Implementing Dyspnea Care Initiatives: A RECOMMENDATIONS REPORT
EXECUTIVE SUMMARY

Dyspnea, or shortness of breath, is a distressing symptom that occurs in 75% of Ontario lung cancer patients (CCO Informatics, 2010-2012). Research demonstrates that pharmacological and non-pharmacological interventions for dyspneic patients can improve dyspnea levels, as well as performance status, quality of life and emotional well-being (Ben-Aharon, Gafter-Gvili, Leibovici & Stemmer, 2012; Hately, Laurence, Scott, Baker & Thomas, 2003; Zhao & Yates, 2008). Nonetheless, the management of dyspnea in lung cancer patients is currently not standardized across Ontario. In response, the Disease Pathway Management (DPM) Secretariat of Cancer Care Ontario (CCO) identified the improvement of dyspnea care for lung cancer patients as one of the “Priorities for Action” for lung cancer care in Ontario. In 2010, the DPM Secretariat provided funding to seven Regional Cancer Centres (RCCs) across Ontario to implement dyspnea care initiatives. This recommendations report summarizes the lessons learned from these pilot projects sites and provides guidance regarding the effective implementation of a dyspnea care initiative. The goal of this report is to catalyze action towards improving dyspnea care across Ontario, in alignment with the strategic priorities of the Ontario Cancer Plan III (Cancer Care Ontario, 2010).

Though guided by the requirements for implementation specified by CCO, the seven RCCs approached this project with varying methodologies. For instance, the initiatives differed in their mode of delivery, patient referral eligibility, model of care, and offered interventions.

Through interim and final reports, the seven pilot project sites shared several successes and challenges in implementing dyspnea care initiatives. In terms of successes, the interventions led to improvements in patients’ dyspnea levels, self-management of dyspnea, and quality of life. Furthermore, caregivers expressed gratitude for the education pertaining to dyspnea that was provided as it enabled them to better care for their loved one. Common challenges across the pilot project sites included low patient recruitment, limited resources to sustain initiatives, and difficulties in gaining initial physician engagement and support for the initiatives.

The experiences of the pilot project sites led to several recommendations for the development of a dyspnea care initiative. For instance, it was learned that a critical success factor is a dedicated nurse who has expertise in dyspnea assessment and management, as well as available time to devote to the initiative. Other factors that were found to be essential included referring physician engagement, interdisciplinary collaboration at the RCC, and support from administration and management groups.

This recommendations report provides background information on dyspnea as a symptom experienced by lung cancer patients, as well as an overview of CCO’s work to-date regarding lung cancer. Specific details of the dyspnea management pilot project site methodologies and experiences are also included in this report. Finally, based on the findings of the pilot project sites and the current literature on the subject, key recommendations related to elements of a dyspnea care initiative are outlined.
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# TABLE OF CONTENTS

- REPORT OBJECTIVES .................................................................................................................. 2
- BACKGROUND ON DYSPNEA.......................................................................................................... 3
- OVERVIEW OF DISEASE PATHWAY MANAGEMENT .................................................................. 5
- OVERVIEW OF LUNG CANCER DISEASE PATHWAY MANAGEMENT ........................................ 6
  - The Lung Cancer DPM Team ........................................................................................................ 6
  - Priority for Action: Improving Dyspnea Management ................................................................. 6
- CANCER CARE ONTARIO WORK ON DYSPNEA ................................................................. 7
  - Symptom Management Guides on Dyspnea .............................................................................. 7
- OVERVIEW OF THE DYSPNEA MANAGEMENT PILOT PROJECTS ........................................... 8
  - Pilot Project Methodologies ....................................................................................................... 8
- SUCCESSES & CHALLENGES ..................................................................................................... 10
- RECOMMENDATIONS ................................................................................................................. 12
  - What tasks need to be carried out in order to plan for and implement a Dyspnea care initiative? .......... 12
  - What is the appropriate model of care: Who needs to be involved and in what capacity? ............. 14
  - What services should the Dyspnea care initiative offer? ............................................................ 16
  - Who should be referred to the Dyspnea care initiative? ............................................................ 18
  - How can the impact of this initiative be measured? .................................................................. 18
  - What are the best approaches to managing logistical concerns? ................................................. 19
  - How much time is necessary to plan for and initiate a Dyspnea care initiative? .................... 19
- CONCLUSION ............................................................................................................................... 19
- REFERENCES ............................................................................................................................... 20
- APPENDIX I – CANCER CARE ONTARIO’S AND DISEASE PATHWAY MANAGEMENT’S FRAMEWORK .......................................................... 22
- APPENDIX II – LUNG CANCER DPM PRIORITIES FOR ACTION ............................................... 23
- APPENDIX III – CCO DEVELOPED DYSPNEA RESOURCES ................................................... 24
- APPENDIX IV – DYSPNEA PILOT PROJECT RESULTS ............................................................ 25
- APPENDIX V – CHECKLIST FOR IMPLEMENTING A DYSPNEA CARE INITIATIVE .................... 26
- APPENDIX VI – PROGRAM PLANNING MODELS ....................................................................... 28
- APPENDIX VII – LIST OF ACRONYMS .................................................................................... 29
REPORT OBJECTIVES

The goal of this report is to describe elements to consider when implementing a dyspnea care initiative. The recommendations provided throughout this report are based on current literature as well as key learnings from the dyspnea care pilot projects that were funded by CCO. It is hoped that this report will serve as a guide for healthcare professionals, managers and administrators who provide and organize care for dyspneic cancer patients. Furthermore, this report is anticipated to drive improvements in the quality and consistency of dyspnea care for lung cancer patients across Ontario.

The following questions will be answered in this report:

- What key elements need to be considered in order to plan and implement a dyspnea care initiative?
- What is the appropriate model of care: Who needs to be involved and in what capacity?
- What services should the initiative offer?
- Who should be referred to the initiative?
- How can the impact of this initiative be measured?
- What are the best approaches to managing logistical concerns, such as scheduling appointments for patients?
- How much time is necessary to plan and initiate a dyspnea care initiative?

This report aligns with several of CCO’s goals, which are outlined in the Ontario Cancer Plan III (Cancer Care Ontario, 2010); namely, this report addresses CCO’s goal to “improve the patient experience along every step of the cancer journey” by outlining recommendations for optimal care of dyspneic patients. The recommendations in this report also supports CCO’s goal to “improve the performance of Ontario’s cancer system” as they define a high standard of care to which healthcare providers should adhere.

Furthermore, this report supports the vision of the DPM Secretariat, which is “high quality care, processes and patient experience across the patient pathway for specific cancers”. It does so by addressing the need for standardization of dyspnea care for cancer patients across Ontario. The recommendations outlined in this report will promote the implementation of effective dyspnea care initiatives that will minimize the impact of dyspnea as a cancer symptom (refer to Appendix I: Cancer Care Ontario’s and Disease Pathway Management’s Framework).
BACKGROUND ON DYSPNEA

Lung cancer is a major global health problem with a high incidence rate and the highest mortality rate of any cancer in a developed country. In Canada alone, approximately 25,600 new cases of lung cancer will have been diagnosed in 2012, with 8,500 of these cases being patients in Ontario (Canadian Cancer Society, 2012). Recent data indicates that dyspnea is a priority symptom for many lung cancer patients with approximately 75% of patients reporting some level of dyspnea and 43% reporting moderate-to-severe dyspnea as measured by the Edmonton Symptom Assessment System (ESAS). These rates do not take into account patients who are treated palliatively in the community (CCO Informatics, 2010-2012).

Dyspnea is defined as “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity” (American Thoracic Society, 1999). The terms “breathlessness”, “dyspnea”, and “shortness-of-breath” are often used interchangeably in the literature. Breathlessness is a subjective description of “an uncomfortable awareness of breathing” (Bruera, MacEachern, Ripamonti & Hanson, 1993, p. 906). Dyspnea, or difficulty breathing, is the medical diagnosis often accompanied by tachypnea or a measurable increase in respiratory rate. Shortness-of-breath is the most common public term, which equates with the multidimensional subjective experience that accounts for a high proportion of disability, impaired quality of life and human suffering (Cohen & Mount, 1992). For the purposes of this report, dyspnea is the chosen terminology as it is considered to encompass aspects of all three terms.

Dyspnea is often described as “a frequent and devastating symptom among advanced cancer patients” (Ripamonti, Fulfaro, & Bruera, 1998) due to its impact on physical and emotional wellbeing. Physically, a dyspneic patient may experience discomfort and tiredness associated with breathing, an inability to increase ventilation, as well as chest tightness. Emotionally, dyspnea episodes can be very distressing for patients, as the experience is compared to drowning, suffocation or breathing through cotton wool (Cachia & Ahmedzai, 2008; Dudgeon & Rosenthal, 2012). Nevertheless, there is evidence to support the assertion that interventions and coaching can help improve lung cancer patients’ dyspnea and associated symptoms such as anxiety.

The literature demonstrates that both pharmacological and non-pharmacological interventions for dyspnea can result in improvements in breathlessness and performance status in addition to improvement in physical and emotional states (Ben-Aharon, Gafter-Gvili, Leibovici, & Stemmer, 2012; Thomas, Bausewein, Higginson, & Booth, 2011; Zhao & Yates, 2008). Five studies outlining non-pharmacological interventions were highlighted as effective dyspnea management strategies in a systematic review conducted by Zhao and Yates (2008). Specifically, approaches such as counseling, relaxation and adaptation strategies, activity pacing, and psychosocial support are demonstrated to reduce Visual Analogue Scale breathlessness ratings, and improve functional capacity and activity levels (Corner at al., 1996; Hately et el., 2003). Ben-Aharan et al. (2012) also conducted a systematic review and
meta-analysis with the aim of evaluating interventions for alleviating cancer-related dyspnea. Ben-Aharon et al. (2012) concluded that pharmacological interventions, such as opioids, are effective treatment options for cancer-related dyspnea. Another study demonstrated that nursing interventions, such as education on breathing control strategies and relaxation techniques, can improve breathlessness, level of depression, and World Health Organization (WHO) performance status (Bredin, Corner, Krishnasamy, Plant, Bailey, & A’Hern, 1999). Examples of nursing interventions that can minimize dyspneic episodes include patient education on breathing control strategies, relaxation techniques and behavioural strategies (Bredin et al., 1999).

There are a number of resources and tools that have been developed by CCO for dyspnea management, including clinical guidelines and symptom management guides. Although other tools exist provincially and nationally, dyspnea management resources are not found widely across Ontario. Currently, there is no consistent, standardized approach to dyspnea care for cancer patients, at either the individual or program level within the province. Thus, this report provides advice on various effective delivery models and strategies for dyspnea management program implementation across Ontario.
OVERVIEW OF DISEASE PATHWAY MANAGEMENT

Disease Pathway Management (DPM) is CCO’s unifying approach to quality improvement in Ontario. Specifically, DPM focuses on improving the quality of care, processes and the patient experience. For a given disease site, DPM serves as a catalyst to identify current strengths, recommend priority areas for improvement, and promote action towards those priorities.

Using a phased approach, DPM brings together multidisciplinary experts spanning the entire cancer journey (refer to Figure 1: The Cancer Journey) for a given type of cancer, including physicians, nurses, healthcare administrators, patients and advocates. With the support of DPM staff, this working group uses their experience and expertise to:

- characterize the patient journey by developing pathway maps of the ideal state
- identify, prioritize, and validate areas for improvement across the cancer journey
- present priority areas to the Ontario cancer community for discussion and action
- develop a performance management strategy to evaluate the impact towards identified priority areas

The formal DPM cycle for a given disease site consists of three phases:

**Phase 1** Detail the “ideal state” patient journey; identify areas for improvement; prioritize areas for improvement; seek feedback on these priorities from additional stakeholders

**Phase 2** Regional engagement: share issues with the regions, promote and support action

**Phase 3** Implement and measure impact

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**The cancer journey**
*Better cancer services every step of the way*

![Figure 1: The Cancer Journey](image)

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5| Implementing Dyspnea Care Initiatives
OVERVIEW OF LUNG CANCER DISEASE PATHWAY MANAGEMENT

The Lung Cancer DPM Team

In June 2009, the Lung Cancer DPM team, consisting of 48 clinicians, patients and system stakeholders, was formed under the leadership of two co-chairs. Care was taken to select a geographically diverse, multidisciplinary team with varying experience and expertise spanning the entire lung cancer journey. Based on each member’s area of expertise, the team was divided into five working groups, each representing a specific phase in the cancer patient journey. Over the course of the year, each team met on a monthly basis with the goals of mapping the patient journey, identifying priorities for action, and generating initial concepts to address the identified areas where there was opportunity for improvement. The teams met for a total of 50 hours and yielded 18 improvement project concepts (Refer Appendix II: Lung Cancer DPM Priorities for Action). As a result of a review of data, and patient and provider input, eight initiatives were selected from the larger list.

Priority for Action: Improving Dyspnea Management

In its first year, the Lung Cancer DPM team identified improving dyspnea management for lung cancer patients as a key issue. Data had previously been obtained through a provincial initiative that captured the symptoms of lung cancer patients at RCCs using ESAS. The results from this data collection illustrated the high prevalence of dyspnea amongst lung cancer patients; in fact, it was determined that 51% of the sample population experienced severe to moderate dyspnea levels (Cancer Care Ontario, 2010). The importance of addressing dyspnea in the lung cancer population is underscored by the higher prevalence of the symptom at diagnosis as compared with other cancers (Dudgeon, Kristjanson, Sloan, Lertzman & Clement, 2001). In the lung cancer population, dyspnea results in distress and suffering on the physical, functional and psychological wellbeing of individuals (Hately, 2003). However, despite the high incidence of lung cancer as well as the significance of dyspnea to the population and its effects on quality of life, the management of this symptom has been inconsistent across the province. Nonetheless, an evidentiary review demonstrated that a minimal nursing intervention is effective in improving patients’ dyspnea, performance status and levels of depression (Bredin et al., 1999). It was therefore decided that action would be taken to minimize the prevalence and impact of dyspnea for the population of lung cancer patients in Ontario.
CANCER CARE ONTARIO WORK ON DYSPNEA

Symptom Management Guides on Dyspnea

CCO has developed resources to help healthcare providers monitor and manage their patients’ dyspnea more effectively. These symptom management resources include the Dyspnea Guide-to-Practice, a detailed document outlining guidelines for dyspnea care, as well as condensed summaries of this information in the form of a Pocket Guide and Algorithm (refer to Appendix III: CCO Developed Dyspnea Resources). A YouTube video/DVD series on managing shortness-of-breath was also developed by Lorraine Martelli-Reid. Additional videos on relaxation have been added by Cathy Kiteley and Adrienne Pringle in order to educate patients on various dyspnea management techniques, such as breathing and muscle relaxation exercises, and music therapy approaches (refer to Appendix III: CCO Developed Dyspnea Resources).
OVERVIEW OF THE DYSPNEA MANAGEMENT PILOT PROJECTS

To address the prevalence and impact of dyspnea on lung cancer patients in Ontario, the Lung Cancer DPM team funded seven RCCs across the province to develop and implement one-year pilot projects in dyspnea management. Six of the funded sites were chosen based on pre-defined criteria such as potential impact, level of innovation and cost-effectiveness, and started their projects in July of 2010. A seventh site also started a dyspnea management project in November of 2011 as part of a different initiative funded by DPM. The seven funded sites undertook several project requirements as specified by CCO. Beyond these requirements, the centres approached the project with varying methodologies (refer to Table 1: Pilot Project Methodologies). Following the launch of all dyspnea care initiatives, each site submitted interim and annual reports. The report findings were analyzed to observe trends and measure the success of the initiatives in improving lung cancer patients’ dyspnea. After the pilot projects ended, several lessons were noted regarding the best manner to establish and operate a dyspnea care initiative.

Pilot Project Methodologies

The funded sites followed specific project directions as outlined by CCO. These centres were required to address both the physical and psychosocial aspects of dyspnea that affect not only patients, but their families and caregivers as well. In the first six projects, four measures were tracked and reported on by the RCCs: the ESAS tool that measures patient-reported severity of symptoms, the Palliative Performance Scale (PPS) that scores patients on their functional status, the European Organization for Research and Treatment of Cancer Quality of Life (EORTC-QOL) Questionnaire that measures patient-reported health-related quality of life scores, and a patient survey that captures the patients’ knowledge of dyspnea and preparedness for self-management, as well as their overall satisfaction with the dyspnea care initiative. Similarly, the seventh project tracked shortness of breath and anxiety scores on ESAS, improvements in quality of life, and patient and provider satisfaction. The funded sites were also required to leverage existing dyspnea management resources, such as provincial clinical guidelines and symptom management guides-to-practice. Lastly, the projects were to be guided by the DPM Secretariat’s key objectives; namely, to improve the quality of care, processes and the patient experience.

Each centre implemented a different approach to dyspnea care according to the anticipated needs of their local lung cancer patient population. Specifically, pilot project sites varied in their mode of delivery. Some sites led group support and education sessions while others focused on individual counseling and personalized treatment plans. The method of patient accrual also differed between sites. For instance, while the majority of the sites utilized the Interactive Symptom Assessment and Collection (ISAAC) system to identify appropriate patients for the program, sites varied in their additional dependency on physician referrals or referrals gained via word-of-mouth. Lastly, each site offered a different variety of treatment interventions, such as breathing exercises, psychosocial support, or pharmacological interventions.
Table 1: Pilot Project Methodologies

<table>
<thead>
<tr>
<th>Site</th>
<th>Patient Accrual Method</th>
<th>Services Offered</th>
<th>Scheduling of Patient Visits</th>
<th>Program Team Specialties</th>
</tr>
</thead>
</table>
| Site 1 | - Referral Criteria: dyspnea ESAS score of 7 or higher, lung cancer diagnosis  
- Referral Method: ISAAC notifications were used to identify patients to invite to the program (arranged appointment via telephone), also received referrals from healthcare professionals within centre | - Medical assessment  
- Individual counseling | - Two visits, four weeks apart (per patient)  
- Weekly half-day program | - Medical Oncology, Palliative Care, and Respiratory Medicine |
| Site 2 | - Referral Criteria: dyspnea ESAS score of 4 or higher, primarily targeted lung cancer patients but were willing to see patients from all disease sites  
- Referral Method: Referrals received from healthcare professionals within centre, also invited patients to attend program based on ISAAC notifications | - Breathe Easy Patient Education Class  
- Individual treatment plans based on ESAS score including education and other interventions | - Education class held twice a month | - Two Advanced Practice Nurses saw all patients  
- Patients saw an Occupational Therapist and Physiotherapist as needed |
| Site 3 | - Referral Criteria: dyspnea ESAS score of 4 or higher, but would provide educational interventions to those with lower scores, lung cancer diagnosis (later expanded criteria to encompass all cancer patients)  
- Referral Method: Used ISAAC notifications to flag appropriate patients, also received referrals from other healthcare professionals within centre | - Individual education sessions  
- Referral to Advanced Practice Nurse if necessary | - Two visits (per patient)  
- Bi-weekly 90 minute group session | - Specialized Oncology Nurse led patient education classes and saw patients  
- Support from Advanced Practice Nurse was available when necessary |
| Site 4 | - Referral Criteria: dyspnea ESAS score of 4 or higher, cancer diagnosis  
- Referral Method: Other healthcare professionals and clinics within the centre promoted program and made referrals | - Individual counseling sessions  
- Group classes led by Occupational Therapist and Social Worker | - Two visits, two weeks apart (per patient)  
- Bi-weekly half-day program | - Physician and Palliative Care Nurse saw all patients  
- Support from an Occupational Therapist, Social Worker, Interventional Pulmonologist, and Respiratory Therapist was available when necessary |
| Site 5 | - Referral Criteria: symptomatic and/or dyspnea ESAS scores of 4 or higher  
- Referral Method: Dedicated registered nurse researched potential patients based on ISAAC notifications, also received referrals from healthcare professionals within centre (i.e. primary nurses) | - Individual counseling to develop individualized treatment plan based on underlying cause of dyspnea  
- Assessments by both Registered Nurse and Physician | - Three visits, three weeks apart (per patient)  
- Half-day clinic | - Registered Nurse saw all patients  
- Support from Palliative Care Physician, Dietician and Social Worker was available when necessary |
| Site 6 | - Referral Criteria: dyspnea ESAS score of 7 or higher, lung cancer diagnosis (later extended to all disease sites)  
- Referral Method: Received referrals from healthcare professionals within centre, also used ISAAC notifications to identify possible patients and contact their medical care team | - Individual counseling  
- Follow-up telephone calls | - Two to four visits, two weeks apart (number of visits depended on patient’s preference)  
- Weekly half-day program | - Advanced Practice Nurse saw all patients |
| Site 7 | - Referral Criteria: any patient diagnosed with lung cancer including family members and guardians  
- Referral Method: Received referrals from healthcare professionals within centre, oncology team also used ISAAC scores to identify possible patients | - Offer information about dyspnea management program during initial consult  
- Educational program for patients and family members  
- Nurse-led dyspnea symptom management clinic | - Educational program; 1 day a month  
- Symptom management clinic; 1 morning a week | - Referring Physician, Nursing, Physiotherapy, and Respiratory Therapy |
SUCCESSES & CHALLENGES

Successes

Over the one year pilot projects at the first six sites, 188 lung cancer patients were seen with a median dyspnea score of seven at first visit. These patients varied in terms of the phase they were at along the cancer journey. For instance, some patients were receiving treatment, while others were undergoing follow-up or palliative care. Overall, these six projects demonstrated significant impacts in dyspnea care; for example, patients who came for multiple visits saw a statistically significant improvement in their dyspnea levels as measured by their ESAS scores (refer to Appendix IV: Dyspnea Pilot Project Results). In fact, 45% of patients with severe dyspnea scores reported a moderate or mild score by their last visit. Of the patients with an initial moderate dyspnea ESAS score, 32% reported a mild score by their last visit. Patients reported high levels of satisfaction with the interventions, in addition to feelings of empowerment and the ability to continue with daily activities as a result of the interventions offered. Moreover, caregivers reported a benefit from the information provided through the initiative and indicated that they better understood the symptom of dyspnea and felt more able to support their loved one. The project conducted at the seventh site entailed six dyspnea management workshops, with an average of six patients and five family members attending each session. This site had patients and providers reporting high levels of satisfaction with the educational program, and while there was no significant improvement in tracked ESAS scores, there was a general improvement in wellbeing and quality of life. Although the total patient population seen across the seven sites was smaller than anticipated over the yearlong pilot projects, positive impacts of the dyspnea care initiatives were nonetheless observed.

From the clinicians’ perspective, they saw a noticeable difference in patients who attended the dyspnea care initiatives and found it to be a valuable supportive care measure for their patients. Clinicians also valued the targeted teaching and expertise provided by the dyspnea care team and found it a helpful resource to which they could refer dyspneic patients. The program increased the staff and physicians’ awareness of the importance of assessing, screening and applying interventions to reverse the cause of dyspnea as much as possible and to address the symptom using both pharmacological and non-pharmacological methods.

Challenges

Despite fruitful results, the funded project sites faced a handful of challenges during the implementation and execution of dyspnea care initiatives. During the initial stages, fewer patients than expected participated, in part due to a lack of clinical engagement. In addition, lung cancer patients were either not interested or well enough to attend. Thus, the high number of dyspnea ESAS scores reported at the RCCs
was not reflected in the number of patients who participated in the dyspnea care initiatives. Low accrual also resulted because supportive care programs, such as the dyspnea care initiatives, can be overlooked in favour of more common, established treatment options. It took time for the initiatives to be embraced as a standard of care for lung cancer patients at the RCCs. Recruitment of the appropriate healthcare professionals was also a challenge given their multiple priorities. However, it is the hope of the authors that as practices evolve, the integration of dyspnea management within care plans will become an understood and accepted approach.

After the launch of the initiatives, one of the main difficulties was in scheduling patients’ appointments. Due to the numerous medical appointments that cancer patients require, there were often conflicts between the dyspnea care initiative visits and other appointments, which resulted in the patients visiting the RCC multiple times. Where this was less burdensome, the initiatives were well integrated into existing care paths, and thereby separate scheduling was not required and patient’s satisfaction was greater.
RECOMMENDATIONS

Although each approach to the development of a dyspnea care initiative will differ, the following questions and answers highlight potentially useful suggestions for such an initiative. For a checklist summarizing these recommendations, refer to Appendix V: Checklist for Implementing a Dyspnea Care Initiative.

What tasks need to be carried out in order to plan for and implement a dyspnea care initiative?

During the planning phase, there are several key elements to be considered:

Program Team:

Ensure that an appropriate clinical champion and team is recruited, comprised of individuals with time to commit to the initiative as well as knowledge of dyspnea. Outline the roles, responsibilities, and time commitments for each team member. Build the knowledge and expertise of all team members related to dyspnea and related interventions (i.e. breathing exercises). As much as possible, build the skills of existing healthcare providers, and integrate this initiative into existing clinics and programs.

Vision and Goals:

Identify the vision and foundational principles that will guide the development, implementation and evaluation of the dyspnea care initiative. Examples of such principles could include sustainability, cost-effectiveness, comprehensiveness, and patient-centeredness. Define the short- and long-term goals for the initiative. Confirm that all team members understand and accept these goals.

Treatment Approach:

Determine the best treatment approach for patients who experience dyspnea at varying severities. Consider the extent of interventions that will be offered, both pharmacological and non-pharmacological in nature. Identify methods for the coordination of care for patients between transitions. For instance, establish partnerships with the appropriate Community Care Access Centres (CCACs) in the region in order to best provide care for patients who live at a distance from the RCC. Furthermore, set up working relationships with outpatient palliative care teams. Define strategies for equipping caregivers who wish to look after their loved one at home.

Patient enrollment:

Determine the method of patient enrollment. Consider using services or processes already in place to recruit and book patients. For instance, the ISAAC tool is a useful means of identifying patients who would
benefit from the dyspnea care initiative. In addition to the ISAAC tool, patient self-referrals and physician referrals are other methods used to increase patient accrual numbers.

**Resources:**

Ensure support from relevant management groups by including them in all discussions of the plans.

**Clinical Engagement:**

Engage referring clinicians, nurses and allied healthcare providers in the development of the dyspnea management initiative and keep them informed of the program’s ongoing activity. Communicate with all relevant healthcare team members throughout the planning, initiation, and execution of the dyspnea care initiative. Ensure that referring clinicians, nurses and allied healthcare workers have an understanding of dyspnea and its impact on patients. Also, confirm that they are aware of the goals and services offered as well as the appropriate referral process. Provide ongoing written summaries or reminders of this information. Educate clinicians, nurses and allied healthcare workers on the effectiveness of the interventions offered. Work towards implementing the initiative into the standard of practice for dyspneic patients.

**Awareness:**

Ongoing promotional tactics should be carried out to promote the initiative within the broader medical community and amongst patients. Posters and notices should be displayed in visible, high-traffic areas near where patients are seen. Information brochures should be circulated to healthcare providers, specifying that the materials be passed on to appropriate patients. In-person meetings should be conducted with the relevant treating physicians; these conversations are especially important if the family doctor is responsible for patients’ palliative care needs. Presentations at medical and nursing rounds can also promote awareness and referral.

**Systematic Approach:**

Overall, it is crucial that the initiative is implemented based on a strategic, well-planned approach. Various planning models, knowledge-to-action cycles or project management tools may provide useful examples of effective approaches. For instance, Lawrence Green’s “Precede-Proceed” framework (refer to Figure 2) outlines steps that precede an intervention, as well as methods of proceeding with its implementation and evaluation (1980). Steps that “precede” the intervention include the assessment of the problem and the identification of contributing factors. The “proceed” stage includes the implementation and evaluation of the program, in terms of its processes, impact and outcomes. For additional program planning models, refer to Appendix VI: Program Planning Models.
Figure 2: Precede-Proceed Program Planning Model as Proposed by Lawrence Green (1980)

Patient- and Family-Centered Approach to Care:

A patient- and family-centered approach to care should act as an important guiding principle behind a dyspnea care initiative. According to the Institute for Patient- and Family-Centered Care (2010), patient- and family-centered care is defined as “an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families”. In the context of dyspnea care, a patient- and family-centered approach would entail developing strategies to involve input from patients and families throughout the development, execution and evaluation of an initiative. For instance, patients and families could provide insightful feedback on matters such as the scheduling of patient visits to the dyspnea care initiative, or services and educational materials that they find beneficial in managing dyspnea.

What is the appropriate model of care: Who needs to be involved and in what capacity?

An effective team requires enthusiastic, dedicated and knowledgeable healthcare professionals, as well as support from administrative, information technology, and management teams. The participation of at least one specialized oncology nurse who can devote a portion of his or her working hours to the initiative is critical. This nurse should be trained in basic dyspnea care and clinical assessment. For example, he or she should possess knowledge of cognitive behavioural strategies for dyspnea management. The nurse ideally should also perform follow-up visits in-person or via telephone, respond to urgent patient needs,
and participate in patient education. It is recommended that a physician with a specialty in palliative medicine or oncology supports the nurse. The nurse and physician would therefore be the core members of the team, who work collaboratively to identify the underlying cause of dyspnea and develop the patient’s individualized education and treatment plan.

In addition, individuals from other disciplines such as respirology or respiratory therapy, social work, patient education, occupational therapy or physiotherapy would expand the breadth of dyspnea care. The role of the occupational therapist would be to assess how dyspnea affects activities of daily living, as well as to teach practical strategies to minimize these effects and manage them optimally. Interventions led by the occupational therapist would revolve around topics such as fatigue management, energy conservation, safety assessments, and anxiety management. The occupational therapist would also determine whether there was equipment that may help the patient manage dyspnea in their home setting. The patient education expert would provide patients with knowledge of dyspnea and the underlying causes as well as cognitive behavioural strategies to manage dyspnea, in order to increase the patient’s self-efficacy in caring for themselves. The role of the respiratory therapist would be to assess the patient’s lung functioning. The respiratory therapist would carry out assessments such as pulmonary function tests and walk tests with the patients, and they may also provide instruction in breathing techniques. The social worker would provide counseling as required to assist in anxiety management and psychosocial support for the patient and family as they deal with this distressing symptom. Psychotherapy interventions could also be initiated by the social worker, based on the patient’s quality of life as measured by the EORTC-QOL tool. Nevertheless, if certain disciplines cannot participate as team members, it may be beneficial to still involve these disciplines with the initiative. For instance, if resources do not allow for the involvement of a social worker on the team, this individual could be included in the planning or evaluation of the initiative.

An individual should be selected from amongst the team to oversee the design, implementation, functioning, and evaluation of the program. Overall, team members should look to reverse medical causes of the dyspnea if they exist, provide pharmacological and non-pharmacological interventions to manage the symptom, and psychosocial support to help the patient cope with the impact of the symptom on their quality of life.

Some administrative and clerical support may be allocated for the dyspnea care initiative via the current administrative team on site. Biomedical engineering support should also be considered, as they will be needed to provide expertise in managing the treatment equipment. Examples of treatment equipment include a thoracentesis set or a spirometer. Relevant management groups are also important to include in the development and implementation of the initiative, in order to maintain a sustainable initiative and ensure that its goals are in alignment with the broader site’s priorities.
A dyspnea care initiative would also benefit from individuals or groups promoting the initiative, providing feedback on its effectiveness, and providing further dyspnea care beyond the scope of the initiative services. Clinical champions who will refer patients and inform others about the initiative are critical to the success and effectiveness of the initiative. Support from the RCC administration and other management bodies is also necessary. Partnerships should also be developed with programs at the RCC, such as Oncology, Psychosocial Oncology, Patient Education and Palliative Care. If patients’ needs cannot be met through the dyspnea care initiative, partnerships with other services or clinics could be beneficial as patients can be referred to services provided at these external programs. Lastly, collaboration with CCAC partners is essential in order to provide extended dyspnea care beyond the capacity of the initiative and to accommodate the needs of patients who are situated further from the initiative location. It should be ensured that CCACs have the plan of care from the oncology nurse for their records and written materials to promote non-pharmacological strategies to improve dyspnea management for these patients.

**What services should the dyspnea care initiative offer?**

Ideally, the initiative should consist of a variety of services that can be incorporated into an individualized treatment plan depending on each patient’s needs. Firstly, an initial consultation is necessary, consisting of a comprehensive health assessment using the acronym OPQRSTUV. The acronym OPQRSTUV refers to assessing the symptom in regards to: Onset, Provoking/Palliating, Quality, Region/Radiation, Severity, Treatment, Understanding/Impact on You, Values (refer to Appendix I: CCO Developed Dyspnea Resources). Pulmonary function tests may be undertaken if necessary. The team should work to identify the underlying cause of the dyspnea and determine the individual’s plan of care, comprising pharmacological and non-pharmacological treatment interventions. This plan should be noted in the shared health record (physician portal) for all team members’ reference.

Non-pharmacological interventions are also useful to help patients manage dyspnea. The patient’s level of anxiety and fear should be assessed and evaluated for its impact on their dyspnea. Appropriate anxiety management and supportive counseling to identify the meaning of dyspnea to the patient can then help minimize levels of anxiety and fear associated with this symptom. Other examples of non-pharmacological interventions include cognitive behavioural interventions, such as providing instructions on breathing control and relaxation techniques, or suggesting various positions that maximize respiratory function without significant physical effort. Lastly, directing ambient air flow onto the face using a fan, window or nasal prongs is another example of a non-pharmacological intervention (refer to Appendix III: CCO Developed Dyspnea Resources).

In terms of pharmacological dyspnea care, interventions will vary depending on the severity of dyspnea exhibited by patients. Supplemental oxygen may benefit hypoxic patients experiencing mild dyspnea.
Systemic opioids are most commonly recommended in various doses and by a variety of routes for patients with all severities of dyspnea. Benzodiazepines may be used for anxiety in patients with moderate dyspnea. Trials of chlorpromazine or methotrimeprazine may be considered for those experiencing moderate or severe dyspnea that is not remedied by other therapies. For detailed, evidence-based information on pharmacological interventions, refer to Appendix III: CCO Developed Dyspnea Resources.

Apart from the aforementioned pharmacological and non-pharmacological treatments, interventions that address the underlying cause of dyspnea are essential. For instance, a thoracentesis procedure may be necessary to relieve pressure on the lungs due to excess pleural fluid (Dudgeon, 1996). The use of tracheal or bronchial stents to maintain the airway open or brachytherapy to provide high-dose radiation locally may alleviate areas of obstruction and associated dyspnea (Lee, P., Kupeli, E., & Mehta, A. C., 2002) (refer to Appendix III: CCO Developed Dyspnea Resources).

Optimal care is provided only when the comprehensive assessment leads to interventions to alleviate and manage the symptom. While non-pharmacological interventions will almost always assist with dyspnea management, it is critical to complement this strategy with medical treatments aimed to reduce or eliminate the symptom if required. Dyspnea must be addressed holistically. As stated by Corner and O’Driscoll, developers of a breathlessness assessment guide, “breathlessness [should] be addressed as a multidimensional problem, in which the emotional experience of breathlessness is inseparable from the sensory experience and the causative biological mechanisms” (Corner & O’Driscoll, 1999, Abstract). Attention to both non-pharmacological and pharmacological treatment needs provides patients with the most comprehensive care. However, as demonstrated by Zhao and Yates (2008), providing patients with any form of care will lead to greater improvements than providing no services at all.

Patient education is another important component of a dyspnea care initiative. Education can be held in the form of individual teaching or group classes, or via resources provided to patients. For instance, patients should be supplied with appropriate resources at their initial visit that include information about dyspnea, such as the main causes of dyspnea, common concerns about dyspnea, and basic management techniques to minimize dyspnea. As well, practical information about the dyspnea care initiative should be included with the resources provided, such as an introduction to the team members, the initiative hours and patients’ scheduled visit times, emergency contact information for the team members in case the patient experiences an exacerbation of dyspnea, an outline of the patient’s treatment plan, space for the patient to list their medications, and space for the patient to list their questions for the team members.

It should be noted that not all of these services need be included in a dyspnea care initiative. Rather, the aforementioned list should be considered a summary of the potential services that could be incorporated
into such an initiative. If a service cannot be offered at a dyspnea care initiative, patients should be referred to an alternative option or source for the service that is lacking.

**Who should be referred to the dyspnea care initiative?**

Patients who have a moderate to severe ESAS score (equal to 4 or higher) should be targeted for such an initiative. Data show that those patients with moderate to severe scores demonstrate greater improvement from dyspnea management interventions (refer to Appendix IV: Dyspnea Pilot Project Results). However, any interested patient experiencing dyspnea should be referred, provided that there is the required expertise amongst the clinical team. A broader range of referral candidates would increase patient accrual numbers as well as public awareness of the initiative.

Caregivers should also be encouraged to attend the initiative. Dyspnea care initiatives can serve as a source of education and support for caregivers as they endeavor to care for their loved one. The attendance of a caregiver may also help reinforce concepts that are taught through the initiative, as the caregiver could remind the patient of the information that has been learned. Finally, the caregiver is often familiar with the patient’s medical history and current condition; thus, they may prove to be a helpful resource as the patient’s individualized treatment plan is finalized by the team.

**How can the impact of this initiative be measured?**

Program impact can be measured quantitatively, by patient accrual numbers or by a decrease in patient ESAS scores from their first visit to their last visit. However, the literature shows that objective, numerical measures often do not demonstrate a reduction in the impact of dyspnea. Dyspnea is a subjective symptom experienced by patients in different ways. Furthermore, the trajectory of dyspnea for cancer patients versus those with Chronic Obstructive Pulmonary Disease (COPD) differs. There are several more causes for dyspnea and it can progress far more rapidly in cancer patients (Jantarakupt, 2005). It is therefore important to consider measuring impact through qualitative measures such as feedback from clinicians, patients and caregivers, patients’ scores on the EORTC-QOL Questionnaire, and patients’ ability to self-manage their dyspnea.

In order to monitor initiative effectiveness aptly, regular meetings should be held to review and revise components, processes and services. These meetings should include the initiative team, as well as supporting clinicians and engaged patients and caregivers who could provide feedback. In general, the focus of these meetings should be on improving the quality of care, processes and patient experience.
What are the best approaches to managing logistical concerns?

Although logistics will vary between dyspnea care initiatives, a few general considerations should be kept in mind. Patients with lung cancer often have many appointments; therefore, incorporating dyspnea care into existing visits is important in order to efficiently make use of the time that the patient spends at the cancer centre. Ensuring that time is allotted at the beginning of a patient assessment to review the patient’s file and allowing time at the end of an assessment to determine the integrated plan of management amongst all team members will enable the integration of the care plan and ensure the consistency of information provided to patients. For patients who must travel from a far distance, provide consultation notes and teaching materials to their rural family health and CCAC teams to continue their dyspnea care closer to home. Alternatively, follow-up telephone calls could be made to appropriate patients.

How much time is necessary to plan for and initiate a dyspnea care initiative?

Planning and gaining momentum for any new initiative takes time. The length of time will vary significantly depending on the resource requirements of the initiative and the level of leadership supporting its development. Each of the funded pilots projects noted that several months were required to create public awareness and build significant patient volumes, and also for team members to become a cohesive group.

CONCLUSION

Dyspnea is a common distressing symptom experienced by a large proportion of lung cancer patients over the course of their illness trajectory. Through the Lung Cancer DPM initiative, dyspnea management was recognized as an opportunity to improve the quality of care for lung cancer patients as it did not appear to be consistently well-managed across the province. CCO provided funding to seven cancer centres to implement a dyspnea care initiative. From these pilot projects, CCO learned about a variety of dyspnea management approaches, all of which involved a combination of medical interventions, educational initiatives and training sessions to support individuals or groups. This recommendations report provides guidance on how best to plan and implement dyspnea care initiatives.
REFERENCES


APPENDIX I - CANCER CARE ONTARIO’S AND DISEASE PATHWAY MANAGEMENT’S FRAMEWORK

Ontario Cancer Plan III Strategic Framework:

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Disease Pathway Management Goals and Objectives Framework:

<table>
<thead>
<tr>
<th>Vision</th>
<th>High quality care, processes and patient experience across the patient pathway for specific cancers.</th>
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<tbody>
<tr>
<td>Goals</td>
<td>Describe and share evidence-based best practice along the cancer continuum for specific cancers.</td>
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<tr>
<td>Identify quality improvement priorities for specific cancers.</td>
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<tr>
<td>Monitor performance against best practice for specific cancers and catalyze action.</td>
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<tr>
<td>Objectives</td>
<td>Develop and maintain clinical disease pathway maps based on best practices for all major cancers by 2015.</td>
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<tr>
<td>Identify and understand the audiences for pathways and develop approaches to make them more readily available (patient pathways, interactive pathways).</td>
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<tr>
<td>Identify and promote opportunities to embed best practice (as defined by the pathways) into care delivery processes.</td>
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<tr>
<td>Identify and promote opportunities to employ the pathways to model system-based change.</td>
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<tr>
<td>Develop and implement DPII programs for all major cancer types by 2015:</td>
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<tr>
<td>Identify and promote alignment of current CI work across the cancer continuum.</td>
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<tr>
<td>Identify performance gaps for which quality improvement work is not already underway, with attention to transition, integration, and processes.</td>
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<tr>
<td>Identify gaps in evidence-based guidance.</td>
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Bold objectives = in OCPII

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APPENDIX II – LUNG CANCER DPM PRIORITIES FOR ACTION

Prevention, Screening and Early Diagnosis
1. Increasing support and resources for smoking cessation
2. Linking historical exposure to awareness of increased risk at the primary care level
3. Raising awareness of lung cancer and its causes to reduce stigma for patients
4. Mobilizing for action as a result of research advancements in screening and tobacco control

Diagnosis
1. Developing synoptic reporting for diagnostic imaging
2. Supporting the ongoing training and education of radiologists
3. Ensuring physicians receive sufficient contextual information about a patient in a timely fashion

Treatment
1. Educating and raising awareness regarding proper referrals
2. Developing standards of access to care for diagnosis and treatment
3. Developing a framework for how to prioritize patient care
4. Improving the management of urgent problems along the disease trajectory

Palliative Care
1. Identifying supportive care needs early on in the cancer continuum
2. The management of lung cancer-specific symptoms
3. Improving the integration of the family practitioner into the patient’s care team

The Patient Experience
1. Improving psychosocial support offered to individuals in the diagnostic phase
2. Defining provincial standards for patient information: what should be offered and when
3. Explicitly addressing transitions between phases of the cancer journey and care providers
4. Improving alternative access to care where appropriate
APPENDIX III – CCO DEVELOPED DYSPNEA RESOURCES

**Figure 1.1: Dyspnea Algorithm**
http://www.cancercare.on.ca/CCO_DrugFormulary/Pages/FileContent.aspx?fileId=97465

**Figure 1.2: Dyspnea Pocket Guide**
http://www.cancercare.on.ca/CCO_DrugFormulary/Pages/FileContent.aspx?fileId=97467

**Figure 1.3: Dyspnea Guide-to-Practice**
http://www.cancercare.on.ca/CCO_DrugFormulary/Pages/FileContent.aspx?fileId=97469

**Figure 1.4: Managing Shortness of Breath Video Series**
http://www.youtube.com/user/ManagingSOB
APPENDIX IV – DYSPNEA PILOT PROJECT RESULTS

Figure 2.1: Lung patients visiting the dyspnea clinic demonstrated an improvement in dyspnea ESAS scores

Figure 2.2: Patients that improved tend to have initial higher dyspnea ESAS scores

Note: Patients were considered to have an improved dyspnea ESAS score if they:
- Had the same or lower ESAS score on their last visit, based on an initial dyspnea ESAS score between 0-6
- Had a lower ESAS score on their last visit, based on an initial dyspnea ESAS score 7 and above
APPENDIX V – CHECKLIST FOR IMPLEMENTING A DYSPNEA CARE INITIATIVE

Team
- Decide the appropriate model of care for your program team (Consider available resources.)
- Recruit the appropriate program team members.
- Identify the program lead from amongst the team.
- Outline the roles, responsibilities, time commitments and compensation of each program team and ensure their agreement with these position requirements (i.e. signing of contract).
- Arrange for the training of team members as needed.

Mission
- Identify the vision and guiding principles that will form the basis of all program activity.
- Identify short-term and long-term goals for the program and discuss the plan of action to complete each goal with your team.
- Review program planning models, knowledge transfer cycles, and/or project management tools and decide on the systematic approach that will guide the program planning, implementation and evaluation.

Services
- Decide on the interventions to be offered at the program, as well as the mode of delivery.
- Ensure the expertise required to lead these interventions is represented in the program team.
- Create materials needed to run interventions (i.e. patient education materials).

Equipment
- Purchase treatment equipment needed for the various intervention options offered by the program.
- Purchase operational equipment needed for the functioning of the program, such as the computer, printer/fax/scan machine, and telephone system.

Working Relationships
- Establish working relationships with other programs at the cancer centre.
- Engage referring physicians, nurses and allied health care providers in the development of the dyspnea program and keep them informed of the program’s ongoing activity. Ensure that these individuals have an understanding of dyspnea and its impact on patients, the program’s goals and the effectiveness of the interventions offered, as well as the appropriate referral process.
- Seek clinical champions who will advocate for the program’s effectiveness and act as reliable referring physicians.
- Connect with administration to ensure smooth scheduling of the program’s patient visits.
- Gain support from management for the program and ensure that the program’s goals are prioritized.
- Establish partnerships with the appropriate Community Care Access Centres in the region in order to coordinate care for patients who live at a distance from the program.
- Set up working relationships with outpatient palliative care teams.

**Logistics**
- Establish a space where the program will be held.
- Determine the scheduling of the program (i.e. program hours, number of visits per patient).
- Establish working relationships with administrative staff at the cancer centre who would be able to book patient visits to the program.

**Patient Accrual Methods**
- Determine the eligibility criteria for patient referrals.
- Identify the key methods to be used in gaining patient referrals (i.e. ISAAC notifications based on dyspnea ESAS scores, physician referrals, and patient self-referrals).
- Establish strategies that will be employed if an increase in patient volumes becomes necessary.

**Finances**
- Ensure that funding is available for ongoing and one-time expenses (See Table 2: Program Expenses).
- Create a budget to keep track of program spending.

**Promotion of Program**
- Create promotional materials to advertise the program to patients (i.e. brochures/one-pagers that outline the program’s services and hours, posters to display in high traffic areas).
- Inform all referring physicians and other relevant individuals in the cancer centre of the program’s services, referral eligibility criteria and other important information about the program.

**Evaluation of Program**
- Identify the appropriate measures of impact (both qualitative and quantitative measures).
- Establish a method for acquiring the appropriate data from patients.
- Determine the methods for maintaining data records on patient volumes and various impact measurements (i.e. Quality of Life Questionnaire responses, Dyspnea ESAS scores, etc.).
- Create an evaluation group that will steer the direction of the program based on its successes and challenges as measured by the previously defined program impact measures.
APPENDIX VI – PROGRAM PLANNING MODELS

- **Ottawa Model of Research Use**

- **Rogers’ Diffusion of Innovation Theory**

- **Health program planning: A diagnostic approach**

- **Berwick’s Rules for Dissemination**

- **Plan-Do-Study-Act Worksheet**

- **Knowledge to Action Framework**
APPENDIX VII – LIST OF ACRONYMS

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>CCO</td>
<td>Cancer Care Ontario</td>
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<tr>
<td>DPM</td>
<td>Disease Pathway Management</td>
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<td>RCC</td>
<td>Regional Cancer Centre</td>
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<tr>
<td>ESAS</td>
<td>Edmonton Symptom Assessment System</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<tr>
<td>PSS</td>
<td>Palliative Performance Scale</td>
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<tr>
<td>EORTC-QOL Questionnaire</td>
<td>European Organization for Research and Treatment of Cancer Quality of Life Questionnaire</td>
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<tr>
<td>ISAAC</td>
<td>Interactive Symptom Assessment and Collection</td>
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<tr>
<td>CCAC</td>
<td>Community Care Access Centre</td>
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<tr>
<td>OPQRSTUV</td>
<td>Onset, Provoking/Palliating, Quality, Region/Radiation, Severity, Treatment, Understanding/Impact on You, Values</td>
</tr>
<tr>
<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
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