

Unmet Needs in Chronic Obstructive Pulmonary Disease: A Metasynthesis Protocol

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Abstract: Problem statement: Chronic obstructive pulmonary disease is a chronic progressive illness. Despite the high burden experienced by individuals in the advanced stages of illness, individuals with advanced COPD continue to have unmet needs and limited access to palliative care. This Metasynthesis seeks to describe: the barriers and facilitators care access and provision; the unmet needs of individuals with advanced COPD, their families and carers; and the experiences of health professionals. Data sources: Medline, PsychINFO, AMED, CINAHL and Sociological Abstracts were searched for articles published between 1990 and December 31st 2011. Medical Subject Headings (MeSH) and key words will be used to guide the search. The strategy will be reviewed by the CareSearch palliative knowledge network and a health informatics expert. **Approach:** Metasyntheses are increasingly used to gain new insights and understandings of complex research questions through the amalgamation of data from individual qualitative studies. The principles of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) and thematic synthesis will be used to achieve consistent reporting and transparency of methods. **Results:** Inclusion of studies, quality assessment and allocation of free codes into EPPI-Reviewer 4 software will be carried out by two independent investigators. Auditing of random cases will be undertaken and disagreements resolved through group discussion of an expert panel. Descriptive and analytical themes will be developed through thematic synthesis and expert panel discussion. **Conclusion:** Qualitative data provide useful information in understanding the individual's unique experience. Combining discrete qualitative studies provides an important opportunity to provide a voice to patients, their families and professional careers in managing advanced COPD.

Key words: Medical Subject Headings (MeSH), Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), Chronic Obstructive Pulmonary Disease (COPD)

PROBLEM STATEMENT

Chronic Obstructive Pulmonary Disease (COPD) is a life-limiting illness affecting 80 million people worldwide, is the fourth most prevalent cause of death globally and accounts for 3.5% of total years lost due to disability (WHO, 2008). Despite the high symptom burden, individuals with advanced COPD continue to experience unmet needs and have limited access to palliative care at the end-of-life (Elkington *et al.*, 2005; Gore *et al.*, 2000; Luddington *et al.*, 2001; Curtis, 2008; Gysels and Higginson, 2008).

A focus on acute care and challenges in predicting the end-stage of disease creates a milieu that is commonly reactive and *ad hoc* rather than an approach which is responsive to individuals' ongoing needs. (Elkington *et al.*, 2005; Gore *et al.*, 2000; Luddington *et al.*, 2001; Curtis, 2008; Gysels and Higginson, 2008).

The fluctuating and episodic decline is characteristic of the COPD trajectory and makes it difficult to determine when death is likely (Creagh-Brown and Shee, 2008; Curtis, 2008; Gardiner *et al.*, 2009; Hansen-Flaschen, 2004). 'Life-limiting' illness is

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defined as an illness where death will likely be a consequence of the specified illness and likely shorten an individual's life (Clayton *et al.*, 2007). The term 'life limiting' illness is inclusive of non-malignant terminal diseases such as COPD (Steinhauser *et al.*, 2011). While not synonymous with advanced COPD, 'Severe COPD' or 'Stage 3' COPD is defined by the Global Initiative for Chronic Obstructive Lung Disease (GOLD) as 'characterized by further worsening of airflow limitation (FEV1/FVC <0.7; 30% <FEV1 < 50% predicted)' along with 'greater shortness of breath, reduced exercise capacity, fatigue and repeated exacerbations that almost always have an impact on patients' quality of life' (GICOLD, 2011). Independent predictors of death from COPD include: hospitalization; functional limitation; severe reduction in lung function; use of long term oxygen therapy; depression; low nutritional state; and the presence of co-morbidities (Gore *et al.*, 2000; Hansen-Flaschen, 2004; Pinnock *et al.*, 2011; Murray *et al.*, 2006). Additionally a clinician's assessment that an individual is unlikely to survive two years is also seen as a useful prognostic tool (Hansen-Flaschen, 2004; Murray *et al.*, 2006).

Metasyntheses have increasingly been used to gather qualitative data from different studies in order to gain an understanding of complex research questions (Thomas and Harden, 2008; Walsh and Downe, 2005). The integration of a number of individual qualitative studies is argued to provide an interpretation that 'will not be found in any one research report but, rather, are inferences derived from taking all of the reports in a sample as a whole' (Sandelowski *et al.*, 1997). Through the amalgamation and syntheses of these data new insights and meanings may be generated which may not have been evident in individual qualitative studies (Sandelowski *et al.*, 1997; Thomas and Harden, 2008; Walsh and Downe, 2005).

In the context of health care, metasyntheses are used to 'enrich understanding of complex and multifaceted health experiences and health care practices' (Walsh and Downe, 2005). The outcomes of metasyntheses are not merely summative of individual qualitative studies but also cast a lens on a broader experiential perspective (Walsh and Downe, 2005).

This technique also responds to a desire to make qualitative data and the unique perspective it presents, accessible to wider audiences who may not have the capacity to interpret large bodies of qualitative evidence (Thomas and Harden, 2008). Metasyntheses consequently have the potential to increase the leverage of qualitative data to inform policy and practice (Thomas and Harden, 2008).

The conduct of metasyntheses has not been without contention (Thomas and Harden, 2008; Walsh and Downe, 2005). Separating qualitative data from the timing and participant characteristics of each study opens authors to accusations of 'de-contextualising findings and wrongly assuming that there are commensurable' (Thomas and Harden, 2008). However the summarizing and synthesis of primary data (i.e., Direct quotations) and themes identified by article authors does allow metasyntheses to summarize the individuals' experience within the context of the study (Thomas and Harden, 2008; Walsh and Downe, 2005).

This metasynthesis will allow the authors to explore the complexities of individuals' experience of advanced COPD (Thomas and Harden, 2008; Walsh and Downe, 2005). Developing greater insight into the experience of COPD-including the unmet needs and barriers faced by individuals with advanced COPD, their families and the healthcare professionals who care for them-has unique potential for informing the coordination and responsiveness of services for this burdensome condition.

In exploring individuals' experiences of illness, we take this to be a constructed and experiential phenomenon concerned with how individuals come to understand and live with their illness and its management (Conrad and Barker, 2010). We anticipate that this will include not only perceptions of how disease and management have impacted daily life (e.g., through symptom burden) but also cultural and societal meaning for the individual as well as the way in which society interacts with individuals with illness (Conrad and Barker, 2010). Exploration of unmet needs will be based on those experiences in which individuals require assistance but for which inadequate management is in place. In the context of chronic illness, individuals' needs may include physical, psychological, cultural, existential, sexual and financial (Desai *et al.*, 2001; Elkington *et al.*, 2005; Gore *et al.*, 2000).

The objectives of this review are to describe:

- The barriers and facilitators to care access and provision for individuals with advanced COPD, their families and carers and health professionals
- The unmet needs of individuals with advanced COPD and their families and
- The experiences of healthcare professionals caring for individuals with advanced COPD

Approach:

Methods: The principles of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) approach have been used to achieve

consistent reporting and transparency of the methods used in this metasynthesis (Moher *et al.*, 2009).

Eligibility criteria:

Studies will be included if:

- Reported in English
- Published in a peer reviewed journal between 1990 and December 2011
- The publication reports the perspectives of individuals with advanced COPD and/or their family/carers and/or health professionals involved in COPD management
- The publication contains qualitative data; that is, presentation and or synthesis of primary data (i.e., direct quotations) and themes identified by article authors. To ensure a minimum quality standard, we will require reports to include at least one excerpt of raw data; and
- Data collection included interviews, focus groups, or open-ended survey questions

Studies with samples that include but are not limited to COPD individuals, family/carers and health professionals will be included provided COPD-specific data can be extracted. Qualitative data from mixed methods studies will also be included if the above criteria are met.

Population: For the context of this metasynthesis, individuals with advanced COPD are defined as those with an advanced life-limiting illness and predictors associated with adverse outcomes (Gore *et al.*, 2000; Hansen-Flaschen, 2004; Pinnock *et al.*, 2011; Murray *et al.*, 2006). Family and carers (both informal and formal) will be taken to be any significant person involved in the care and management of individuals with advanced COPD (Seamark *et al.*, 2004; Spence *et al.*, 2008; Gysels and Higginson, 2009). Healthcare professionals will include healthcare professionals who discuss their experiences of management of advanced COPD, including nurses, physicians and allied health professionals (Blackler *et al.*, 2004; Goodridge *et al.*, 2008).

Information sources: The following electronic databases - Medline, PsychINFO, AMED, CINAHL and Sociological Abstracts-will be searched for articles published between 1990 and February 29th 2012. These dates were decided to reflect contemporaneous approaches to COPD management, particularly approaches to chronic disease management. Included article reference lists will be hand searched for additional studies.

Table 1 Search Strategy (Medline example)

1	exp Pulmonary Disease, Chronic Obstructive/	17330
2	COPD*.mp.	19799
3	exp Airway Obstruction/	18032
4	airway obstruction.mp.	21470
5	COAD*.mp.	185
6	Exp Lung Diseases, Obstructive/	144900
7	1 or 2 or 3 or 4 or 5 or 6	49454
8	advance care planning.mp. or exp Advance Care Planning/	6307
9	exp Attitude to Death/ or attitude to death.mp.	12505
10	bereave\$.mp. or exp Bereavement/	10837
11	Death/ or death.mp.	467014
12	dying.mp.	22516
13	end of life.mp.	9102
14	hospice\$.mp. or exp Hospices/	9912
15	exp Palliative Care/ or palliat\$.mp.	57391
16	exp Terminal Care/ or terminal\$.mp.	392871
17	7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15	899336
18	6 and 16	3367
19	exp Interview/ or interview\$.mp.	207087
20	experience.mp.	378908
21	exp Qualitative Research/ or qualitative.mp.	102207
22	18 or 19 or 20	640536
23	17 and 21	292
24	limit 23 to English language	261
25	limit 24 to "all adult (19 plus years)"	182

* COPD: chronic obstructive pulmonary disease, * COAD: chronic obstructive airways disease, \$: wildcard, exp: explode terms

Search: Medical Subject Headings (MeSH) and key words will be used to guide the search including the terms outlined in Table 1 for Medline and will be adjusted as appropriate for each database. These search terms and strategies have been reviewed by the CareSearch palliative knowledge network (CareSearch, 2012). Terms of filtering for qualitative research were those recommended by the McMaster University Health Information Research Unit (HIRU, 2011). The overall search strategy will be reviewed by a health informatics expert (Fig. 1).

Study selection: Inclusion of studies will be independently assessed by two researchers specialized in COPD, palliative and chronic care (RTD, PMD). These entries will be checked by a third independent investigator (AG) through random selection and checking. Disagreements will be resolved by consensus (Fig. 2).

Data management: Data from the selected papers will be entered into EPPI-Reviewer 4 software by one investigator (RTD) to allow for assessment against inclusion criteria and coding by multiple investigators (Thomas and Harden, 2008). These entries will be checked by a second investigator (AG) through random selection and checking. Any disagreements over quality assessment will be resolved through group discussion (Walsh and Downe, 2005).

Descriptive details of the selected studies will be recorded with country of origin, sample characteristics (participant type, setting and demographics), study characteristics (method, conceptual approach) and results (themes identified by the authors). Where

possible description of the stage of illness trajectory will be collected, as well data on family and career relationship to the individual and the characteristics of the assistance they provide. Provider data will be collected on discipline and role in patient care.

Quality assessment: The quality of studies will be independently evaluated with by two investigators (RTD, AG) with the checklist developed by Kitto *et al.* (2008). This checklist evaluates studies in terms of clarity of aims/research question, justification of the approach used, procedural rigor, representativeness of the sample, interpretation of the data, reflexivity and

evaluative rigor and transferability of findings (Kitto *et al.*, 2008; Walsh and Downe, 2005).

Synthesis of results (Fig. 2): This metasynthesis will use a thematic synthesis of qualitative research as developed by (Thomas and Harden, 2008; Barnett-Page and Thomas, 2009). It is anticipated that the systematic approach to combining qualitative data in this metasynthesis will generate new insights and meanings which may not have been evident in the discrete studies (Sandelowski *et al.*, 1997; Thomas and Harden, 2008; Walsh and Downe, 2005).

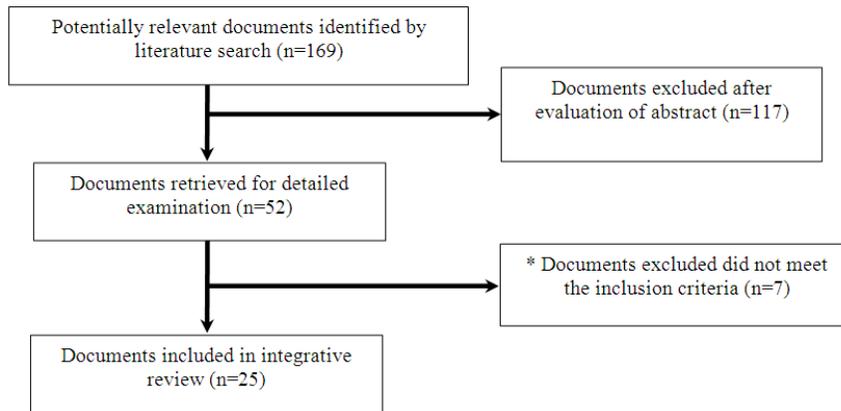


Fig. 1: Flow chart of studies from search for inclusion (Medline example)

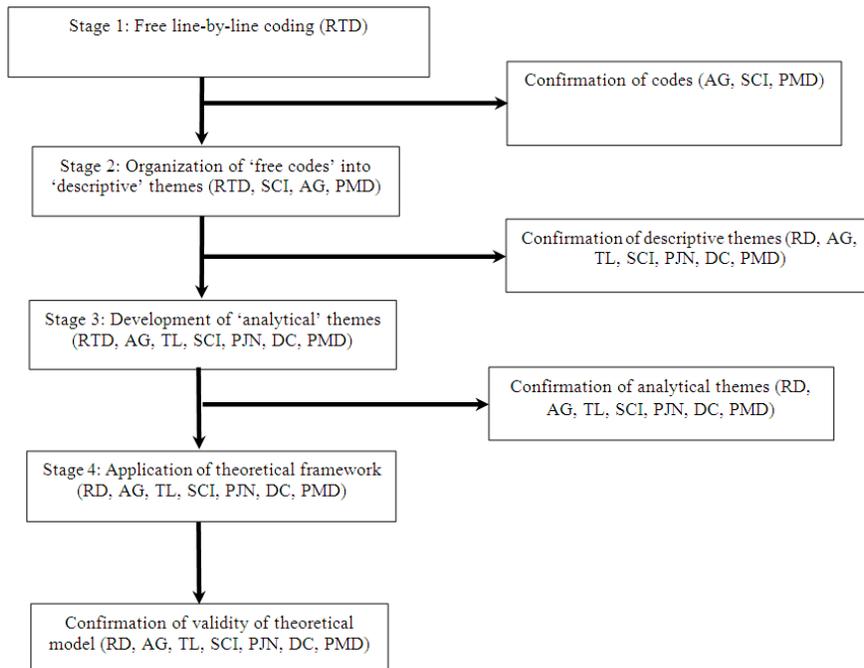


Fig. 2: Flow chart of data synthesis

Stage 1: Free line-by-line coding: Line-by-line free coding will be carried out by two independent investigators (RTD, AG). Free codes will be kept as close to the primary data as possible (Thomas and Harden, 2008). Coding will be carried out on the presentation and/or synthesis of primary data (interpreted within the context of the setting) of the perspectives of individuals with advanced COPD, or their family and careers, or health professionals (Thomas and Harden, 2008). The trustworthiness of the data will be ensured through random selection and checking (PMD, SCI). Disagreements will be resolved by consensus of four reviewers (RTD, PMD, AG, TL).

Stage 2: organization of 'free codes' into related areas to construct 'descriptive' themes: The free codes will be organized into descriptive themes by three investigators initially (RTD, AG, PMD) and then confirmed through discussion of an expert panel in COPD, palliative and chronic care (RTD, AG, TL, SCI, PJN, DC, PMD) (Walsh and Downe, 2005; Thomas and Harden, 2008). In the first instance, codes will be grouped into a topic area and super- and sub-ordinate relationships. Disagreements in descriptive themes will be resolved through group discussion (Walsh and Downe, 2005; Thomas and Harden, 2008).

Stage 3: Development of 'analytical' themes: An expert panel in COPD, palliative and chronic care will be used to develop central themes and analytical inferences not overtly evident in the initial codes (RTD, AG, TL, SCI, PJN, DC, PMD) (Thomas and Harden, 2008; Walsh and Downe, 2005). The development of analytical themes will allow for a broader understanding and interconnectedness between themes within the data (Walsh and Downe, 2005; Thomas and Harden, 2008). A theoretical framework will be sought to assist in the organization of analytical themes organizing the relationships between those issues found to be central to individual with advanced COPD, their family and carers and health professionals (Lovell, 2012).

Rigor: The use of qualitative primary data is an inductive, reflective and critical process in theme development and understanding of complex issues (Walsh and Downe, 2005). Rigor is supported in qualitative research through reflexivity and systematic approaches to data analysis, interpretation and synthesis (Barnett-Page and Thomas, 2009). The transparent presentation of the method of undertaking metasynthesis, as well as the use of independent investigators and panel discussion to promote the validity of findings increases the rigor of this metasynthesis (Thomas and Harden, 2008).

CONCLUSION

Qualitative data provide useful information in understanding the individual's unique experience. Combining discrete qualitative studies provides an important opportunity to provide a voice to patients, their families and professional careers in managing advanced COPD.

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