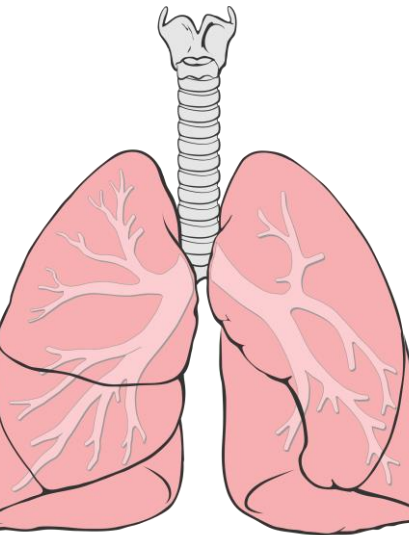


What does the grey literature tell us about patient education for people living with Chronic Obstructive Pulmonary Disease (COPD): The results of a scoping review



uOttawa



Katarina Vukovojac, BSc (student) UROP laureate and Dr. Judy King, PhD, MSc, BSc (PT), Assistant Professor, Physiotherapy Program, School of Rehabilitation Sciences, Faculty of Health Sciences

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a progressive lung disease with high prevalence and mortality rates in Canada (Evans et al., 2014). One of the most critical aspects of treatment for the disease is patient education geared towards improving a person's ability to self-manage their condition. However, very little is known about how accessible and effective patient education found in the grey literature is for people living with Chronic Obstructive Pulmonary Disease.

Grey literature has been described as "information produced on all levels of government, academics, business, and organization in electronic and print formats not controlled by commercial publishing" (Farace & Frantzen, 2005). This study is a part of a larger research project that aims to optimize patient education interventions for people living with Chronic Obstructive Pulmonary Disease.

Methodology

A scoping review methodology was used for this project. A scoping review is an "exploratory project that systematically map[s] the literature available on a topic, identifying the key concepts, theories, sources of evidence, and gaps in the research" (Canadian Institutes of Health Research, 2015). An internet search of websites was conducted of key organizations, such as the Canadian Lung Association, were reviewed for relevant grey literature material using specific inclusion/exclusion criteria. The findings from the review were compiled and categorized.

Grey Literature Inclusion Criteria

- Resource geared towards people living with COPD
- Available in pdf or paper format
- Published between 2006-2016

Grey Literature Exclusion Criteria

- Not available in English and/or French
- Resource only available from commercial websites via paying a fee
- Resource appears to be selling some sort of products and/or medication

Results

A total of 25 different grey literature resources were identified through internet searches using Google's search engine. Resources were published between 2006-2015; these resources included reference guides, brochures, booklets, fact/info sheets, and infographics. The majority (approx. 76%) consisted of fact/info sheets and booklets. All resources found were available in PDF file form.

- Reference Guides
- Brochures
- Booklets
- Facts/Info Sheets
- Infographics

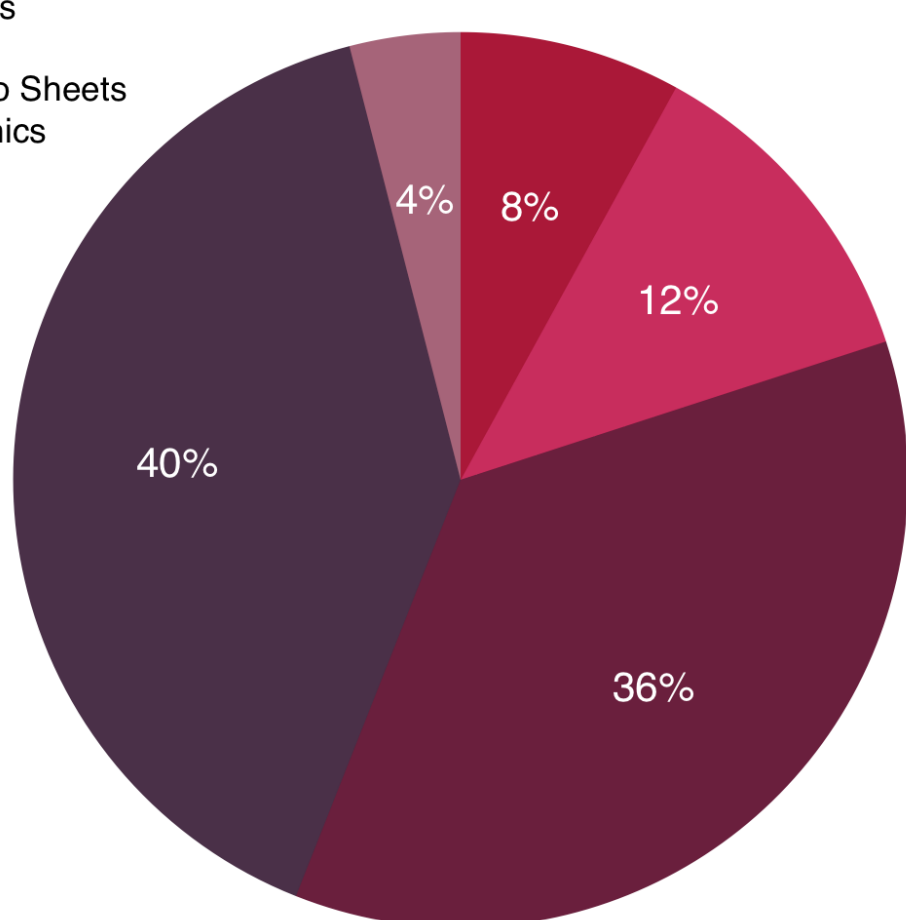


Figure 1. Forms of patient-education resources that were found.

Results (cont.)

Grey literature patient education resources were found on websites of various organizations. For example, on the Canadian Lung Association website, 5 different resources were identified (5).

Other organizations included Advance Health Network (1), Asthma and Respiratory Foundation of New Zealand (1), British Columbia Lung Association (1), British Lung Foundation (1), COPD Canada (1), COPD and Asthma Network of Alberta (1), Canadian Thoracic Society (1), Chest Foundation (2), European Lung Foundation (3), International COPD Coalition (1), Lung Foundation Australia (2), MaineHealth (1), NHS Redbridge Clinical Commissioning Group (1), National Heart Lung and Blood Institute (2), and The Global Initiative for Chronic Obstructive Lung Disease (1).

Website Link and Date Accessed	PDF Title & Link	Year Published	Organization	Patient Population	Patient Interventions	Results of Education	Search Terms/Process (in Google, unless stated otherwise)	Critical Reasoning Behind choice of website	References Included
https://bc.lung.ca/lung-health/patient-education-support-order-info-resources (Jan 21st, 2016)	COPD What You Need to Know https://bc.lung.ca/files2/download?token=mxChXt1n	Not Available	British Columbia Lung Association	People with COPD in BC	Interventions listed include: patient education, medicines, and various non-pharmacological treatments such as surgical treatment	Better understanding/management of COPD	On British Columbia Lung Association Website Under Support and Services Tab at Download/Order Services	Fits Inclusion Criteria	No

Figure 2. Grey Literature Charting Format.

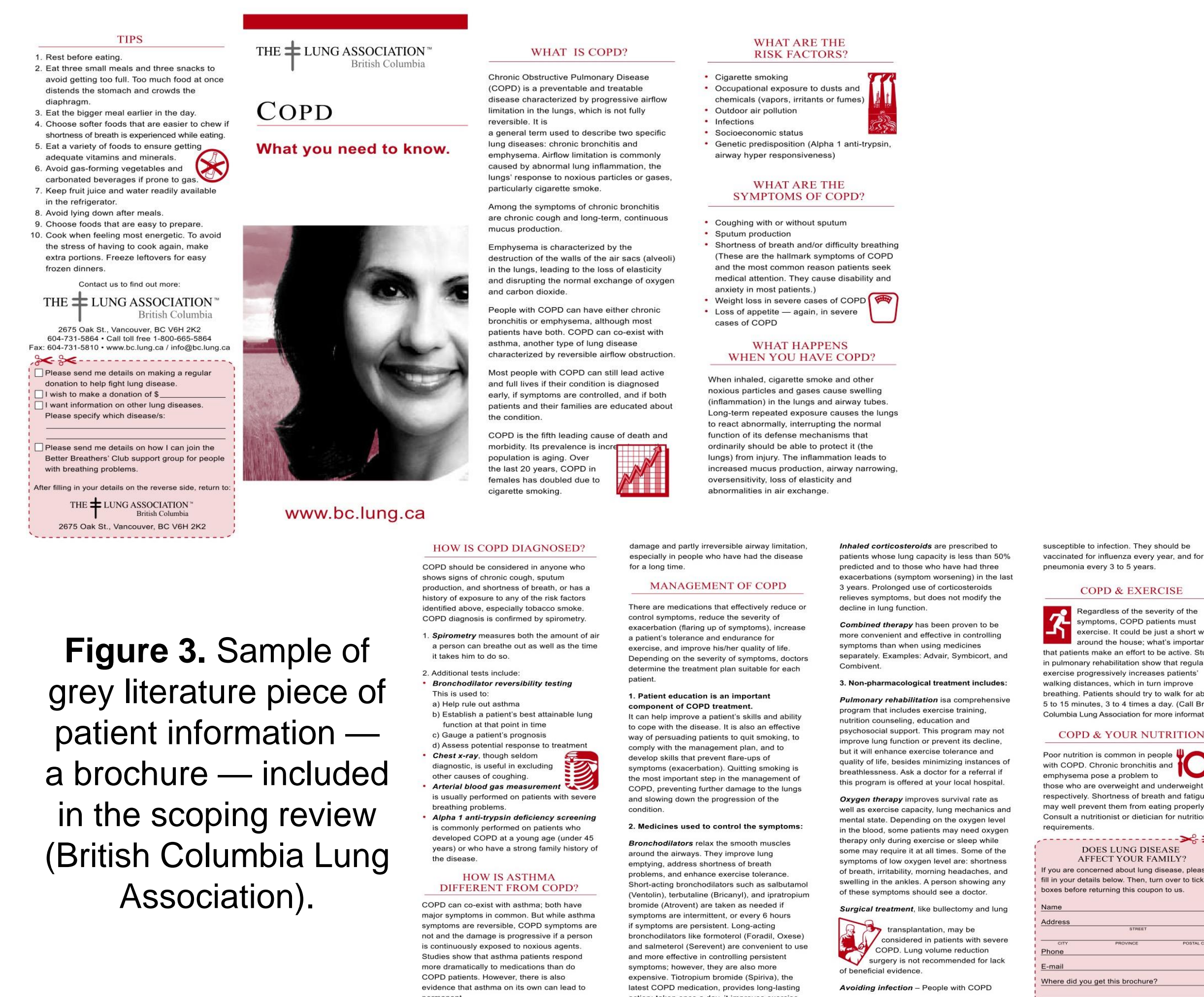


Figure 3. Sample of grey literature piece of patient information — a brochure — included in the scoping review (British Columbia Lung Association).

Of all 25 resources, 9 were produced by Canadian organizations. Information was always presented in the English language, however some resources provided information translated into additional languages such as French (20%) and Spanish (20%).

Resources were directed to a population of people diagnosed with COPD in various countries, as well as family members and/or carers of people living with COPD.

Topics covered in the general Chronic Obstructive Pulmonary Disease facts/info sheets included causes and symptoms of Chronic Obstructive Pulmonary Disease, and lung function. In addition, management advice, diagnostic tests, and self-administered treatment and therapy options for patients were discussed.

Results (cont.)

The majority of the grey literature included in this scoping review had no visible references listed (72%), and the remainder (28%), listed various health professionals and organizations as contributing sources. The type of grey literature that comprised the majority of referenced resources were booklets.

Conclusions

The results of this research project give an insight into just what kind of patient education is available to the public about Chronic Obstructive Pulmonary Disease. It is evident that there is an increased amount of free and relevant patient education available that patients can easily access through a Google search.

Interesting to note in a time when people are beginning to be more critical of health information they find on the internet, the majority of the resources found did not contain any academic or scientific references even though the grey literature resources originated from websites of recognized organizations involved in lung health.

No matter how thorough the information appears to be, or the credibility of the website, references not being listed within patient education material may serve as a deterrent for some patients, making them unwilling to use particular resources that are available.

The findings in this study provide further information to researchers and health system stakeholders on which resources are already available to patients, and which resources may be lacking.

References

- British Columbia Lung Association. *COPD What You Need to Know* [Brochure]. Retrieved from <https://bc.lung.ca/lung-health/patient-educations-support/order-info-resources>
- Canadian Institute of Health Research. Synthesis Resources. 2015. Retrieved from <http://www.cihr-irsc.gc.ca/e/36331.html#2>
- Evans, J. et al. (2014). Estimating the prevalence of COPD in Canada: Reported diagnosis versus measured airflow obstruction. *Statistics Canada Health Reports*, 25(3), pp. 3-11. Retrieved from <http://www.statcan.gc.ca/pub/82-003-x/2014003/article/11908-eng.pdf>
- Farace, D.J. and Frantzen J. (eds.) (2005). Sixth International Conference on Grey Literature: Work on Grey in Progress, GL 2004 Conference Proceedings, New York, 6-7 December 2004, TextRelease, Amsterdam.

Acknowledgements

I would like to specially thank my supervisor, Dr. Judy King, for giving me this opportunity, and for opening my eyes to the world of research. I would also like to thank Marie-Cécile Domecq from the university's Health Sciences Library. Lastly, I would like to thank the UROP committee.

Katarina's Contact Info: kvuko094@uottawa.ca
Dr. Judy King's Contact Info: jking@uottawa.ca