which surprised me. Within ten days I was talking to him (INTS-PA-014)		chest and I was on medication and so on. Then I finally got in a number of years after it was first mooted…. (INTS-PA-009)
Specialist HCPs with specific knowledge of lung cancer	Patient : I think my first time of meeting [name of specialist oncology doctor], and I think I remember saying to him, 'I just would like you to treat me as though it was a member of your own family', and he has done. He shook my hand, and I know he's very passionate about this disease. So I would say that I had that immediately. I just felt that warmth from him. I don't know what it was. I	Doctors/nurses in primary care who lack specific knowledge of COPD	Patient:…I said, 'Is there any more you can do?' [Practice nurse with responsibility for respiratory patients] said, 'Well, not really.' She said, 'What do you want me to do?' I said, 'Well, help me breathe.' And she said…I said, 'Oh, well, don't worry about it', so that was that….even the doctors, I don't think - you know, kind of, 'Oh, well, you've got COPD, you just get on with it', you know? 'Just take it

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	just knew that…I feel very, very comfortable there [in the hospital]. (INTS-PA-010)		easy, keep indoors, rest up, take some paracetamol, and have your puffers, and just get on.' (INTS-PA-004)
Structured treatment pathway	Specialist oncology doctor: Yeah. How many have you had [cycles of immunotherapy] now? Two or one? Patient and Informal caregiver: Two Specialist oncology doctor: Yeah. Good. So, you're due a scan after four, that's the plan which will be in about 5 weeks' time. I'll just print the form off and we'll just carry on and we'll see you back here in 3 weeks Patient: Lovely (OBS-PA-028)	Fragmented treatment pathway	Daughter: The other problem that we have is that when you prescribed her the B…whatever it is you prescribed her she was given [other inhaler name] and took that. So for 2 weeks she was taking both. And the locum doctor flagged her up and confused her over the phone and that's when I got in touch with your thingy. So she's now taking [inhaler name]. She's taking 2 in the morning and 2 in the afternoon Patient: At night Daughter: Oh sorry, 2 in the morning, 2 at night. Now when she was taking both

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			inhalers she was fine on it and she's felt fine haven't you? Patient: I had no idea that I was taking the wrong inhaler Specialist respiratory doctor: No, no, no. All you were doing a little bit was doubling up on one of the medications which is… Patient: That's what he said Daughter: Not dangerous Specialist respiratory doctor: Not dangerous, it's fine…. Daughter: So she's back on the [inhaler name] which is what she should be on Specialist respiratory doctor: She should be on Daughter: And the [inhaler name]. Specialist respiratory doctor: Yeah

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			Daughter: All sorted I think. I've got a repeat prescription in my purse for the [inhaler name] which [GP name] gave her just so that she would never run out. Now that's a 50 dose Specialist respiratory doctor: Yep Daughter: which obviously if you're taking 4 puffs a day will only last 12 days isn't it? Specialist respiratory doctor: That's ridiculous. (OBS-PA-021)
Specialist treatment workload in secondary care with debilitating pathophysiological side effects	Patient: You have the chemo, and then you don't even know you've had it, and then, say, you have it on a Monday, you're all right, and then by about Thursday, Friday, Saturday you start feeling rough, not well. By Sunday and Monday you feel quite ill. Lifeless, no energy. All I wanted to do was lay on the settee, and I	Multiple appointments for treatment in primary, secondary care and in the community	Researcher: It seems like your daughters keep you well organised. Patient: Oh god, yes! Researcher: Do they keep on top, on track of all your appointments for you, do they? Patient: Yes, yes. .. [coughs] except we had a cock up today. I've got an appointment with

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	really felt ill. That lasts for about three or four days, four or five, and then - you see, what happens with chemo, as you probably know, it kills all the white corpuscles. The white corpuscles grow back, the chemo that it's killed doesn't. So you've got no white corpuscles, so you feel very, very ill. Your white corpuscles start growing back, so you start coming back up. So by the end of the second week, if you like, you start feeling fine. Then you're all right for a week, and then you go and see them and they do it all over again. That's how it went on. (INTS-PA-014)		[name of consultant respiratory physician] it was my fault, tomorrow. I thought it was today and we went down there today….I'd written it on the calendar the correct date. I don't know how I got it into my head that it was today, but sometimes I do have quite a few appointments. Researcher: How do you keep on - do you have a calendar? Patient: I have a calendar and I also put them in the phone [laughs]. (INTS-PA-003)
Limited delegated tasks from HCPs	Specialist oncology doctor: And this is important, erm I know it sounds a bit alarming but essentially any chemotherapy, any treatment we give for cancer carries risk. The biggest risk with this sort of treatment	Significant workload of delegated treatment tasks at home from HCPs	Specialist respiratory nurse: I'm saying if you were to be unwell, you would notice that you would perhaps get more secretions on your chest and you're quite right, they would change colour if you were to get an

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	as I said is infection. If someone gets an infection with low blood counts I don't know if you remember this, we call it neutropenic sepsis so you can get blood poisoning without the blood cells to fight it. And very occasionally people end up very unwell with that and it can become a life threatening problem if it goes untreated. Whenever anyone ends up ill in hospital and we work out what went wrong, nearly always it's that someone was ill for a few days at home and didn't get in touch with us. So the thing about chemotherapy-related problems are, if you ignore them and hope that they get better, they tend not to, they tend to get worse, whereas if you contact us then we can normally sort it out. So, I know it's not nice to talk about these sort of things. Patient: Well, you've got to haven't you?		infection. So then you would need some antibiotics and steroids. Patient: I've got a kit Specialist respiratory nurse: You have. I remember, you've got a rescue pack. So you would start those yeah? Patient: Yeah Specialist respiratory nurse: and let your GP know that you had a chest infection, would you? Patient: I suppose you would, so that he can renew it. (OBS-PA-016)
		Workload of changing health behaviours at home	Specialist respiratory doctor: Very good. And are you keeping going [with exercise following pulmonary rehabilitation]? Patient: No.

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	Specialist oncology doctor: Well, I think that my responsibility is to make sure, you know, what to do if there is a problem...About 1 in 10 people might get something that we'd need to do something about. And we would expect you to ring up on the phone number you know that you've got Patient: The same as you would do for chemotherapy? Specialist oncology doctor: Yeah. (OBS-PA-027)		Specialist respiratory doctor: Why not? Patient: I dunno [laughs] Specialist respiratory doctor: What do you mean you don't know? Patient: I haven't done nothing since I finished it. Specialist respiratory doctor: Well, flipping well… Wife: Get off your backside and do something. I'm sorry Patient: I need to go back onto it [PR] then Specialist respiratory doctor: Well, I can't do that. Not yet. Not for a year or so but um come on get down the gym, get down the stairs in the hall. You've got to do it… we know that this is the most important thing… Patient: Exercise

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			Specialist respiratory doctor: Intervention that we can do. Better than any drug. Um and we know that that changes lives. So you've changed your life doing the rehab. No question. You've changed from here to here. So you've got to push on and follow through now. (OBS-PA-012)
		Clinicians performance manage patients against delegated tasks	Specialist respiratory doctor: Ahh. You've put on a bit of weight [patient's name] what's that about? No, a lot of weight. Patient: I know! A lot of weight. Specialist respiratory doctor: What's? Patient: Just things have gone wrong. Specialist respiratory doctor: What's, what's going on? (OBS-PA-001)

LUNG CANCER	**Exemplar quote**	**COPD**	**Exemplar quote**
		Informal caregivers report failure of patients to perform against delegated tasks to clinicians	Specialist respiratory nurse: Are you doing any of those exercises at home? Patient: Yes, tonnes of them Wife: No you’re not. Specialist respiratory nurse: [laughs] Informal caregiver: [gasps] God’s… Patient: I get up to the toilet and go back again. That’s walking… Specialist respiratory nurse: Do you have that book that we gave you with all the exercises in? Wife: Yeah Specialist respiratory nurse: Is it gathering cobwebs somewhere? Wife: Yeah Patient: No

LUNG CANCER	**Exemplar quote**	**COPD**	**Exemplar quote**
			Wife: Yeah it is. You don't use it Patient: *I* don't, no. Where is it? Wife: You see. Where is it? He doesn't even know where it is. (OBS-PA-016)
Generally high quality information provided in written form and from specialist HCPs	Specialist oncology doctor:…this new group of drugs which is called immunotherapy drugs. So these drugs are antibodies, they don't attack the cancer cells themselves, what they do is they latch onto your body's immune cells and they basically switch on the immune cells so that *they* attack the cancer. In trials that have been done, we've shown that these new immune drugs are better than chemotherapy. And they also seem to have fewer side effects. So it's a good treatment to be able to have. So the	Patients typically poorly informed about condition from diagnosis to death adding to treatment workload	Patient: Just going back to what you were saying about the appointments and stuff like that, I personally don't get a lot from them. I sometimes think it's because they're frightened to tell you the truth. Researcher: The healthcare professionals are frightened to tell you the truth? Patient: I do get that impression sometimes…When you go to [name of oxygen assessment location], and you do your six minutes, and they do the saturation and listen to you. They don't actually say to you, 'You're

LUNG CANCER	**Exemplar quote**	**COPD**	**Exemplar quote**
	treatment that we are using is a drug called Pembromizulab. It's an intravenous treatment and it's done every 21 days so it's once every 3 weeks. It takes half an hour to give so it's very quick. So all you have to do is come and see me and then a day or two afterwards you come back and you have a cannula put in and a drip of this treatment put through and then you go home afterwards and I'll give you some information to read about for that... (OBS-PA-031)		falling apart, you're getting bloody worse,' or they don't say, 'You're improving,' or anything. They ask you about smoking and stuff like this, which is fair enough… I want to know what's actually going on with my body, for someone to tell me. If it's falling apart I want to know that. Researcher: What about the doctor at the hospital? Patient: When I go and see [name of specialist respiratory doctor], we have a chat there, and I get the impression he's reserved on what he says to me. I think he says to me enough to, if you like, satisfy me but he's not giving me the blunt truth. (INTS-PA-001)
Lack of information as a deliberate choice on the part	Patient: …the surgery was an interesting case in point, because obviously they had gone	Conflicting/contradictory information adds to	

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
of patients – a tactic for maintaining hope in the face of a poor prognosis	through what they were going to do and I knew roughly what they were going to do. They had suggested I go away and read some other things, but I found it all a bit intimidating at that stage. So, actually, I didn't, I didn't go on the internet, the website they recommended. I didn't want to go near the internet to be honest because typing the words 'lung cancer' into Google is literally the worst thing you can do [laughing] if it might actually be happening to you…I did feel a bit stupid because I hadn't done as much research as I could have done before my operation because I just didn't really want to know. I felt it might be better to go into it a little bit ignorant, because otherwise it was just too scary. As soon as you start thinking about what's	patient/informal caregiver distress	Specialist respiratory nurse: And how many puffs [of the inhaler]? Patient: sometimes 4, sometimes maybe 6 Specialist respiratory nurse: What puffs? Patient: Yeah Specialist respiratory nurse: In one go? Patient: Yeah Specialist respiratory nurse: OK. So that's not really how we should be using the inhaler. We should only use maybe 2 puffs in one go Patient: Yeah, I've had this….My first doctor told me I was allowed up to 10 puffs Specialist respiratory nurse: So that's only if you're really Patient: out of puff Wife: which he gets

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	actually going to happen, you get really freaked out. (INTS-PA-017)		Specialist respiratory nurse: So that’s the equivalent of a nebuliser, yeah? Patient: yeah Specialist respiratory nurse: which it seems quite extreme perhaps. So generally, general maintenance, if you were out of breath and struggling a little bit, you would just use it 2 times. Patient: Just a couple of times Specialist respiratory nurse: I wouldn’t really promote that you use it 8 times in one go because it can have side effects Patient: Well they tell me it can’t. Specialist respiratory nurse: OK Patient: …The nurse at this new doctors. She said up to 8.
Conflicting/contradictory information adds to patient/informal caregiver distress	Patient: I think the main thing is to - because they didn't have all my full results. They were going on the basis of the first result, and I think it would be more beneficial to wait until they'd got the full picture and then tell you what's - because with me they jumped in at the deep end, the worst scenario. Then when it worked out it - well, when I went to see [name of consultant oncologist] the first time, he said, 'Oh, now we've got all the results it's the less aggressive one', whereas they were, I think, going on the aggressive one. It does, if you're not well as well, panic you and pull you right down…You think my God, my world's finished sort of thing, but, yes, I think if they waited until they'd got all the test results and		

LUNG CANCER	**Exemplar quote**	**COPD**	**Exemplar quote**
	the full picture and give you the correct diagnosis right from the start, then it would - for me, it would work… (INTS-PA-020)		Specialist respiratory nurse: OK. Well we're all singing off different song sheets then aren't we? Wife: It's very confusing for him. He gets very confused. (OBS-PA-016)
Family and friends are seen as the main source of support post diagnosis (but fear of being a 'burden' on family)	Researcher: You were saying how supportive your family… Patient: Oh they're marvellous, they are marvellous….I've got step children as well, and they're marvellous as well….the family's lovely, all-important… As I say, the support from the family is very important. (INTS-PA-015)	Family and friends are seen as the main source of support post diagnosis	Specialist respiratory doctor: Are you still taking that little…I…I…to help you with the swallowing, I gave you a little tablet of antibiotics that sometimes helps swallowing. Has that helped at all? Are you still taking that? Patient: Yes Specialist respiratory doctor: Cos again, it's not on your list.

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			Patient: The wife's got them there and the boss feeds them to me. (OBS-PA-015)
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	Patient: Yes, my son lives three minutes' walk… I've only got to pick the phone up and he'll be there…he's self-employed. I don't like him doing it because he's losing money, isn't he? So, but…I've told him, I'll get transport, I've been offered transport. 'No father,' he said, 'You'll get it all wrong when you've got to go back and all the rest of it.' He said, 'Two heads are better than one. Two heads are better than one,' so, there you go…Well, the thing is there's only my two boys, that's all there is. When my wife was doing it, I went with her every time. He said, 'You've got to have someone with you.' It's no fun playing	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	Wife: …you had a chest infection. We didn't really, we got so used to them, we'd take no notice. Patient: Yes. Wife: We were going on holiday with our [name of tour operator] and it was [date] and [name of patient] said to me, 'I don't feel like going but please will you go because I'm always forcing us to cancel things.' We were going to [name of county] and it was Monday to Friday and, anyway, we were having the hall painted and I set off and rang up and said, 'We've arrived.' This was tea time and he said to me, 'Well, you know where I am, don't

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	with chemo, because it's not the best thing in the world, but…he waits with me, yes, yes… but he likes to be there when there's a doctor there giving me information. Yes, he likes to be there see what's going on which is fair enough. (INTS-PA-016)		you?' I said, 'Well, where?' He said, 'I'm in [name of local teaching hospital].' Researcher: Blimey. Wife: Because he was in such a bad state that the painter, who was also an asthmatic, said to him, '[name of patient], I've had attacks of coughing and et cetera and I've never been as bad as you. I think we ought to call the ambulance.' He was rushed in, blue light, to resuscitation. I didn't come back because my daughter lives close by and she said, 'Mum, there's nothing you can do and I'm here', et cetera, but he was in there for three or four days. (INTS-PA-009)
Support for the patient's treatment workload seen as an affirmation of the strength	Patient: …my son was like, bless him, he was like, 'Mum, you've got to get your immune system built up', and he was getting me all	Support for the patient's treatment workload may be seen as an affirmation of the	SYSTEMATIC REVIEW ONLY

LUNG CANCER	**Exemplar quote**	**COPD**	**Exemplar quote**
of the patient/family member relationship in the face of imminent death	these different fruits, and making these smoothies and that. I'm thinking oh, my God, I'm getting indigestion, bless his heart. It was all these berries and everything. But bless my son's heart, and my daughter… I couldn't say anything. Because he started going to – [name of supermarket] - and buying these big bags of frozen fruit. They must have cost him a fortune. I'm thinking, oh, gosh, I just don't know how to tell him. I just couldn't stomach another one. But bless him, I mean he was just... (INTS-PA-010)	strength of the patient/family member relationship	
		Caregivers feel compelled to take on a care-giving role over the long duration of the disease trajectory	Patient: I often feel guilty…I can tell she [patient’s wife] is dying to try and do something and only when I'm really, really bad, I'll say to her, 'Oh, you do whatever you think.' That usually involves phoning up somebody and what have you. I make it difficult for my wife, by not letting her see that I'm actually struggling big time. I'm only struggling a little bit….Up until only recently, I've started to consider [name of wife] and the worries she's having…I'll be feeling like a barrel of shit to be honest. She'll say to me, 'Are you all right?' I say, 'Yes, I'm fine babe.' What help is that to her? How can she respond to that? Actually, when it gets really bad then she does say, 'That's it, I've had

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			enough, I'm calling somebody,' but that's when it gets really bad. (INTS-PA-001)
		Delegated workload of treatment tasks that informal carer has to carry out	Patient: [My family] help carry [the oxygen concentrator] around and [daughter's name] is very adept at switching from this to the full size concentrator which I have in one of the rooms which I normally - but of course the lead won't stretch from here. Researcher: Do they keep a little eye…out for your flare-ups? Patient: Oh yes, [daughter's name] especially watches me like a hawk! (INTS-PA-003)
		Informal carer has to undertake domestic tasks previously undertaken by patient	Patient: I'm very mindful that lots of heavy stuff I can't come and do any more, you know, and I'm very reliant on [name of wife] - bless her - in doing a lot of that heavy work,

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			you know, like mowing the lawn and things like that, that I can't do. (INTS-PA-002)
Importance of support from empathetic, trusted HCPs in whom patients have faith	Patient: …I carried on seeing [name of specialist oncology doctor] on three-monthly intervals, right up until my last [treatment]. …[Name of specialist oncology doctor] is very nice. He did, in fact, probably a few months ago, say to me did I want to start going to [name of local district general hospital closest to patient]? I said to him, 'Definitely not.' Definitely no, I know what to expect. He said, 'I hope you don't look at me as being a devil!' Obviously the wrong thing to say to him! …That's the sort of rapport I built up with him as well. I don't feel there isn't anything I can ask him (INTS-PA-019)	Importance of support from trusted HCPs, especially those with specialist knowledge of COPD	Patient: I do a bit of work at [name of local hospice]. I was in there once and I heard them talking about a doctor coming in to give a talk; so I put my hand up and said, 'Please can I come along?' I went, and that was when I met [name of specialist respiratory doctor], who I thought was absolutely wonderful. Next time I saw my GP, I said, 'Oh, by the way, is there any chance I could be referred to him? - because he specialises in my illness and he might be able to give me a bit more idea on how to manage - and maybe even treatment plan.' The GP's very good as well, and he said, 'Of course.' So he made a referral, and that's when I came to see Dr [name of consultant respiratory physician], who is a fantastic man

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			- person, individual - as well as being, what I think, is a very good doctor. (INTS-PA-005)
Less commonly, loss of faith in HCPs	Patient: I haven't had a lot of faith…in certain GPs. (INTS-PA-010)	Importance of relational continuity with HCPs making access to and navigation of the healthcare system and its institutions easier	Researcher: You've got a specific respiratory consultant, have you, that you… Patient: Yes, [name of respiratory consultant], he's lovely. Wife: We just think that, even though it means going to [name of local teaching hospital] for a lot of them, it's just the consistency… Patient: Continuity of care, and the same very luckily at the GP practice…[Name of GP practice] is famous for actually getting that part right, you have your own GP and 90 per cent of the time you will see your own GP who knows you well. Obviously, if you've got an emergency appointment, then you see

LUNG CANCER	**Exemplar quote**	**COPD**	**Exemplar quote**
			someone else if we want to, but as a general practice you have a doctor who you can get to know at a personal level and who can get to know you, and who, in my case, I didn't know, I didn't think they did have house calls any more, but they have been prepared on several occasions, 'Oh right, stay there, be there in half an hour' (INTS-PA-007)
Specialist clinicians encourage priorities other than treatment	Specialist oncology doctor: I think that if that scan looked fine and everything's stable and under control, you know, it'll be post holidays and you may want to then go and have a holiday because that will be a nice time to go [general laughter] Specialist oncology doctor: I'm not trying to be a travel agent but, you know,	Loss of faith in healthcare professionals	INTS-PA-006: There was a lady in a wheelchair with an oxygen cylinder about the same age as me….She was pulling her oxygen cylinder behind her when we're doing the walk at the end. I remember thinking, no, I'm not going there, I have to do something about this. Okay? I started reading up and looking on YouTube. I think what disappointed me, we had 12 sessions and only one session on diet [at pulmonary

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	Husband: No commission on is there? Specialist oncology doctor: Well, I may have some brochures next door [general laughter] Specialist oncology doctor: [suddenly serious] But I think it’s the right thing to do, you know. I think the chemo was harder than you let on, I think. And I think I pushed you quite hard because it seemed to be doing you a lot of good but I just think you probably got as much good out of it as you could get…and I think that it’s probably the right time to have a little rest from it (OB-PA-042)		rehabilitation]. The other 11 were on physical activity. It also made me feel was, it was really all about managing your symptoms, not trying to better your symptoms. Basically they were expecting us to have lots of exacerbations, going to hospital when it got really bad, and I'm thinking no, this is not good enough. Really from that first time I went, which is - I've looked elsewhere for treatments, okay? (INTS-PA-006)
Flexible and responsive treatment experience	Doctor: Perfect. So that means erm, and let me get this right, [days] are good?	Knowledge and skills gained from specialist care vital	Patient: [pulmonary rehabilitation was a] real major turning point because apart from actually getting me working a little bit, not

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	Wife: Yes. [days] I don't look after a lot of other people, yes it is good. Doctor: Fine. So obviously go ahead next week and then if I see you guys three weeks from today Patient: Three weeks from today Doctor: Another set of bloods on the day. Then it'll save you having to faff around with taxis and all of that won't it? (OBS-PA-030) Patient: [name of lung cancer CNS]…I can get in touch with…and she's been very helpful. If anything I'm not sure, I'll just phone [name of lung cancer CNS] and she deals with it for me (INTS-PA-015)		very much but a bit, I learned a lot more about COPD and that was very important… because I started going forward (INTS-PA-009)
		Inflexibility of treatment experience	Specialist respiratory doctor: Have you managed to get on the rehab thing at all? Patient: I think January I've got an appointment er…assessment Specialist respiratory doctor: That's really important…that's really good news um. … Patient: Cos she rung me up…it was either um I think it was this Friday [sound of computer clicking] or…but until the last moment I couldn't get an appointment…I couldn't get me holidays off…I've got to sort my working week out now. Specialist respiratory doctor: You do need to do that

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			Patient: Because it [rehab] is Monday and Friday. (OBS-PA-010)
Little peer support available for patients with lung cancer. What is available appears impromptu and transitory	Patient: I know of a couple of people, and I can pick up the phone to them… every so often we'll catch up on the phone, or we'll try and meet up for a coffee or something. Researcher: Did you meet them at the hospital? Patient: I have done, but they're not on the same treatment as me. They were on chemotherapy and then went on to have radiotherapy, and that's all stopped. So now and again I might bump into them when they have their three-month check-up…so, yes, I sometimes bump into them then.	Peer support is an important resource and is generally accessed through pulmonary rehabilitation	Patient: I had more difficulty [doing pulmonary rehabilitation (PR) exercises] and it was not just me, there was another lassie that goes called [name of peer]. I was really glad that she was there because we seemed to have difficulties on the same days. Again, we sat and thought about this: What's going on? Why can't we do it? Then you do one day and another and we found atmospherics and, you know…because I said to [name of peer], 'I don't know what's going on; I found it really, really hard today.' 'So did I.' 'Ah, right.… I've got a friend called [name of peer] and a friend called [name of peer] and we were together

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
	(INTS-PA-010)		earlier. We are there for each other…It rather shames me when I'm feeling like: Oh, I don't really want to do this - and I look and I think: You will! You will! (INTS-PA-005)
		Shared experiences with peers reduces isolation	Researcher: So having that peer, it almost pushes you, you find? Patient: Yes, motivates you and stops you feeling sorry for yourself and you get on with it… having these two pals is helpful, very helpful; we lift each other up and commiserate and laugh and just generally help each other. (INTS-PA-005)
		Peer support is used as a resource for information sharing	Patient: …one of the things that I noticed was different people [at pulmonary rehabilitation], people who were on oxygen,

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			they had different pieces of equipment, and some of them weren't too good [laughs] and people used to ask me about that. Yes, so I suppose it was good because I was able to give some people information about what else was available and what they could do. (INTS-PA-003)
Short disease trajectory: ill equipped to self-manage symptoms at home	SYSTEMATIC REVIEW ONLY	Long disease trajectory: get to know their bodies and symptoms, through trial and error	Patient: I took control over the specialist with that because when I listened to them they've landed me back in hospital…I said to [the specialists] I'm listening to my body now and I'm going to go by my body with needs for medication, everything…I did cut a lot of my medication out because what I used to do was cut it down and see if I could manage it. If I felt I didn't need it, wouldn't take it. I know it's sometimes a bit naughty but it worked….I

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			know you're supposed to take your tablets all separate; I have so many - well, it's like a chemist….I take them all together and I got so fed up of swallowing tablets every time I ate anything that I argued with the nurse about the diabetic stuff and she gives me 1,000 milligrams in the morning and 1,000 milligrams in the evening, plus the insulin so that I can have a rest in the mid-day; I can go out and not worry about any tablets whatsoever, just my insulin. But I take my tablets in the morning and I take it with - I don't swallow them with water, I put them all in my mouth and swallow them with my breakfast! (INTS-PA-013)

LUNG CANCER	**Exemplar quote**	**COPD**	**Exemplar quote**
Patients are considered culpable for their illness and stigmatized by society	SYSTEMATIC REVIEW ONLY	Patients are considered culpable for their illness and stigmatized by society	Patient: Oh yes, and the thing that amazed me, I guess, at the very beginning, when it was first diagnosed, and it was, you know, 'Do you smoke?' Obviously, I mean, COPD is very smoking related but it's not. Smoking is just another aspect of it, but everyone assumes, 'Oh he's a smoker.'… people around me. If they saw you out of breath, 'Oh you ought to give up the fags,' and all of these sorts of things. Initially I thought it was just the fags, you know, I was totally unaware it was anything else. (INTS-PA-002)
Patients consider themselves culpable for their illness: a “self-inflicted” disease	SYSTEMATIC REVIEW ONLY	Patients consider themselves culpable for their illness: a “self-inflicted” disease	Patient: Plus years of smoking I expect didn’t help [in relation to respiratory symptoms]. Specialist respiratory nurse: No, I don’t think so.

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			[patient laughs] Specialist respiratory nurse: Might have a slight part to play mightn't it? Pt: Well, I didn't listen though, did I? Specialist respiratory nurse: But you're not smoking now? Pt: No, no. 4 years now. Yeah but, I've been ill ever since I've packed up. Specialist respiratory nurse: Yeah and that's sometimes…smokers hear that and don't want to give up because they think oh I'm just going to get ill. Pt: If I'd have known I wouldn't have given up… well, no if I hadn't given up, I'd be dead by now yeah so. Specialist respiratory nurse: Well, I can't predict the future but you may well be in a

LUNG CANCER	**Exemplar quote**	**COPD**	**Exemplar quote**
			worse situation if you hadn’t given up smoking Pt: I’ve got no intention of going back. (OBS-PA-002)
Patients experience ‘felt’ stigma of blame, guilt and shame	SYSTEMATIC REVIEW ONLY	Patients experience ‘felt’ stigma of blame, guilt and shame	Patient…I was then told I was suffering from COPD. It's smoking related - I presume, anyway. I remember being quite shocked, and ashamed to a degree. I think this is very much an element of people with COPD that have been smokers - self-blame, you know, and not expecting any sympathy, really… (INTS-PA-005)
Patients attempt to conceal their condition owing to fear of ‘enacted’ stigma leading to social isolation	SYSTEMATIC REVIEW ONLY	Patients attempt to conceal their condition owing to fear of ‘enacted’ stigma leading to social isolation	Patient: …The other thing is, I actually do still suffer from embarrassment of what my complaint is…as I explained to somebody the other day, everybody has heard of the big C, cancer, if you say cancer everybody, 'Oh,

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			terrible,' yes. If you've got one leg missing people can easily see it…I've got a blue badge, my wife parks in a disabled bay, she's all right because she's got more brass neck than I have. I actually feel guilty getting out, because when I get out of the car people look at me and go, 'Two arms, two legs, two eyes, doesn't look as if he's struggling. No walking stick, no - why is he parked there?' What they don't realise is me walking from that car to the hole in the wall and back again, by the time I've done that my chest is boom, like that, and I - but they don't see that, all they're seeing is, 'Well he doesn't look as if he's old, he doesn't look like he's disabled. Why the hell is he doing that?' Whereas if somebody says, 'Well, he's got cancer,' they all go, 'Oh, well that's fine, ah yes, that makes sense.' Maybe COPD and pulmonary disease isn't,

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			things like that, need to be, I was going to say advertised but that's not…it needs to be made, people need to be made more aware of it. (INTS-PA-012)
Patients feel 'marked' by visible treatment leading to social isolation	SYSTEMATIC REVIEW ONLY	Patients feel 'marked' by visible treatment leading to social isolation	Patient: I must admit when I first started to go out with this there was a very big embarrassment about it [oxygen]. I didn't want to use it. I carried it, but I never put the thing on…you carry it in a carrier bag so it's not necessarily so visibly obvious….We went shopping in [name of local town] somewhere and we were sat down having a bite to eat for lunch, [name of wife] went off to get what we were eating, and I was sat on the chair and I saw a little girl with her mum suddenly come along and I knew what the little girl… She looked at me and I knew exactly what she was going to say to her mum before she even said

LUNG CANCER	**Exemplar quote**	**COPD**	**Exemplar quote**
			it, you know, 'Mummy that man there's got something on his nose,' and of course mum turned around and realised and smiled and obviously I smiled back and said, 'It's not a problem'. (INTS-PA-002)
		Patients internalise stigma, considering themselves undeserving of treatment	Patient: Er no, because every time you've explained most of it, it's just me that's been lacking… holding everything up by smoking Specialist respiratory doctor: I'm not that, well I'm not in that, I'm not in that whatever. To be honest with you, that's in the past. Move forward Patient: Like I say, it was all there for me in the past. And as I say just… (OBS-PA-010)

LUNG CANCER	**Exemplar quote**	**COPD**	**Exemplar quote**
		Patients experience ‘enacted’ stigma from HCPs, making access to treatment challenging	Patient: I had a bit more extensive x-ray. I think I had an MRI, didn't I, and so on? They started talking about COPD, which my GP explained. 'There's lots of cilia getting burnt off and that's because you've been smoking, you silly fool', et cetera. (INTS-PA-009)
Embarrassment about symptoms, medications and treatment technologies which mark the patient as ill leading to fear of ‘enacted’ stigma	SYSTEMATIC REVIEW ONLY	Embarrassment about symptoms, medications and treatment technologies which mark the patient as ill leading to fear of ‘enacted’ stigma	Patient: I don't use mobile phones as such, but I've got a mobile phone for the simple reason…it took the place of what I'd started doing, which was window shopping, which is - everybody's so used to seeing people walking down the street and then stopping and going, I used to think oh no, wait, actually if I get hard of breathing, I can take my mobile phone out and I can stand there and I can go like that. I can be typing away, I write a load of rubbish as well, but nobody knows that. People will just wander by and think there's a bloke on his mobile phone texting somebody.

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			Embarrassment gone away, nobody knows any different… I'd rather people ignored me than stop and go, 'Are you okay? Can I do something?'…That makes me even worse, because then I start getting, 'Yes, yes, I'm fine, yes, just go away, leave me alone.' (INTS-PA-012)
		Exacerbation triggers – leads to avoidance of social situations	Patient: Touch wood, you know touch wood I haven't touched any antibiotics for now, it must be a year-and-a-half. Wife: About a year I'd say, yes, but I think the main thing for that very, very sadly is to isolate ourselves and that is tough, and people don't really talk about it. They say, especially with [name of patient]'s prognosis, you have to get out there and you have to live, but the problem is, in winter especially,

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			in doing that it could actually kill you. You haven't really been out during the winter months at all, certainly this winter, and where I'm not at work any more and we're not handling paperwork or the same materials et cetera, and I've also had to restrict my social activities during winter. Patient: Yes. Researcher: Because of the risk of infection? Wife: Absolutely, I'm paranoid with hand sanitizer. You can buy stuff, whether it works or not, but it seems to have worked perhaps, Cold Guard around your nose and how you touch, so just to be very, very aware, very aware of people around you. If they have colds, you don't go and see them. That has been, I think, psychologically on both of us, extraordinarily tough (INTS-PA-007)

LUNG CANCER	**Exemplar quote**	**COPD**	**Exemplar quote**
Illness as contagious: social networks contract as friends withdraw	Patient: Yeah, too many horror films. It’s like saying, you know. You’d be surprised how many people I get the impression that they shouldn’t get too close to you if you’ve got or had cancer. They get the impression that it’s going to… Specialist oncology doctor: They think it might be catching. I’m not going to have a very long life then am I? [general laughter] Patient: You’ve had it! You shouldn’t be here now [laughs] (OBS-PA-035)	Illness as contagious: social networks contract as friends withdraw. Isolation worsens with disease progression and deterioration of physical function	Wife: We had been going through - well, *I* had been going through hell, to be quite honest, because 'I'm going to die. I'm going to die….No, you're not. No. You're fine.' In the streets [gasp] and people stopping and saying, 'Can we help?' 'No, no, no.' Patient: Thinking you're drunk. Researcher: Did it stop you going out? Patient: Yes. Wife: Yes. Patient: I still don't like going out on my own. In fact, it's a very rare event even now. I haven't got used to it. Wife: You *never* go out on your own. Researcher: Is that because - why is that?

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			Patient: Nervous about making too much of a fool of myself. Some of these attacks have unwanted side-effects, one of which is to lose control, continence, and that's pretty horrible and that's happened several times and you know, sort of pads and all that sort of thing… Well, it's not nice. Heaven's above you know, I played rugby, you know [laughs]. All that sort of thing is a bit, well, to me, very degrading (INTS-PA-009)
Psychological co-morbidities lead to avoidance of social situations	SYSTEMATIC REVIEW ONLY	Logistical difficulties of treatment workload limits patient to home	Specialist respiratory nurse: Have you ever thought about getting a little walker or something? Patient: Um. Well I have one of them well you know. I have got one actually. Specialist respiratory nurse: You can put your oxygen in that possibly.

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			Patient: It used to fill up all the room in the bus. I used to feel all you know sort of Specialist respiratory nurse: I wouldn't worry about it. You're perfectly entitled… Patient: There's all these yummy mummies with their prams and me with my walker [laughs]. Specialist respiratory nurse: I expect they feel the same though. They probably feel that they take up a lot of room with the prams. Patient: Nah, nah. (OBS-PA-002)
		Social isolation extends beyond patient to affect informal caregiver	Wife: I think the main thing for that very, very sadly is to isolate ourselves and that is tough, and people don't really talk about it. …I've also had to restrict my social activities during

LUNG CANCER	Exemplar quote	COPD	Exemplar quote
			winter….[you have] to be very, very aware, very aware of people around you. If they have colds, you don't go and see them. That has been, I think, psychologically on both of us, extraordinarily tough (INTS-PA-007)
		Psychological co-morbidities lead to avoidance of social situations	SYSTEMATIC REVIEW ONLY

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