



Identifying functional impairment and rehabilitation needs in patients newly diagnosed with inoperable lung cancer: a structured literature review

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Abstract

Purpose Patients newly diagnosed with inoperable lung cancer experience a symptom distress burden that may impact upon functional performance in daily activities. This structured review examines empirical evidence to see how functional limitation and rehabilitation needs are represented in the supportive care literature in this population. Early access to rehabilitation services may ameliorate the impact, but evidence of need following diagnosis is required.

Method Electronic databases Medline, Web-of-Science, Cinahl, AMED and PsychINFO were searched in April 2014. Hawker's criteria were used to assess methodological quality. The World Health Organization International Classification for Functioning Disability and Health (WHO-ICF) guided framework analysis and narrative synthesis.

Results Thirty-two articles selected for further analysis included heterogeneous studies exploring the following conceptually diverse dimensions: quality of life, symptoms, functional performance and unmet supportive care needs at diagnosis and first treatment phase. Studies, mostly utilising patient self-report measures, reveal functional impairments, limitations and restrictions influenced by personal and environmental factors across all WHO-ICF domains. Two studies included objective evaluations of function. Six studies explored functional performance as a primary aim. Five studies

suggested specific or general rehabilitation interventions to address identified needs.

Conclusions Needs associated with a diagnosis of inoperable lung cancer impact on daily life in the peri and early post-diagnostic period across all WHO-ICF domains. Specific functional impairments, limitations and restrictions and the potential role of rehabilitation services are rarely explored objectively or discussed in the supportive care literature for this population. Research is needed to guide the development of effective rehabilitation interventions acceptable to patients, health care commissioners and providers that address the impact of a new lung cancer diagnosis on functional performance.

Keywords Inoperable lung cancer · Rehabilitation · Functional activities of daily living · Supportive care

What is already known about this topic?

- Patients living with inoperable lung cancer experience a high symptom burden and unmet supportive care needs.
- Symptom burden and unmet supportive care need are associated with psychological distress and adversely impact on daily life activities.

What this paper adds

- No studies were found to specifically explore rehabilitation need following diagnosis in patients with inoperable lung cancer.
- Patients experience specific functional impairments, limitations and restrictions across all World Health Organization International Classification for Functioning Disability and Health (WHO-ICF) domains, which can be described as rehabilitation needs.

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- Functional well-being is commonly evaluated using health-related quality of life measures. Validated measures of objective and patient-reported functional performance are rarely used in this population.

Implications for practice, theory or policy

- Conceptualisation of supportive care needs may influence assessment processes and the composition of supportive care services commissioned and delivered in the post-diagnosis period as patients commence anti-neoplastic or palliative treatments.
- Greater understanding of rehabilitation need following diagnosis is needed to guide research, development and delivery of effective and acceptable rehabilitation interventions in the post-diagnosis period for this population.

Background

Lung cancer remains the second most common cancer in the UK, the most prevalent cancer worldwide and the main cause of cancer deaths in the UK and worldwide [1, 2].

A diagnosis of inoperable lung cancer and subsequent treatment impact negatively on functional activities of daily living [3]. Patients experience a high symptom burden, including breathlessness, fatigue, cough and pain alongside unmet need and sarcopenia throughout their illness [4–9], which are risk factors for decreased quality of life, increasing functional decline and disability. Fear of functional decline, disability and dependency are associated with psychological distress [3, 10, 11]. A systematic review of unmet supportive care needs in patients with cancer found difficulties in activities of daily living were most frequently reported or observed [12], although they were not described as rehabilitation needs.

How supportive care needs are conceptualised may influence assessment processes and the composition of supportive care services provided [13]. If rehabilitation needs are not specifically identified within the supportive care literature and guidelines, it may adversely affect the provision of rehabilitation as an integral component of supportive care services. Cancer rehabilitation, as described by Silver et al, should ‘treat patients’ physical, psychological and cognitive impairments in an effort to maintain or restore function, reduce symptom burden, maximise independence and improve quality of life’ [14]. Although functional participation in daily activities can be maintained, supported or restored with rehabilitation interventions targeting specific symptoms to meet patient-centred goals [15], many cancer patients experience unmet rehabilitation needs [13, 16–21]. It has been suggested that functional impairment and disability may occur ‘insidiously’ and go unrecognised by health care providers delivering supportive

care services [22]. The National Institute for Clinical Excellence Quality Standard for Lung recommends holistic need assessment at key stages of care from diagnosis to ensure that patients are referred to appropriate specialist services, including rehabilitation [23], in accordance with domain 3 of the current UK NHS Outcomes Framework ‘Helping people recover from episodes of ill health.’ Services should support people ‘to maintain wellness and independence’ with rehabilitation services ‘tailored to the needs of individual patients’ [24].

Although exercise [25–28] and psycho-educational relaxation interventions [29] are associated with some improvements in lung cancer symptoms, physical functioning, emotional well-being and single quality of life scores, studies exploring cancer rehabilitation in the early lung cancer treatment pathway are scarce [30]. However, the burden of distressing symptoms and the high prevalence of sarcopenia suggest that proactive rehabilitation interventions delivered in the post-diagnostic period have the potential to mitigate the onset and impact of functional restrictions or limitations across all domains of the WHO-ICF, including body structures, body functions, activities, participation, the social and physical environment and personal factors. An evaluation of rehabilitation need in the post-diagnostic phase would facilitate future research and implementation of evidence-based interventions in this population.

This review aims to

- Synthesise information on whether patients with inoperable lung cancer have functional impairments, activity limitations and participation restrictions as classified in the WHO-ICF [31], amenable to proactive rehabilitation interventions in the early post-diagnosis phase.
- Identify how studies in the supportive care and rehabilitation literature evaluate and represent functional rehabilitation needs in patients newly diagnosed with inoperable lung cancer.
- Highlight gaps in the evaluation and representation of rehabilitation need within the supportive care literature.

Methods

The review processes were structured according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement [32] and European Guidance on the Conduct of Narrative Synthesis in Systematic Reviews [33].

- Search strategy
- Eligibility criteria
- Assessment of relevance to review aims
- Assessment of methodological quality
- Data extraction and synthesis.

A search of the Cochrane Database of Systematic Reviews revealed no current reviews on this topic area. Initial mapping of the literature using rehabilitation and lung cancer as search terms revealed few hits. To identify studies that explore potential rehabilitation needs, broader terms associated with supportive care were selected to identify patients' functional daily living experiences following diagnosis. Selected search terms (Appendix 1) and eligibility criteria are presented using the SPIDER tool (Table 1) [34]. Search terms were combined with 'or' within groups and 'and' between groups.

Electronic databases Medline, Web of Science, Cinahl, AMED and PsychINFO were systematically searched in April 2014 for period of January 2000 to April 2014 (Fig. 1). This time frame was selected as rehabilitation was only formerly included in national supportive and palliative care guidelines in 2004 [35]. Reference lists of relevant papers were searched manually. A search of the content pages of key rehabilitation, supportive and palliative care journals, including Clinical Rehabilitation 2002–2013, International Journal of Therapy 1996–2014, Archive Physical Medicine and Rehabilitation 1995–2014, Palliative Medicine 2012–2014 and BMJ Supportive and Palliative Care 2011–2014, yielded no papers relevant to the review.

JB reviewed all papers retrieved against the agreed inclusion criteria. MLW reviewed 10 % of the full text papers retrieved. All decisions regarding eligibility were confirmed.

Data extraction and synthesis

As the review included heterogeneous study designs, including quantitative, qualitative and mixed methods, narrative synthesis was utilised [32]. Hawker's criteria [37] were used to assess methodological quality. Nine items, title and abstract, introduction and aims, method and data collection, sampling, data analysis, ethics and bias, results and transferability or generalisability, are graded from 4 (very good) to 1 (very poor), giving a total possible score of 36.

Studies were investigated for data exploring the impact of a diagnosis of inoperable lung cancer on daily functional activities and roles. Analysis was guided by the WHO-ICF 2001. The WHO-ICF classification provides a bio-psychosocial framework for exploring the complexity of function in daily

living in health care research (Fig. 2). This review utilises the most salient one-level classifications of the WHO-ICF for rehabilitation services. Impairments in physical and psychological body functions are identified alongside limitations in performance and restrictions in participation in daily living activities. Environmental and personal contextual factors are also identified (Table 2) [31].

Findings/results

Phenomena of interest: impact of a new diagnosis of inoperable lung cancer on daily functional activities and participation in usual roles and rehabilitation needs

Thirty-two heterogeneous studies exploring 25 data sets in patients with varied lung cancer histology, performance status and treatment from seven countries were included in this review (Table 1). Qualitative and quantitative studies exploring symptoms and quality of life were most prevalent with few studies exploring functional impact in daily activities and roles as a primary aim. No studies explored rehabilitation needs as a primary aim. Studies were of mixed methodological quality with a mean score of 30 (range 26–35). Ethics and bias scored particularly badly across the included papers, 12 papers scored 'poor'. Individual scores are presented in the tables of findings 3 and 4. Against the WHO-ICF classifications, specific impairments in body functions (29/32) were more frequently explored than specific difficulties in activities and participation (22/32) or personal and environmental factors (16/32). Utilising predominantly quantitative self-reported measures, the majority of studies explored symptom experience (20/32). Self-reported functioning in daily life was largely reported through the use of quality of life measures (10/32) with just four studies including objective or self-reported measures of function.

Main findings are presented in Tables 3 and 4 and discussed below.

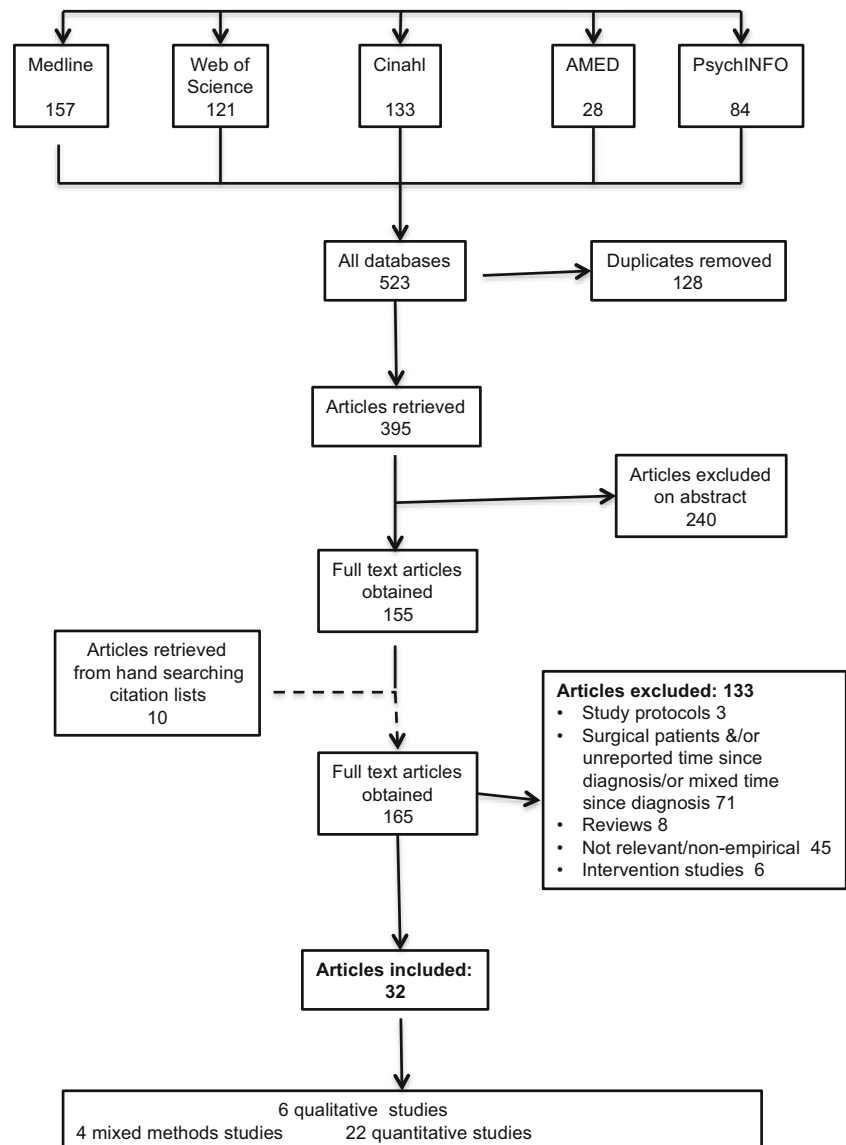
Studies exploring functional impairment as a primary aim

Of six studies exploring function in daily life as a primary aim, five utilised patient self-reported measures with just two

Table 1 Search strategy

SPIDER	This review	Search terms
S—sample	Patients newly diagnosed with any inoperable lung cancer, any stage, pre-, during and post-first treatment	Group 1
PI—phenomenon of interest	(1) Impact of new diagnosis of inoperable lung cancer on daily functional activities and (2) rehabilitation needs	Group 2 and Group 3
D—design	Empirical studies, qualitative, quantitative and mixed methods with abstract written in the English language from any country	
E—evaluation	Views of participants and outcomes	Group 2 and Group 3
R—research type	Any	

Fig. 1 PRISMA flow diagram of study selection [31]. *PRISMA* Preferred Reporting Items for Systematic Reviews and Meta-Analyses



reporting participants' performance status. Potential rehabilitation targets across a range of WHO-ICF domains were identified (Table 3) [38–43]. One qualitative study and a mixed-method study reported limitations and restrictions in activity and participation domains influenced by personal and environmental factors [38, 43]. Three quantitative studies utilising

quality of life [40] or symptom outcome measures [39, 42] reported negative impact on body function, activity and participation domains. One quantitative study utilised objective and functional performance measures to identify impairments in the cardiovascular, haematological, immunological and respiratory function domains [41].

Fig. 2 Interactions between the components of WHO-ICF [31]

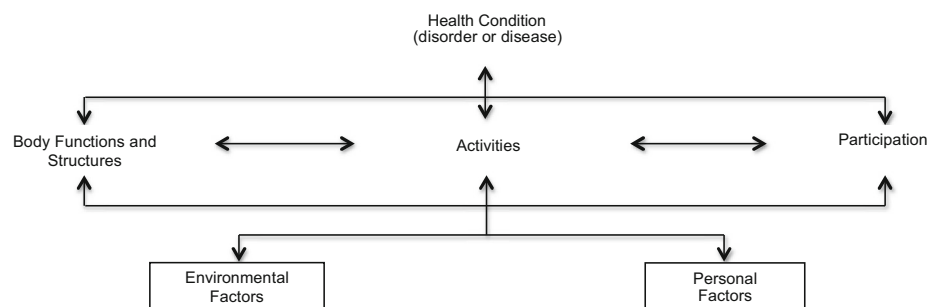


Table 2 WHO-ICF classifications key

Body functions (associated body structures are not included in this review)	Activities and participation
b1 Mental functions	d1 Learning and applying knowledge
b2 Sensory functions	d2 General tasks and demands
b4 Cardiovascular, haematological, immunological and respiratory system functions	d4 Mobility
b5 Digestive, metabolic and endocrine system functions	d5 Self-care
b6 Genitourinary and reproductive functions	d6 Domestic life
b7 Neuromusculoskeletal- and movement-related functions	d7 Particular interpersonal relationships
b8 Skin and related structure functions	d8 Major life areas
Environmental factors	d9 Community, social and civic life
e3 Support and relationships	Not defined, covered or classified by WHO-ICF
e4 Attitudes	Nd-ph Not defined physical health
e5 Services, systems and policies	Nd-gh Not defined general health
Personal factors	Nd-mh Not defined mental health
Not currently classified in the WHO-ICF, these include patients' beliefs, behaviours, coping mechanisms and cultural values	Nc Not covered by WHO-ICF

Source: [31]

Despite identifying potential targets for rehabilitation interventions, only one study discussed a rehabilitation intervention. Wang et al. [41] examined pre-treatment functional exercise capacity. Poorer functional exercise capacity was variably predicted by age, gender, spirometry, haemoglobin and dyspnoea; factors that the authors recommend are considered in exercise intervention design for this population.

In a longitudinal analysis of functional abilities, symptoms and emotional distress, Fodeh et al. [39] observed a symptom and functional impairment cluster of cough, walking, eating, breathing and insomnia in patients with lung cancer. Functional impairments amenable to intervention are suggested to precede and act like other symptoms in the diagnostic phase. Specific interventions were not discussed. Fatigue was most prevalent amongst multiple symptoms associated with interference in daily life activities identified in longitudinal studies by Lovgren et al. [40] and Wang et al. [42]. Improved symptom management is recommended. Westerman et al. utilised a mixed-method approach to explore response shift in perceived physical and role functioning in patients with small-cell lung cancer at the start of first-line chemotherapy [43]. Using the three-step interview test technique, response behaviour on completion of a quality of life measure was explored. Stable quality of life scores were observed in patients reporting deteriorating disease and declining function.

Bertero et al. [38] found respondent-reported items largely in the personal factor domain of the WHO-ICF in a qualitative study exploring lived experience. Respondents reported wanting to live as usual, not be a burden and maintain independence, though experienced uncertainty, hope, thoughts of death, sadness, shame and guilt. Asking for help was perceived to be difficult. Recommendations include giving

patients and their support network clear information and time to talk about feelings.

Studies exploring symptoms, concerns, unmet need or quality of life

A range of conceptually diverse subjective experiences were explored as primary aims in 26 studies. Symptoms and concerns impacting across all WHO-ICF domains with potential to be targets of rehabilitation interventions were revealed (Table 4). A range of standardised symptom and/or quality of life self-reported outcome measures was used for data collection in 17 quantitative studies. The European Organisation for Research and Treatment of Cancer Core Quality of Life Questionnaire and Lung Cancer Module (EORTC-QLQ-30 + LC13) was most commonly used followed by the symptom distress scale in nine and five studies, respectively. Semi-structured interviews were conducted in three qualitative studies. Three mixed-method studies explored EORTC-QLQ-C30 + LC13 findings.

Twelve studies explored symptom experience [44–55]. One study explored the views of health care professionals on symptom control [56]. Quality of life was explored in five studies as the sole aim [57–59] and in relation to symptoms in two [60, 61]. Three studies explored distressing concerns [53, 62, 63]. Unmet concerns, the impact of caregiver burden on distress, experiences of care and perceptions of anxiety in patients and their support network were each the subject of one study [64–67].

Symptoms

Fatigue was most commonly reported among multiple symptoms impacting on functional daily life in 16 studies. Borthwick

Table 3 Phenomenon of interest: studies exploring functional impairments, limitations or restrictions in daily life as a primary aim

Study, year, origin	Research design, data collection and time since diagnosis (TSD)	Scope of study	Quality score ^b	Number	Relevant findings	WHO-ICF domains linked to findings (using ICF linking rules (Cieza A. et al. 2005))	Implications for rehabilitation interventions discussed?
Bertero et al. 2008, Sweden	Qualitative, cross-sectional, semi-structured interviews. Phenomenological hermeneutic approach TSD = 6–7 weeks	Impact of diagnosis of inoperable lung cancer on life situation and quality of life in patients having palliative chemotherapy or radiotherapy No histology, staging or performance status reported	30	23	Made up of six themes: (1) Experience of uncertainty, (2) experience of hope, (3) network of support, (4) thoughts of death, (5) feeling shame and (6) guilt. Next of kin reactions. 'Essence' of findings: living as usual, maintaining independence and integrity, maintaining status, being treated as the person they always had been, meanings to fulfil in life. Participants reported difficulty asking for help and not wanting to be a burden. Remaining independent and responsible in daily life important.	b1 d2, d7 e3, e4 nc life situation, symptoms, treatment; nd-qol, quality of life; and pf living as usual, independence and integrity, uncertainty, outlook, hope, coping, self perception, reactions of others.	No. Authors suggest that information obtained in study will be useful for the development of interventions and treatment guidelines.
Fodeh SJ et al. 2012, USA	Quantitative, secondary analysis. <i>Symptom Distress scale, Emotional Distress Thermometer, Enforced Social Dependency Scale (personal competence component)</i> TSD = <100 days	Symptoms and functional impairments in patients within 100 days of diagnosis. Stage and PS not given.	31	22/11 20 %	Impairments in functional daily activities may act as symptoms in diagnostic phase. Assessment needs to include questions on functional impairment as well as symptoms. Overall sample had moderate levels of symptom distress. Small sample. Lung symptom cluster = cough, walking, eating/feeding, breathing and insomnia.	b4, b5, b1, d4, d5, nc symptom distress	No. Functional impairment should be considered a symptom 'amenable to intervention', although intervention is not described.
Lovgren M et al. 2008, Sweden	Quantitative, descriptive longitudinal secondary analysis. <i>EORTC QLQ-30 EORTC LC13</i> . TSD = median 23 days and mean 31 days	Symptoms and problems with functioning in women and men in patients with NSCLC and SCLC receiving radiotherapy over time. Stages 1–4. No PS.	35	159	Patients have many and varied symptoms. Fatigue associated with most prevalent symptoms and functional problems at all time points (88 % of women and 86 % of men). Statistically significant improvements in emotional functioning, dyspnoea, insomnia, cough and pain in arm/shoulder. Statistically significant deterioration in physical functioning, fatigue, constipation, dysphagia, peripheral neuropathy and alopecia over time. Biological sex and education level influence emotional and role functioning but not symptom prevalence or severity.	b1, b2, b4, b5, b8 d1, d2, d4, d5, d6, d7, d8, d9 e5 nd-qol quality of life nd-gh	No. Need for intervention not related to severity or intensity level of symptoms. Some symptoms may need intervention at lower levels than others due to impact on function. No actual interventions discussed.
Wang LY 2013, Taiwan	Quantitative, descriptive <i>maximum inspiratory and expiratory muscle pressure, spirometry, Karnofsky</i>	To identify functional exercise correlates in three age groups at diagnosis	31	105	Factors influencing functional exercise capacity varied between age groups.	b4, b5, d4	Yes. Findings should influence design of exercise protocols for this population.

Table 3 (continued)

Study, year, origin	Research design, data collection and time since diagnosis (TSD)	Scope of study	Quality score ^b	Number	Relevant findings	WHO-ICF domains linked to findings (using ICF linking rules (Cieza A. et al. 2005))	Implications for rehabilitation interventions discussed?
Wang XS et al. 2006, USA	Performance Scale, Barthel Index and Modified Borg Scale. TSD = at diagnosis	Stages IIb–IV, NSCLC and SCLC KPS 86.84 (8.20).	33	64	<=50 years, female, reduced maximum expiratory pressure, increased dyspnea and decreased HgB. 51–65, decreased FEV ₁ , and FVC, increased weight loss >65, increased dyspnoea 63 % patients had moderate to severe levels of multiple symptoms by end of treatment. Variable patterns and clusters. All had significant impact at level of functional interference. Fatigue = most severe symptom throughout radiotherapy, did not return to baseline levels 5–6 weeks post-treatment and highest predictor for interference in daily life. Highest levels of symptom interference in 'general activity' and 'work'. Physical symptoms had greatest interference when moderate to severe. Affective symptoms had greatest interference when mild to moderate.	b1, b2, b4, b5, b7 d2, d4, d7, d8 PF enjoyment of life	No. Discussion suggests need for better symptom understanding and management.
Westerman MJ et al. 2008, Netherlands	Qualitative, longitudinal, Three-step test interviews and EORTC QLQ C30-items 1–7 (physical and role functioning). TSD = 7–10 days	Physical and role functioning in patients with SCLC evaluated for first-line chemotherapy. Aim to explore response shift and to understand why EORTC QoL scores can be stable in context of deteriorating condition.	32	23	Most patients reported higher quality of life at second interview. Physical functioning scores worsened, role functioning scores improved. Patient responses suggested greater actual than perceived limitation. Patients answered literally, guessing function in activities not performed, ignored/excluded activities they couldn't perform. Focus on literal meaning of question. Variance in patients' perceptions of what questions mean. Subjective interpretation of activity levels.	d2, d4, d5, d6, d8, d9 nd-gh (stay in bed/chair during day) nd-gh (general health) nd-qol (quality of life) pf perceptions and beliefs about current activity levels.	No. Maintained quality of life outcome scores across the disease trajectory may conceal changes in physical and role function as patients present their function more positively subjectively than can be observed objectively.

NSCLC non-small-cell lung cancer, SCLC small-cell lung cancer, PS performance status

^a Rehabilitation defined as 'an educational problem solving approach, focusing on activity limitations, aiming to optimise social participation and well-being and reduce stress on carer and family' [36]

^b Quality was assessed across the following nine areas (after Hawker et al. [37]): title and abstract, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability or generalisability, implications and usefulness. Max score = 37

Table 4 Phenomenon of interest: potential rehabilitation targets revealed in studies exploring concerns, unmet need or quality of life

Study, year, origin	Research design, data collection and time since diagnosis (TSD).	Scope of study	Quality Score ^e	Number	Relevant findings	WHO-ICF domain linked to findings (using ICF linking rules (Cieza A. et al. 2005))	Implications for rehabilitation interventions discussed?
Auchter RM et al. 2001, USA	Quantitative, longitudinal. <i>FACIT-Lung questionnaire</i> TSD = day of first treatment	Acute toxicity and quality of life in patients with NSCLC PS 0–1 stage III accelerated radiotherapy.	26	30	Physical and functional quality of life decreased significantly during treatment then returned to baseline 4 weeks post-treatment. Emotional functioning improved at all time points. No deterioration in social well-being or relationship with doctor was observed. Data collection limited to 4 weeks post-treatment.	b1, b2, b4, b5, d2, d5, d6, d8, d9 e3, e4	No. Variance in participants' perceived function. Relationship between poor base line scores and shorter overall survival. 'Quality of life' as measured by FACT-Lung can remain stable and improve following treatment despite progressive disease.
Borthwick et al 2003 UK	Mixed method, <i>longitudinal. Structured diaries (all participants). Semi-structured interviews (subset-1)</i> TSD = pre-first treatment	Nature, severity and intensity of fatigue and perceived effectiveness of self-care strategies in patients receiving radiotherapy for NSCLC, stages I–III.	29	53	Fatigue increased through treatment then decreased by 1-month post-treatment. Not considered significant at 1 month post-treatment but remained greater than baseline. Greater in patients with other symptoms or comorbidities. Less than expected interference with daily activities. Self-care strategies used: 100 % used 'taking it easy' which helped 50 % time. Other strategies used: sleeping during day—76.1 %, distraction techniques—96 % and walking—67.4 %. Participants found it hard to describe fatigue, minimised, self-presented as accepting and tolerating symptom. Data collection limited to 1 month post-treatment.	b1, b4, b7, d2, d9 PF self-care strategies	Yes. Patients use a range of 'common sense strategies', which have limited success. Guidelines are needed for fatigue management with a multi-professional rehabilitation focus, including energy conservation, education and exercise.
Brant JM et al. 2011, USA	Quantitative, retrospective chart review. Latent growth curve analysis of symptoms. <i>Patient Care Monitor</i> . TSD = first day of first treatment	Pain, fatigue, sleep disturbance, depression, distress in patients with lung, colorectal or lymphoma receiving first line chemo stages I–IV. Disaggregated data.	34	55/118 46.6 % of sample	Lung patients all had high levels of symptoms at start of treatment. Fatigue increased over time. A cluster of symptoms including pain, depression, distress, fatigue and sleep disturbance were reported.	b1, b2, b4, b7 ne-symptoms	No. Significant depression, fatigue, pain and sleep disturbance at start of treatment indicates supportive care may be required for some early in the course of the disease and treatment.
Broberger E. et al 2005, Sweden	Quantitative, longitudinal exploratory, <i>Symptom distress scale, Thurstone scale of symptom Distress-lung cancer</i> TSD <2 months	Discrepancies in assessment of symptom occurrence and symptom distress in patients undergoing radiotherapy, radiotherapy nurse and family caregiver. Stage and PS not given.	33	85	Nurses rated symptom occurrence higher than patients. Patients and informal carers more in agreement re distress and occurrence than patients and nurses. Greater discrepancies in less observable symptoms like outlook, mood and fatigue. Breathing, pain and fatigue	b1, b2, b4, b5, b7, d4, nd-qol quality of life pf appearance, outlook	No. Authors suggest that patients may underreport symptoms, are concerned to cope, not be a burden on carers. Prioritisation of preventative care for potentially distressing symptoms needed.

Table 4 (continued)

Study, year, origin	Research design, data collection and time since diagnosis (TSD).	Scope of study	Quality Score ^e	Number	Relevant findings	WHO-ICF domain linked to findings (using ICF linking rules (Cieza A. et al. 2005))	Implications for rehabilitation interventions discussed?
Broberger E. et al. 2006, Sweden	Quantitative, longitudinal, exploratory, secondary analysis. <i>Selected items from EORTC-QLQ-C30 = LC13</i> TSD = mean 31 days, median 23 days	Recalibration response shift in patients' assessment of fatigue, global health and quality of life over time in patients undergoing radiotherapy Stage and PS not given.	33	126	associated with greatest distress. Fatigue most intense. Significant changes in fatigue in patients reporting deterioration at 3 months and improvement at 6 months but not in patients reporting improvement after 3 months or deterioration after 6 months. Unable to conclude that global changes in quality of life and fatigue are related to changes in internal standards of fatigue. Variable patterns of changes in quality of life over time in unexpected directions. Some patients retrospectively report worse baseline scores	b1, b4, b7, d4, d5, nd-qol quality of life	No. Patients present at diagnosis with high levels of symptoms. Some patients may adapt to symptoms prior to diagnosis.
Broberger E. et al. 2007, Sweden	Mixed methods, longitudinal, exploratory, secondary analysis Spontaneous report free text question <i>EORTC-QLQ-C30/LC13</i> TSD = <2 months	Most distressing concerns and changes over time in patients newly diagnosed with inoperable lung cancer undergoing radiotherapy. Stage and PS not given.	34	46	Wide range of concerns causing distress which changed over time. 56–62 % of spontaneously reported concerns at baseline, follow-up and in retrospect were picked up by EORTC QLQ C30. At all time points, fatigue, pain and dyspnoea most frequently reported as causing most distress. EORTC QLQ C30/LC13 intensity ratings of these concerns varied. The standardised measures did not capture all changes in patient's specific concerns and priorities over time.	b1, b2, b4, b5, b8, d1, d2, d4, d5, d6, d7, d8, d9, nd-qol quality of life	No. Individualised measures are recommended to capture most distressing needs and concerns not identified as priorities in standardised measures.
Buchanan D. et al. 2010, UK	Quantitative, descriptive, cross-sectional <i>Palliative Outcome Score</i> TSD = 66.5 % <28 days and 33.5 % >28 days	Anxiety, physical symptoms, perceptions of anxiety in support network and PS in NSCLC and SCLC lung cancer patients. Stages 1–4, limited and extensive, PS 0–4.	27	170	Physical performance status self rated with ECOG. As physical function declines and symptoms increase, patients are more worried and perceive more anxiety in their support network. Maladaptive anxiety is associated with impaired function. Social environment may impact on coping.	b1, b2, b4, d7, e4 nc haemoptysis. Pf life not worthwhile, low self-esteem	No. 'Targeted supportive care measures' needed.
Cooley ME et al. 2002, USA	Quantitative, longitudinal, exploratory, secondary analysis, <i>Symptom Distress Scale</i> TSD = <100 days	Symptom distress over time in NSCLC and SCLC patients treated with surgery, chemotherapy and radiotherapy. Disaggregated	35	117	High levels of symptom distress at study entry. Decreased in all at 3/12, increasing again at 6/12. Treatment mode was strongest predictor of symptom distress.	nc symptom distress	No. Patients need individualised symptom management from palliative care services from diagnosis

Table 4 (continued)

Study, year, origin	Research design, data collection and time since diagnosis (TSD).	Scope of study	Quality Score ^e	Number	Relevant findings	WHO-ICF domain linked to findings (using ICF linking rules (Cieza A. et al. 2005))	Implications for rehabilitation interventions discussed?
Cooley ME et al. 2003, USA	Quantitative, longitudinal exploratory, secondary analysis, <i>Symptom Distress Scale</i> TSD <100 days	data presented. Stage = early to late. PS not given. Symptom distress over time in NSCLC and SCLC patients treated with surgery, chemotherapy and radiotherapy. Disaggregated data presented. Stage = early to late. PS not given.	34	117	Symptom distress score higher in patients with inoperable disease after 6/12. Fatigue most prevalent symptom at all time points, followed by pain in all treatment groups. Symptom distress at baseline strongest predictor of distress at 6/12. Breathlessness not assessed.	b1, b2, b4, b5, b7	Yes. Term 'rehabilitation' not used, 'non-pharmacological strategies' discussed include exercise, positioning, relaxation, TENS and goals for care Individualised symptom management recommended from diagnosis.
Henoch I et al. 2009, Sweden	Quantitative, cross-sectional <i>II items from EORTC QLQ-C30, EORTC LC13, symptom distress scale</i> , TSD = mean 31 days (SD 27)	Symptom clusters in patients 1 month post-diagnosis with NSCLC or SCLC receiving radiotherapy Stages 1-4. PS not given.	32	400	Fatigue and appetite loads onto all of three symptom clusters but greatest on pain and respiratory clusters. Cluster 1 = pain, nausea, bowel, appetite and fatigue Cluster 2 = mood, outlook, concentration and insomnia Cluster 3 = respiratory, breathing and cough.	b1, b2, b4, b5, PF outlook	No. Research needed to inform evidence based management of all symptoms in a cluster.
Hill KM et al. 2003, UK	Quantitative, exploratory, cross-sectional, <i>Concern Checklist (modified)</i> TSD = >95 % before first treatment	Met and unmet concerns in patients prior to treatment commencement. Any primary lung cancer. Stage and PS not given.	27	89/169	>50 % patient had major to moderate concerns about illness, family future, burden and energy levels. >40 % had moderate concerns concerning emotions, treatment and breathlessness. <30 % were concerned about independence. Patients reported their health care team discussed 43 % of their concerns.	b1, b2, b4, b5, b7, d2, d4, d6, d8 pf concerns re family emotions, feeling a burden, independence and appearance	No. Authors emphasise importance of early identification of concerns to enable provision of appropriate services.
Hoffman AJ et al. 2007, USA	Quantitative, cross-sectional secondary analysis, <i>Cancer Symptom Experience Inventory (pain, fatigue & and insomnia scores)</i> TSD = <56 days	Relationships amongst pain, fatigue, insomnia and gender in patients with NSCLC or SCLC on chemotherapy Stages 1-4, limited and extensive. PS not given.	30	80	<30 % of patients concerned about being a burden, and 40 % patients concerned about their energy level had their needs addressed by HCPs. Frequency and severity of symptoms assessed. Fatigue most frequently reported (97 % followed by pain (69 %). Three-way interaction between pain, fatigue and insomnia not influenced by stage of treatment, age or comorbidities. 44 % of sample experienced breathlessness.	b1, b2, b4, b5, b7, nc-fever nc- mouth sores	No. Greater emphasis needs to be placed on anticipatory and preventative symptom management alongside cancer treatment.

Table 4 (continued)

Study, year, origin	Research design, data collection and time since diagnosis (TSD).	Scope of study	Quality Score ^e	Number	Relevant findings	WHO-ICF domain linked to findings (using ICF linking rules (Cieza A. et al. 2005))	Implications for rehabilitation interventions discussed?
Krishnasamy et al. 2007, UK	Qualitative longitudinal, <i>semi-structured interviews</i> . TSD = 4–8 weeks	Experiences of care provision following diagnosis in patients with NSCLC, SCLC and mesothelioma. No staging or PS data given.	27	60	Four key domains—delays in pathways to diagnosis, communication of diagnosis and treatment options, provision of coordinated, family orientated care, support away from acute hospital. Awareness of deteriorating physical condition and social isolation. Concerns for family. Increased carer burden at 6 months as patient disability increases. Lack of coordinated supportive and specialist support in home identified. Participants did not ask for or appear to expect specialist support despite needs and concerns expressed.	b1, d9, e3, e5 nc pathway to diagnosis nc carer burden pf feeling a burden on family, feeling unsafe between appointments	No. Authors highlight need for earlier referral to coordinated supportive and palliative care services.
Langendijk JA et al. 2000, Netherlands	Quantitative, exploratory, longitudinal, <i>EORTC QLQ-30 and EORTC LC13</i> TSD = pre-first treatment	Pre-treatment quality of life, impact of prognostic factors and respiratory symptoms on general symptoms and quality of life in patients with stages I–IV inoperable NSCLC referred for radiotherapy. Stage 1 PS 0–3.	28	262	Patients in palliative treatment group had significantly lower levels of physical and psychosocial functioning, poorer global quality of life, and more severe general and respiratory symptoms than those in radical or curative groups. Association between performance status and weight loss with quality of life observed but not other prognostic factors. Dyspnoea significantly associated with general symptoms, physical and role functioning, quality of life and fatigue 6 weeks after radiotherapy.	b1, b4, b5, b7 d2, d4, d5, d6, d7, d8, d9 e5 nd-ql quality of life nd-gh general symptoms	No. Authors suggest that palliation of dyspnoea may have a beneficial effect on patient functional quality of life, fatigue and global quality of life.
Lheureux C et al. 2004, France	Quantitative, exploratory, longitudinal, <i>EORTC QLQ-30 and EORTC LC13</i> TSD = pre-diagnosis	Impact of disclosure of diagnosis on quality of life in patients with neuro-endocrine and non-neuro-endocrine lung cancer. Extent of disease-limited and extensive. PS 0–2.	28	70	Quality of life measured pre and post-diagnosis. A positive diagnosis led to decreases in physical, social, role and emotional functioning in the absence of deterioration in symptom scores (excepting arm pain). Global quality of life remained stable. Symptom distress complex related to perceptions and nature of symptoms, anticipation, novelty, impact on daily life and previous experience. Relationship between causal reasoning and distress. Greater distress if symptoms associated with cancer than	b1, b2, b4, b5, b8 d1, d2, d4, d5, d6, d7, d8, d9 e5 nd-ql quality of life nd-gh	No Psychological support from diagnosis is recommended.
Lowe et al. 2011, UK	Qualitative, longitudinal, <i>semi-structured interviews</i> TSD = at beginning of treatment	Factors influencing patient symptom distress	27	17	Factors influencing patient symptom distress	nc symptoms pf beliefs about relationship between symptoms and possible causal factors.	No Health care professionals should consider potential adaptive benefits of causal reasoning adopted by patients.

Table 4 (continued)

Study, year, origin	Research design, data collection and time since diagnosis (TSD).	Scope of study	Quality Score ^e	Number	Relevant findings	WHO-ICF domain linked to findings (using ICF linking rules (Cieza A. et al. 2005))	Implications for rehabilitation interventions discussed?
Milbury K et al. 2013, USA	Quantitative, longitudinal, <i>Global Severity Raw Index (from Brief Symptom Inventory), Caregiver Reaction Assessment, Dyadic Adjustment Scale</i> TSD = mean 2.3 months (SD 1.7)	Associations between caregiver burden and patient and spouse distress. Stages I–IV. No PS. 57 % on treatment, chemo-radiotherapy (24.2), chemo-radiotherapy (3.2), surgery (16).	High 33	169 patients and 167 spouses	with other causes or if manageable. Symptom distress linked to impact on daily life more frequently than severity, duration or frequency. Baseline carer-related health problems associated with patients and carer distress at 3 and 6 months. Schedule disruption for carers predicted financial strain in carers and distress in patients at 3 months.	b1, e3, e4 nc carer burden	No. Intervention research needed to identify 'behaviour and self-care skills' for patients and caregivers.
Molassiotis A et al. 2011, UK	Qualitative, longitudinal, semi-structured interviews TSD = 2–3 weeks	Exploration of respiratory symptom distress.	35	17	Respiratory symptoms broad and dynamic in nature, varying in severity and frequency, impacting on daily life. Respiratory symptom cluster of cough, fatigue and breathlessness central to patient experience. Pain, nausea, vomiting, loss of appetite and weight change also reported. Psychological problems: depression, anxiety, intrusive thoughts, boredom, and frustration. Patients and carers use same terms to describe different but related symptoms. Body sensations associated with symptoms observed.	b1, b2, b4, b5, b7 d4, d4, d5, d8 e3, e4 nc symptoms pf boredom, not coping, uncertainty	No Inter-relationships between symptoms and coping effort need to be understood. Authors suggest symptom management strategies focusing on all symptoms within clusters.
Montazeri A, 2003, Netherlands	Quantitative, longitudinal, Nottingham Health Profile (NHP), ECOG, <i>EORTC QLQ-30 and EORTC LC13</i> TSD = pre-diagnosis	Quality of life, pre- and post-diagnosis NSCLC and SCLC No stage, PS 0–3 Chemotherapy (28 %), radiotherapy (30 %), surgery (5 %) and best supportive care (37 %).	34	82/133	At 3 month follow-up, significant deterioration in patient physical mobility, energy, physical and role functioning was observed. Symptom changes showed variation over time. Only cough showed significant improvement. Breathlessness remained stable; fatigue worsened.	b1, b2, b4, b5, b8 d1, d2, d4, d5, d6, d7, d8, d9 e5 nd-qol quality of life nd-gh	Yes. Lack of research to improve functional outcomes. Potential role for physiotherapy to improve physical mobility and physical functioning and family support to help with role functioning. Increase funding for palliative care.
Morita S et al. 2003, Japan	Quantitative Longitudinal Quality of Life Questionnaire for Cancer Patients treated with Anti-Cancer Drugs (QOL-ACD Japanese) TSD = pre-first treatment	Quality of life in patients with NSCLC receiving chemotherapy. Stages IIIb–IV. PS 0–2. Quality of life domains assessed: physical, mental, psychosocial and global. Individual	32	377	Wide variation in subject specific quality of life domain scores compared with sample means for physical and psychosocial domains during treatment and psychosocial domains after treatment. Physical domain most strongly associated with global quality of life during	b1, b4, b5, d2, d4, d5, d6, d7, d8, d9 e3, e4, nc are your family troubled? Pf do you worry about the future?	No. Observed variation between individuals should result in individualised tailored supportive care interventions, as targeting domains of concern may influence quality of life.

Table 4 (continued)

Study, year, origin	Research design, data collection and time since diagnosis (TSD).	Scope of study	Quality Score ^e	Number	Relevant findings	WHO-ICF domain linked to findings (using ICF linking rules (Cieza A. et al. 2005))	Implications for rehabilitation interventions discussed?
Tishelman C et al. 2005, Sweden	Quantitative, descriptive, longitudinal, adapted Symptom Distress Scale and Thurstone Scale of Symptom Distress-Lung Cancer TSD = mean 21 days and median 23 days	'weights' for domains also assessed. Symptom intensity, distinguishing from symptom distress in patients receiving radiotherapy Stages 1-4.	32	400	treatment in population mean. Post-treatment, wide subject specific variation in psychosocial and functional domains. Symptom distress and intensity are not equivalent. Symptom distress stable over time, symptom intensity varied. Breathlessness most distressing symptom at all time points followed by pain, then fatigue. Fatigue most intense symptom at all time points, followed by breathlessness then pain. Breathlessness, pain and fatigue most distressing symptoms at all time points even when intensity less severe, potentially due to perceived threat to self.	b1, b2, b4, b5, b7, pf appearance, outlook	No. Authors suggest that the findings highlight the need for a 'preventative paradigm'. Symptoms usually managed after they arise. Services instead should focus on the prevention of symptoms associated with distress, including breathlessness, pain and fatigue.
Tishelman C et al. 2007, Sweden	Quantitative, descriptive, longitudinal, EOCG, EORTC QLQ-30, EORTC LC13, Thurstone Scale of Symptom Distress-Lung Cancer. TSD = mean 21 days and median 34 days	Symptom prevalence, intensity and distress, relation to time of death in patients receiving radiotherapy Stages 1-4.	34	400	Functional quality of life scores lower and higher symptom distress observed in people closer to death. Symptom prevalence more strongly associated with distress in patients closer to death.	b1, b2, b4, b5, b8 d1, d2, d4, d5, d6, d7, d8, d9 e5	No Authors suggest that proactive prophylactic symptom management may be needed for symptoms with low intensity but which are associated with higher levels of distress.
Tishelman C et al. 2010, Sweden	Mixed methods, longitudinal EORTC QLQ30 EORTC LC13, free listing, Memorial Symptom Assessment Scale, modified Distress Screening Tool. TSD = mean 32 days and median 25 days	Assessment of most distressing concerns in patients with NSCLC and SCLC receiving radiotherapy Stages 1-4.	32	343	In free list statements, most frequently identified distressing concerns relate to 'bodily distress' and 'limitations in daily life'. Fewer statements relate to iatrogenic distress. Fatigue most prevalent concern at all time points. 60 % of patients reported fatigue and 38 % patients reported limitations in daily life at one or more time points. 55-59 % of free-listed statements were identified by the standardised measures. All three tools captured statements related to 'bodily distress' thoroughly. Musculo-skeletal and balance problems less well screened than other bodily distress items. 45 % of concerns relating to 'life situation' captured by EORTC measure, 26 % captured by DST and MSAS.	b1, b2, b4, b5, b8 d1, d2, d4, d5, d6, d7, d8, d9 e5 pf appearance, outlook nc sickness as a whole	No Authors suggest that concerns identified as most distressing in this population could and should be met by existing health care systems though appear not to be well dealt with in reality.

Table 4 (continued)

Study, year, origin	Research design, data collection and time since diagnosis (TSD).	Scope of study	Quality Score ^e	Number	Relevant findings	WHO-ICF domain linked to findings (using ICF linking rules (Cieza A. et al. 2005))	Implications for rehabilitation interventions discussed?
Videtic GM et al. 2013	Quantitative Observational Longitudinal, <i>FACT-Lung</i> <i>UCSD Medical Center Pulmonary Rehabilitation Program SOB questionnaire, 6MWT, spirometry, DLCO.</i> TSD = pre-first treatment	Quality of life, fatigue and pulmonary function after stereotactic body radiotherapy in patients with NSCLC. Stage 1 Zubrod PS 0-2 (5/21 PS = 0, 14/21 = PS 1).	27	21	Quality of life and pulmonary function not significantly decreased and fatigue not affecting quality of life at 1 year post-treatment. Authors report no significant change in global quality of life over time, but standard deviations for some outcomes suggest variability within sample.	b1, b2, b4, b5, b8 d2, d6, d7, d8 e3, e4	No Outcomes interpreted in relation to implications for radiotherapy treatment only.
Wagland R et al. 2012, UK	Qualitative, cross-sectional, focus groups, telephone interviews TSD = not applicable	Views of health care professionals on development and delivery of a non-pharmacological symptom management intervention for a respiratory distress symptom cluster in patients with lung cancer.	30	34	Health Care Professionals' (HCP) views on organisation and delivery of non-pharmacological interventions (NPIs) for management of respiratory symptom cluster. Findings: positive attitude but no systematic approach to delivering NPIs. Delivery influenced by if delivered by HCP, close to home, involve carers, personalised, issues re staffing. NPIs should be offered after onset of symptoms although short window of opportunity to deliver them effectively. Perception that patients avoid talking about symptoms, fearing impact on treatment offered, focusing on pharmacological interventions.	nc e4 (attitudes of health care professionals), e5 (organisation of health services)	Yes Term 'rehabilitation' not utilised but physiotherapists considered best placed to deliver NPIs.
Westerman MJ et al. 2007, Netherlands	Exploratory longitudinal multiple-case study. <i>Three-step test-interviews</i> , EORTC QLQ C30 and SeIQoL TSD = start of first treatment	Fatigue in patients newly diagnosed with SCLC evaluated for first-line chemo. No PS or staging.	32	23	Three-step test-interviews, think aloud whilst completing EORTC QLQ C30.15/23 showed discrepancies in responses. Respondents answered 'not at all' on the EORTC QLQ C30 whilst reporting worsening tiredness after each chemo treatment during the interviews. Recalibration, optimistic perspective and positive self-presentation were strategies revealed to add uncertainty to quality of life measurement.	b1, b4 nd-qol quality of life pf self presentation nc response shift.	No. Self-presentation described as a coping strategy.

NSCLC non-small cell lung cancer, SCLC small-cell lung cancer, PS performance status

^a Rehabilitation defined as 'an educational problem solving approach, focusing on activity limitations, aiming to optimise social participation and well-being and reduce stress on carer and family' [36]

^b Quality was assessed across the following nine areas (after Hawker et al. [37]): title and abstract, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability or generalisability, implications and usefulness. Max score = 57

et al.'s [44] mixed-method study in patients receiving radiotherapy for non-small-cell lung cancer found that fatigue had less than expected levels of interference on daily functions corresponding to the WHO-ICF activities and participation domains. However, respondents underreported and had difficulty describing their fatigue, minimising its impact when describing a range of self-care strategies. Data collection was limited to 1 month post-diagnosis. In two papers reporting a longitudinal secondary analysis of symptoms in patients treated with surgery, radiotherapy or chemotherapy by Cooley et al. [47, 48], disaggregated data reports found that fatigue was the most prevalent symptom observed at all time points. Breathlessness was not assessed. Whilst the term rehabilitation is not utilised, Cooley et al. [47, 48] recommend use of recognised rehabilitation strategies (exercise, positioning, relaxation, transcutaneous neuro-electrical stimulation and goal planning) within symptom management from diagnosis. Views of health care professionals on the delivery of interventions to manage a respiratory symptom distress cluster were explored by Wagland et al. [56]. Respondents reported that personalised non-pharmacological interventions, including physiotherapy, should be delivered as soon after the onset of symptoms as possible. Patients are perceived to focus on pharmacological interventions and to avoid talking about symptoms fearing a negative impact on treatments offered.

Westerman [55] observed response discrepancies in the measurement of fatigue during completion of the EORTC-QLQ-C30 question 'were you tired?' Respondents answering 'not at all' on the standardised measure reported worsening tiredness after each chemotherapy treatment, adding uncertainty to the use of standardised measures in quality of life measurement. The authors suggest that patients use 'self-presentation' as a coping strategy. Brant et al. [45] found that patients receiving first-line chemotherapy for stages I–IV disease had high levels of symptoms at the start of treatment. Fatigue increased over time and occurred in a cluster with pain, depression, distress and sleep disturbance. The authors recommend early supportive care for some. Fatigue was identified as causing distress in patients with stages I–IV lung cancer receiving radiotherapy in a series of six studies exploring a large data set in Sweden. Discrepancies in the assessment of symptom occurrence and distress between patients, informal carers and nurses in patients receiving radiotherapy were observed by Broberger et al. [46]. However, all groups ranked breathing, pain and fatigue as symptoms that would cause the most distress. The implications for rehabilitation are not discussed; however, prioritising preventative care for potentially distressing symptoms as highly as symptom management is recommended. Spontaneous 'free-listing' reports of most distressing symptoms were analysed against standardised measures in two studies. Broberger et al. [62] compared spontaneously reported symptoms with ratings on the EORTC-QLQ-C30 + LC13 in 46 patients at diagnosis and

at 6 months. A wide variety of symptoms changed over time with fatigue, pain and dyspnoea spontaneously reported as causing most distress at all time points. This was not reflected in the intensity ratings of the EORTC-QLQ-30 + LC13. Fewer patients spontaneously reported limitations in daily life at 6 months despite a greater number reporting distressing fatigue, pain and breathlessness. Approximately 40 % of the spontaneously reported concerns were not captured by the EORTC-QLQ-30 + LC13. Implications for assessment but not interventions were discussed. These findings were confirmed in a later study by Tishelman et al. [63], where 55–59 % of 'free-listed' symptoms and concerns were identified by standardised measures. Fatigue was most frequently the 'most distressing' free-listed symptom at all time points following diagnosis. Limitations in daily life and existential issues relating to outlook contributed to the impact burden and were more frequently reported than iatrogenic distress. The authors suggest that although they appear to be undermanaged, the concerns identified could and should be met by existing (undefined) health care services. Further studies by this group explored the relationship between symptom intensity, frequency and distress [53, 54]. Symptom distress was found to be stable over time, whereas symptom intensity varied. Fatigue, pain and breathlessness were the most distressing at all time points even when severity was lower. Breathlessness was reported as more distressing than fatigue, yet fatigue was reported with greater intensity than breathlessness [53]. Distress is more strongly associated with higher symptom severity closer to death [54]. In a study examining all 400 patients in this data set for the presence of symptom clusters 1 month following diagnosis, fatigue and appetite loaded greatest onto pain and respiratory symptom clusters but also loaded onto a mood and outlook cluster [49]. The authors recommend that intervention research focuses on managing all symptoms in clusters. In a cross-sectional secondary analysis of fatigue, pain and insomnia data from the Cancer Symptom Experience Inventory, Hoffman et al. [50] found that fatigue was most frequently reported (97 %) in a three-way interaction between symptoms observed and was not influenced by stage of treatment, age or comorbidities. Breathlessness was observed to occur in 44 % of the sample. Anticipatory and preventative symptom management delivered alongside cancer treatment is recommended. The management of symptoms in clusters was supported in the findings of a longitudinal qualitative study by Lowe et al. [51] and Molassiotis et al. [52] A respiratory symptom distress cluster comprising of cough, breathlessness and fatigue, and compounded by distress and associated meanings (corresponding to WHO-ICF personal factors), impacted on activities and participation in daily life.

Symptoms were investigated in relation to quality of life in two studies. Langendijk et al. [61] explored the impact of pre-treatment quality of life, prognostic factors and the presence

and severity of respiratory symptoms on general symptoms and quality of life in patients referred for radiotherapy treatment. Dyspnoea was significantly associated with general symptoms, physical and role functioning, quality of life and fatigue 6 weeks after radiotherapy. The authors suggest that the palliation of dyspnoea may have a beneficial effect on fatigue, functional and global quality of life. Broberger [60] investigated changes in and quality of life over time and found no predictable ‘recalibration response shift’. Variations were observed in global quality of life and fatigue over time in unpredictable and unexpected directions. Implications for interventions are not discussed.

Quality of life

The impact a positive diagnosis on quality of life was explored in a longitudinal study by Lheureux et al. [57] Patients with a high-performance status (0–2) reported quality of life using a standard measure pre- and post-diagnosis. A positive diagnosis led to decreases in physical ($p0.03$), social ($p0.014$), role ($p0.002$) and emotional functioning ($p0.0001$) in the absence of worsening symptom scores (excepting arm pain). The authors suggest that the observed function loss may relate to ‘moral anguish’ as patients’ report that they ‘do not want to have a walk’ or that they ‘want to stay at home’. A significant deterioration in perceived physical and role functioning was observed in a study by Montazeri et al. [58], evaluating quality of life from pre-diagnosis to 3-month follow-up. Findings were significant with moderate effect sizes. Rehabilitation, including a potential role for physiotherapy to improve physical mobility and functioning, is recommended alongside improved funding for palliative care to improve functional outcomes. Morita et al. [59] observed variations in subject specific quality of life scores compared with sample means in physical and psychological domains in psychosocial and functional domains after chemotherapy treatment in patients with advanced disease and suggest that supportive care interventions targeting individuals’ specific domains of concern may influence quality of life. Two studies exploring quality of life did not identify significant changes in function or symptoms following first-line treatment. Auchter et al. [68] explored quality of life in patients with stage III disease and a high-performance status undergoing accelerated radiotherapy. Although physical and functional quality of life as measured by FACT-Lung decreased significantly during treatment, these had returned to baseline by 4 weeks post-treatment. Emotional functioning was found to improve at all time points. No deterioration in social functioning was observed. A relationship was observed between poorer baseline scores and shorter overall survival. The authors report that quality of life as measured by FACT-Lung can remain

stable through treatment despite progressive disease. Standard deviations indicate variability within the sample. As data collection was limited to 4 weeks post-treatment, long-term effects are not identified. Videtic et al. [69] explored quality of life, fatigue and pulmonary function in patients with a high-performance status, following stereotactic radiotherapy treatment. Quality of life and pulmonary function did not decrease significantly at 1 year post-treatment. Fatigue did not affect quality of life at 1 year.

Unmet need, experiences of care and carer burden

Hill et al. explored met and unmet concerns in patients prior to treatment [64]. Over 50 % of patients reported major concerns about the future, their illness and being a burden. More than 40 % had moderate concerns about energy levels and breathlessness. However, fewer patients reported that their concerns regarding the future, being a burden (<30 %) and energy levels (<40 %), were met. Moderate and minor concerns regarding physical symptoms such as nausea and vomiting, pain and breathlessness were more likely to have been responded to by health care professionals. The authors highlight the importance of identifying concerns that are important to patients to enable appropriate services to be provided.

Buchanan et al. [67] explored patient perceptions of anxiety in their support network. Patient and perceived familial anxiety increased as patient physical function declined and was associated with dyspnoea, cough, haemoptysis, low self-esteem and self-worth. Targeted supportive care measures are recommended.

In a qualitative study, Krishnasamy et al. [66] explored experiences of care following diagnosis. Patients reported ‘significant and relentless deterioration in physical function’, which resulted in social isolation and concerns about being a burden. By 6 months post-diagnosis, as disability increased, family members felt more ‘isolated or unsupported’. In an exploration of caregiver burden, Milbury et al. [65] found that baseline carer health-related problems predicted both patient and carer distress at 3 and 6 months. Schedule disruption for carers also predicted financial strain in carers and distress in patients at 3 months. The authors recommend that intervention research to improve behavioural and self-care skills include patients and their carers to promote more successful coping with lung cancer.

Discussion

This systematic review has identified that patients newly diagnosed with inoperable lung cancer do experience functional impairments, limitations and restrictions as described in the WHO-ICF that may be amenable to rehabilitation interventions. This review of supportive care literature supports the

assertion by Rasmussen that there is ‘no comprehensive language to describe bodily experiences’ [70]. Although a wide range of conceptual terms are used to frame patient need, objective functioning and rehabilitation need are rarely explored. This supports the findings of Maguire’s systematic review of supportive care needs in patients with a lung cancer diagnosis, across all time points which found that needs relating to daily living and practical concerns were given less focus than those relating to symptoms, psychological, spiritual/existential, informational, social and family needs [71].

It is notable that the review yielded no results from the rehabilitation literature. Symptom measures were most commonly utilised and revealed impairments in the body functions domain of the WHO-ICF. Self-reported functioning was predominantly evaluated with quality of life measures and revealed perceived limitations and restrictions corresponding to the WHO-ICF activities and participation domains. Personal and environmental factors such as beliefs, behaviours, social context and resources were explored in fewer studies. Fatigue was observed most frequently, occurring in clusters with multiple symptoms including breathlessness, cough and pain. Fatigue, breathlessness and pain are recognised targets for rehabilitation interventions [72–75] and correspond to several body function one-level classifications of the WHO-ICF, including mental functions; sensory functions and pain; functions of the cardiovascular, haematological, immunological and respiratory functions; and also neuro-musculoskeletal and movement-related functions. Symptoms were varyingly associated with psychological distress, reduced physical and role functioning and worsened over time. Despite the symptom burden, personal factors revealed in mixed methods and qualitative studies indicate that patients strive to maintain normality and independence in everyday life activities and fear being a burden to their families. This suggests that symptoms, activities, participation and personal and environmental factors are important potential targets for rehabilitation interventions.

Whilst early identification and management of distressing symptoms and associated functional impact are recommended, the implications for patients’ potential need for specific rehabilitation services are discussed in just five included studies [41, 44, 48, 56, 58].

The findings reveal gaps in the literature and support the view that a limited understanding of the nature of disability exists in cancer [76]. Studies predominantly conceptualise patients’ supportive care needs in terms of symptoms, quality of life, distressing concerns or unspecified unmet need and rarely in terms of rehabilitation need, disability or functional impairment. It has been suggested that in attempting to minimise disablement, rehabilitation services may neglect subjective well-being as an outcome [77]. The findings of this review suggest that the reverse may be the case in supportive care services for patients with lung cancer, where efforts to

maximise quality of life neglect to minimise disability. A theoretical framework of patient experience which fails to fully conceptualise the specific disabling impact of diagnosis alongside symptoms and quality of life influences the research agenda and may affect the composition of supportive care services provided [13, 78], including the underutilisation of rehabilitation interventions in lung cancer [22]. The theoretical nuances of how need is conceptualised are revealed in a study by Ugalde et al., exploring unmet need and distress in lung cancer patients commencing any new course of treatment [79]. Four of the top seven identified needs described as psychological and emotional concerns relate to dimensions of actual or potential functional impairment. For example, ‘feeling dependent on others’ and ‘frustration not being able to do things you used to’ are described as psychological and emotional concerns. However, such concerns may be ameliorated by rehabilitation interventions to support role function in desired daily activities and could be described as rehabilitation need, relating to several domains of the WHO-ICF. Personal beliefs alongside particular environmental and social circumstances may interact and contribute to the development of physical impairments, symptoms and psychological distress, influencing functional performance and coping. Patients may adopt an optimistic perspective, positive self-presentation and normalisation as coping strategies and be reluctant to admit to rehabilitation need, particularly if they feel it may limit treatments offered [22]. If screening for actual and potential functional impairments and decline across all domains of the WHO-ICF is not undertaken, opportunities to refer to appropriate rehabilitation services may be missed [21, 80].

Early rehabilitation interventions to address impact of symptoms and psychological distress may support patients to achieve their expressed desires to remain functionally independent and to minimise their sense of burden on others. As several authors have indicated in this review, a preventative approach to symptom management is likely to be beneficial [46, 50, 53, 54]. Rehabilitation interventions delivered by a coordinated multiprofessional team (including occupational therapy, physiotherapy, dietitians, speech and language therapists and in some countries, psychiatrists) [28, 81–88] may minimise the onset and impact of distressing symptoms such as fatigue, breathlessness and pain on participation in activities of daily living. Cheville describes how rehabilitation has the potential to ‘decelerate disablement’ [22]. None of the studies explored patient preferences for the management of distressing symptoms and functional impairments at diagnosis. Potential barriers to rehabilitation may include fluctuating patient health status, psychological distress and busy schedules of appointments for investigations and treatments [89]. Patients and health care professionals may identify the post-anti-neoplastic treatment phase as the point to introduce symptom and rehabilitation interventions [56, 90, 91], although at this point, disablement may be established and be more

difficult to reverse. These factors should influence future research into the timing and configuration of rehabilitation services for patients following diagnosis with inoperable lung cancer.

Review strengths and limitations

Although the review was conducted using systematic methods according to established guidance to enable critique and reproducibility of the findings [32, 33], we cannot be certain that all relevant papers were retrieved. The grey literature was not searched, and no authors were contacted. The large number of heterogeneous papers created challenges and limits methodological quality analysis of included papers and the findings. Accordingly, Hawker's criteria [37] were selected to evaluate quality, and whilst methodological issues are not presented in detail, the summary findings are presented according to primary aim and provide an explicit indication of the strength of each study. The heterogeneity of included papers precludes statistical analysis of findings, and whilst the narrative synthesis was conducted rigorously, there is a risk of subjective researcher bias. However, the broad and encompassing inclusion criteria of qualitative and quantitative empirical research give strength to the review, enabling the aims of the review to be met.

Conclusion

Patients newly diagnosed with inoperable lung cancer experience a range of disabling symptoms and concerns, which impact on functional quality of life suggesting a need for early rehabilitation interventions. However, this review has highlighted that little evidence exists to determine the specific content, mode of delivery or acceptability to patients of rehabilitation interventions in the post-diagnosis phase. A rehabilitative approach in the management of patients newly diagnosed with inoperable lung cancer would include a baseline assessment of function prior to the commencement of treatment, anticipate the onset of known disabling risk factors and instigate rehabilitation interventions to mitigate their impact, thus decelerating functional impairment and disablement. Further research is needed to identify if tailored and targeted rehabilitation interventions, acceptable to patients and providers of care, support functional performance across all domains of the WHO-ICF in the post-diagnosis phase following diagnosis with inoperable lung cancer.

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Compliance with ethical standards

Conflict of interest The authors have no conflicts of interest to declare. The corresponding author has access to all the data and is willing to allow access to the data.

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