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Breaking the Surface - Breaking the Silence:

How the under-reporting of “Lung Attacks” in Canada impacts patient outcomes in COPD

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Executive summary

Chronic obstructive pulmonary disease (COPD) is a serious, progressive condition associated with significant morbidity and mortality. In COPD, oxidative damage from cigarette smoking or other airborne irritants leads to inflammation and destruction of lung tissues, accompanied by symptoms including cough, sputum production and shortness of breath. Over and above their day-to-day level of disability, patients with COPD can experience episodes of acute worsening of their condition, known as exacerbations, or "lung attacks". These episodes are often triggered by a bacterial or viral infection and contribute to further inflammation and lung damage. Although COPD cannot yet be cured, the progressive deterioration of lung structures and function can be halted or slowed with timely diagnosis, removal of the irritating agent (e.g., smoking cessation) and effective bronchodilatory or anti-inflammatory treatment, with antibiotics as appropriate for management of infection-related exacerbations.

Because of the seriousness of this chronic condition and its costs to the Canadian healthcare system, there is an urgent need to do more in order to provide optimal COPD management in Canada today. As in any chronic condition, effective communication between patients and members of their healthcare team is essential for optimal outcomes. However, differing expectations and pressures on the healthcare system can make this difficult.

This discussion paper is the result of a collaborative effort between the patient group COPD Canada and the Family Physician Airways Group of Canada. The purpose of this initiative was to identify existing gaps in care and communication and suggest how they could be bridged, by drawing on the findings of two research efforts:

- A series of round-table discussions that brought together Canadian patients, general practitioners and respiratory specialists to discuss the realities of living with and managing COPD
- A global survey of patients and physicians about COPD and its impact

This paper highlights two critical findings with the greatest immediate implications for COPD care in Canada:

- The under-reporting of exacerbations, or lung attacks, by patients to their physicians
- The underestimation by physicians of the consequences of exacerbations

The following are some of the other most notable gaps in communication and care identified in these initiatives:

- Many patients do not completely understand the definition of a lung attack; this is compounded by the lack of a common language between physicians and patients when describing the severity of an attack
- The slow progression and late diagnosis of COPD are significant barriers to optimal management
- Smoking cessation is an important component of effective COPD management, but both patients and physicians report that it can be an emotionally loaded issue that leads to communication barriers
- Although physicians' appreciation of the long-term consequences of COPD exacerbations is better than patients', they still underestimate the relative seriousness of exacerbations, compared with other medical conditions (e.g., heart attack, stroke)
- Canadian patients are well below the global average (55% versus 73%) for accessing healthcare services in response to an exacerbation, but above average for relying on the emergency room when they do seek care

The under-diagnosis and under-reporting of exacerbations represent a crucial opportunity to improve patient outcomes and quality of life. Because each exacerbation accelerates the long-term progression of COPD and other serious diseases, there is an urgent need to reduce the number of exacerbations through measures such as:

- Helping physicians, patients and other healthcare stakeholders appreciate the true prevalence and impact of COPD exacerbations
- Enhancing physician–patient communication and education through initiatives such as clinical tracking tools, patient education materials and other resources and programs that support two-way communication
- Ensuring continuity of care by facilitating communication both between physician and patient, and among members of the healthcare team
- Expanding access to effective strategies for managing COPD, its exacerbations and the impact of the disease on patients' lives

Introduction

COPD: Definitions and mechanisms

Chronic obstructive pulmonary disease (COPD) is the term for chronic, progressive inflammatory lung disease that causes irreversible narrowing of the breathing passages of the lung, a phenomenon termed "chronic airflow limitation".[1] This umbrella term encompasses two specific varieties of COPD: emphysema and chronic bronchitis.[2]

COPD is primarily caused by chronic exposure to irritants that damage the lungs. Although cigarette smoking is the most common cause, accounting for 80% to 90% of cases[3], other sources include outdoor air pollution, occupational exposure to inhaled irritants and, in certain countries, indoor air pollution (e.g., from indoor cooking fires).[1]

The most common physical symptoms of COPD are shortness of breath, excessive sputum production and chronic cough. These symptoms vary and may lead to attacks of breathlessness that cause the emotional distress typical of someone experiencing suffocation. These instances of "panic" or sudden anxiety are an important source of psychological and emotional distress in COPD.[4] Breathing obstruction can also lead to dynamic hyperinflation, a process where incomplete exhalations lead to an excessive amount of air retained in the lungs. Dynamic hyperinflation commonly occurs with exercise or other exertion and is a major contributor to patients' symptoms of breathlessness.

In addition to the typical baseline symptoms of breathlessness, patients with COPD can experience episodes of acute worsening of their condition. When COPD symptoms worsen and the worsening persists for 48 hours or longer, they are known as exacerbations, or "lung attacks", and are often linked to a bacterial or viral infection.[5] Some patients, notably those with symptoms of chronic bronchitis or cough and sputum, appear more prone to lung attacks than others.[6] These symptoms are a sign of underlying chronic inflammation[7] and serve as an important marker for risk of a future lung attack.

The progressive tissue damage in COPD can be characterized as accelerated aging of the lung due to oxidative stress provoked by inhaled irritants. This in turn leads to a cycle of chronic inflammation specific to COPD that damages the structures of the lung.[8] This damage is largely irreversible[5] and the extent of the inflammatory response has been shown to be associated with disease progression.[9] Additionally, exacerbations are associated with a precipitous increase in inflammation, which causes further damage.[10] Repeated exacerbations may also increase the risk of complications in other organ systems, notably the cardiovascular system, through increased oxidative stress and a rise in systemic inflammatory mediators.[11]

Consequences and economic burden of COPD

The progressive lung deterioration in COPD can lead to severe complications and death. The World Health Organization (WHO) estimates that 210 million people worldwide have COPD and that 3 million of them die annually. The WHO predicts that COPD will become the third leading cause of death annually by 2030.[1]

COPD is markedly under-diagnosed; the rate of physician-diagnosed COPD in Canada is 3% to 4% of the population 35 years of age and older. However, one Ontario-based study put the prevalence of disease in the population aged 35 and older at around 10%.[12] Screening for the disease with lung function measurements in an international population (including Canada) found a rate of 19%[13], suggesting that about half of those affected are not currently diagnosed. In 2003, over 10,000 Canadians died from chronic respiratory conditions, making these diseases the fourth leading cause of death, behind cardiovascular disease, stroke and cancer.[14] Although COPD incidence and mortality have traditionally been higher in men than in women, in recent years in Canada the balance has shifted; due to the demographic shift in smokers post–baby boom, COPD is now more common in women, and the mortality rate for women may soon overtake that for men.[12, 15]

A large portion of COPD-related mortality is due to exacerbations, in particular those serious enough to require hospital admission. Observational studies have found that mortality rates for serious lung attacks are similar to those for heart attacks, with 8% of admitted patients dying in hospital and one in four patients dying within a year of the episode that caused their hospitalization.[16]

Summary: "Lung attacks" versus heart attacks

	In-hospital mortality	Mortality within 1 year of attack
Lung attack	8–11%	22–43%
Heart attack	8–9.4%	25–38%

In addition to the serious consequences for patients, COPD places a significant strain on the Canadian medical system. COPD now accounts for the highest rate of hospital admissions among major chronic illnesses in Canada, and readmission rates are

also higher than for other diseases; 18% of COPD patients were readmitted once within the year following their first admission, and 14% twice within that year. The estimated average length of hospital stay for a COPD exacerbation is 10 days, at a cost of about $10,000 per stay. A recent report estimated the total cost of COPD hospitalizations in Canada at $1.5 billion annually.[16]

Diagnosis and treatment of COPD

Diagnosis of COPD can be difficult because it often co-exists with other medical conditions, notably cardiovascular disease. Many patients fail to recognize their symptoms and attribute their breathlessness to "being a little out of shape" or "part of the normal aging process". The majority of COPD patients in Canada are diagnosed by their general practitioners (GPs), and roughly 80% continue to receive care primarily through their GPs.[17] COPD is diagnosed based on symptoms, history of smoking or exposure to other pollutants and lung function tests. The gold standard for lung function testing is spirometry, which can assess the amount of airflow limitation and the degree of reversibility. Because spirometry can give an objective and reproducible indication of lung deterioration, it is an essential tool in COPD diagnosis and tracking, particularly in early disease when the patient's symptoms may not yet be severe.

Management strategies for COPD depend on the severity of symptoms and their impact on the patient's life. Regardless of the severity of disease, patients who are still smoking should be encouraged to stop. Short-acting bronchodilators can be prescribed for occasional quick relief of troublesome symptoms. With increasing disease severity, long-acting maintenance bronchodilators can be added. For patients with frequent exacerbations, inhaled corticosteroids can be introduced. Alternatively, if the inflammatory markers of cough and sputum are also evident, the newly approved oral tablet roflumilast, which has COPD-specific anti-inflammatory activity[18], may be added. Patients with very severe disease may require oxygen therapy or surgery.[5] In those with persistent symptoms, pulmonary rehabilitation may help improve quality of life. Although this multidisciplinary program of patient and family education, exercise training and behavioural counselling cannot reverse the underlying lung deterioration, it can help improve patients' walking ability and ease of breathing.

When exacerbations occur, the goal of treatment is to reduce symptoms to their baseline level, usually with bronchodilators and/or oral corticosteroids (e.g., prednisone, usually for as short a course as possible). Antibiotics may be appropriate if a bacterial infection is suspected.[5]

Identifying challenges in COPD care in Canada

The human and economic burden of COPD in Canada suggests there are significant gaps in COPD management in this country. The purpose of this paper is to identify where challenges exist and to explore strategies for optimizing COPD care.

In order to gain a deeper understanding of physicians' and patients' perspectives on COPD and its management, qualitative research sessions were conducted that brought these groups together to discuss the reality of living with and managing COPD. A global opinion survey was also conducted that highlighted differences in practice and understanding between Canada and other countries. Published reports were also reviewed in order to support and supplement the research findings.

Methods: Two round-table discussions with physicians and patients were conducted in October 2010. These research groups were complemented by a global opinion study, the Hidden Depths of COPD survey, highlighting care and communication gaps in Canada and 13 other countries worldwide. Fuller details of the methodologies for both initiatives can be found in Appendix 1.

Objectives: The research questions were designed to help deepen understanding of the following:

- Patients: Experience with COPD – diagnosis, management and impact on quality of life
- Physicians: Experience and challenges in diagnosing and managing COPD
- Patients and physicians: The level of satisfaction with educational programs and support resources
- Patients and physicians: Identifying gaps in communication and care, and how they can be bridged

Patients' perspectives: Living with COPD

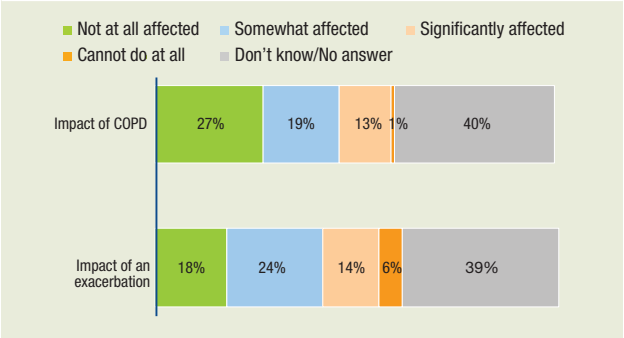
Quality of life

Studies have shown that deterioration of lung function due to progressive airway obstruction has a significant impact on patients' quality of life and psychological well-being. Patients often report limitations to their daily activities, particularly activities involving physical exertion. Their ability to work outside the home or to take care of their families may also be compromised.[16]

Consistent with these wider findings, patients in the research sessions reported that COPD was a major detriment to their quality of life. Most commonly reported symptoms included coughing, fatigue, difficulty breathing, spitting up phlegm and a general feeling of stress. These symptoms led to significant difficulties in activities of daily living, including work, social activities and interactions with family members. In the Hidden Depths survey, COPD symptoms had a significant effect on a range of daily activities for a majority of respondents (Appendix 2). Activities affected included climbing stairs, housework, getting dressed and sleeping. Research group participants reported similar limitations; a selection of their comments is included in Appendix 3.

When asked specifically about COPD exacerbations, patients in the research sessions reported that these acute events had a more dramatic impact on their quality of life. Lung attacks even had a detrimental effect on patients' relationships with their spouses or partners, with more than 40% of respondents in the Hidden Depths survey reporting that exacerbations affected their relationships (Figure 1).

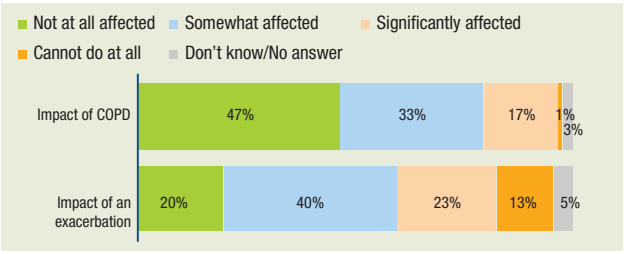
Figure 1. Hidden Depths of COPD survey: Effect of COPD and exacerbations on patient's relationship with his/her partner



Question: From the following list can you indicate to what extent your ability to undertake or participate in these activities or pastimes are directly affected or restricted when you are experiencing one of these attacks?
Population: All respondents who have ever experienced a worsening of at least one symptom of their Chronic Bronchitis/Emphysema/COPD; Canadian (101)

Respondents in both the Hidden Depths survey and the research sessions mentioned that COPD limited their ability to socialize and that exacerbations had a particularly detrimental effect (Figure 2). Reluctance to participate in social activities was due not only to the functional limitations produced by COPD symptoms, but also to the fear of catching a communicable illness, or a feeling of embarrassment when coughing in public. Some patients reported that they found themselves "spending more and more time alone". These feelings of isolation and embarrassment are of particular concern because they can contribute to the depression and anxiety that often accompany COPD.

Figure 2. Hidden Depths of COPD survey: Effect of COPD and exacerbations on patient's ability to socialize freely



Question: From the following list can you indicate to what extent your ability to undertake or participate in these activities or pastimes are directly affected or restricted when you are experiencing one of these attacks?
Population: All respondents who have ever experienced a worsening of at least one symptom of their Chronic Bronchitis/Emphysema/COPD; Canadian (101)

Patient education

In general, patients in the research sessions were well informed about their disease and its causes and management, although they showed a range of attitudes. Some patients were highly motivated and curious and had taken the time to inform themselves, often through websites and other resources recommended by their physicians; others were content to know the basics but not dig deeper. However, in general, patients were unclear about the definition and role of inflammation in COPD. Many associated inflammation only with infectious causes and did not appreciate that chronic inflammation can be present even in the absence of infection. They were also unfamiliar with the manifestations of chronic inflammation (cough, mucus, chronic bronchitis) and the fact that these symptoms are a marker for increased exacerbation, or lung attack, risk. Finally, patients were unclear on the terminology and definition of an exacerbation (persistent worsening of COPD symptoms lasting more than 48 hours). In the research sessions, patients were shown a video of an individual being wheeled into an emergency room (ER) with a severe exacerbation. Although most patients reported having experienced similar symptoms and urgency, few were able to associate the term "exacerbation" with the experience (regardless of terminology used) or fully explain why it might have happened.

Attitudes toward smoking cessation

Smoking cessation is one of the most important – and most contentious – components of COPD management. For patients, the smoking cessation discussion is complicated by many emotional and social factors. Some patients believe that they brought their COPD on themselves by smoking and that they therefore "deserve" their disease. In some cases this sense of guilt can provide the motivation to stop, but other cases show an attitude of fatalism – the patient continues to smoke because "I'm already sick anyway and it won't make a difference."

Across the groups and in the Hidden Depths survey, roughly half of patients reported successfully giving up cigarettes following their COPD diagnosis. Many others mentioned unsuccessful attempts to stop, often repeatedly. Some mentioned lack of coverage of smoking cessation aids (patches, etc.) as a barrier to cessation.

Patients who had continued to smoke past their diagnosis often reported feeling that their doctors were judging or nagging them. This can become a significant barrier to effective communication and disease management because patients often feel reluctant to discuss COPD, and lung attacks in particular, for fear of being given "another stop-smoking lecture". Several participants characterized their doctor's attitude as, "If you won't help yourself by quitting smoking, why should I help you?" Many patients also expressed frustration at their doctor's repeated lectures about quitting; a common comment was, "(S)he doesn't understand how hard it is for me."

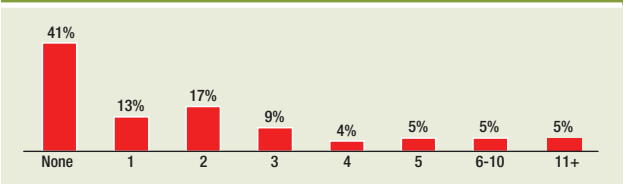
Exacerbations

The Patient's View

"The first time [I had a lung attack], I was thinking, 'This is it. This is how I'm going to die.' And it's true when they say that when you can't breathe, nothing else matters."
–Todd

What clinicians and medical publications call an "exacerbation", patients most often refer to as "flare-ups". In the research sessions, experience with exacerbations varied; some patients reported several episodes per year, others said it had been several years since their last exacerbation. These results were supported by the Hidden Depths survey, where roughly 60% of Canadian patients reported having any exacerbations in the past year, and over 40% reported having two or more during that period (Figure 3).

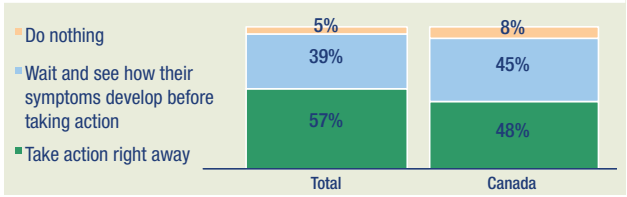
Figure 3. Hidden Depths of COPD survey: Number of exacerbations in the previous 12 months



Question: In the past 12 months, how many times have you experienced one of these attacks?
Population: All Canadian respondents (150)

Although patients reported that exacerbations had a significant impact on their quality of life, many group discussion participants stated that they did not always seek prompt care for a serious exacerbation. In general, patients did not tend to recognize the onset of a lung attack until after several days of worsening symptoms, and many referred to a tendency to wait and see how symptoms developed and to "try to ride it out". These findings were supported by data from the Hidden Depths survey, where more than half of Canadian patients reported waiting or doing nothing at all when an exacerbation occurred (Figure 4); **the proportion of Canadian patients taking no action for an exacerbation was double the global average.**

Figure 4. Hidden Depths of COPD survey: Responses of Canadian and international patients to exacerbations

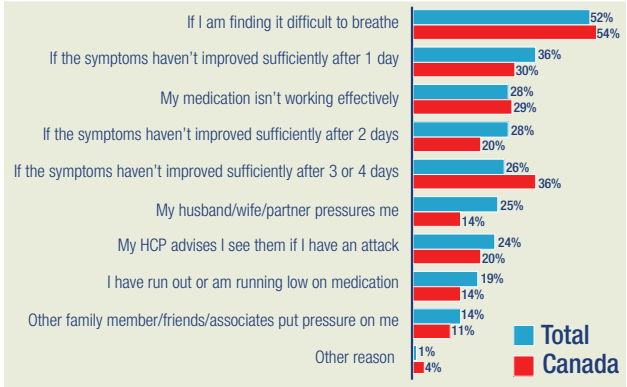


Question: Which, if any, of the following do you typically do if you experience one of these attacks?
Population: All respondents who have ever experienced a worsening of at least one symptom of their Chronic Bronchitis/Emphysema/COPD (1534), Canada (101)

Among patients who did seek medical care for an exacerbation, Canadian patients were more likely than average (i.e., respondents across all countries) to wait at least 3 or 4 days before seeing a doctor.

Apart from exacerbations, other triggers for seeking care included distressing symptoms (e.g., difficulty breathing) and concerns about on-hand medication (e.g., medication not working well enough, running low on supplies) (Figure 5).

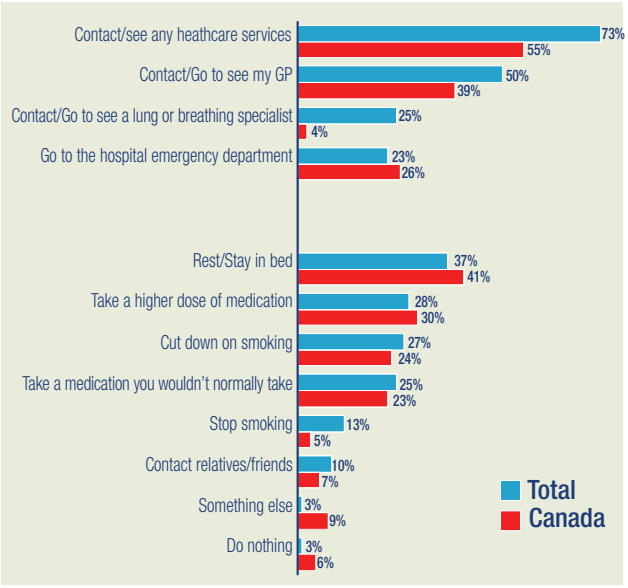
Figure 5. Hidden Depths of COPD survey: Triggers for seeking medical care for an exacerbation



Question: What are the main reasons you seek medical attention or advice if you are experiencing one of these attacks?
Population: All respondents who would contact HCP if experienced a worsening of a least one symptom of their Chronic Bronchitis/Emphysema/COPD (1125) Canada (56)

Many patients in the research sessions and the Hidden Depths survey believed that they were able to manage most exacerbations on their own, without medical assistance. Commonly reported self-management techniques included bedrest, cutting down on smoking and changing the dose or type of medication (Figure 6). A significant proportion of patients reported that they would seek treatment only if symptoms did not improve after several days of attempted self-management.

Figure 6. Hidden Depths of COPD survey: Exacerbation management strategies used by Canadian and international patients



Question: Which, if any, of the following do you typically do if you experience one of these attacks?
Population: All respondents who have ever experienced a worsening of at least one symptom of their Chronic Bronchitis/Emphysema/ COPD – Total (1534) Canada (101)

These findings are of concern because they demonstrate that patients may not fully appreciate the potential long-term consequences of repeated exacerbations, such as permanent lung damage or cardiac complications. By postponing treatment and attempting to self-manage, they may in fact place themselves in a situation where they experience progressive worsening that necessitates a call to 911 and/or hospitalization. **Indeed, the global survey revealed that Canadians were well below the global rate for accessing healthcare services (55% versus 73%) but well above the global average when it came to relying on the ER in those cases where help was sought.** Another alarming finding was that patients did not always report exacerbations to their GP or respirologist, a key piece of information for their disease management, since frequent exacerbations are a risk factor for future exacerbations[19] that also increase COPD-related lung deterioration.

Canadians were well below the global rate for accessing healthcare services (55% versus 73%) when experiencing an exacerbation or lung attack, but well above the global average in relying on the ER for exacerbation care.

Treatment and measures of success

Patients' use of medications in COPD is primarily driven by the pursuit of symptom relief, while delaying or mitigating long-term effects appears to be a lower priority. Likely for this reason, most patients in the research sessions reported being generally happy with the efficacy of their inhaled medications. Side effects such as dry mouth and constipation were reported but were generally thought to be manageable. Some patients mentioned that it was not possible or comfortable to use inhalers during an acute exacerbation; comments included "Sometimes I'm choking so badly that I can't take a breath to get the medication in," and "If I can't breathe, I don't want to have to put anything near my mouth."

Patients seemed unclear on the distinction between short-acting inhalers for symptom relief in acute episodes and longer-acting inhaled maintenance medications; they incorrectly perceived that inhalers of all kinds were intended to have an "immediate impact". This opinion became particularly evident when patients were asked to compare their attitudes to inhalers with, for example, a tablet taken by mouth. The general feeling was that the pill would be an attractive and convenient option, but that inhaled medications would remain the preferred option when rapid onset of relief was required.

Several patients reported that they asked their physicians for antibiotic prescriptions to keep on hand and use in anticipation of an exacerbation. The physician group recognized that this was potentially a useful practice, but that they did not offer it routinely because of the challenge in monitoring actual antibiotic use if patients did not report it back to them.

Although many participants reported taking measures to avoid exposure to infectious agents that could lead to an exacerbation (e.g., scrupulous handwashing, staying away from people who are visibly sick), only about half reported receiving regular influenza vaccinations. Because of the confusion regarding the difference between a milder, panic-attack type of episode and a true exacerbation with an infectious cause, some patients were unclear on what measures they could take to reduce exacerbation risk.

Physicians' perspectives: Managing COPD

Approaches to diagnosis and treatment

The majority of physicians in the research groups reported having access to a spirometer for diagnosis of COPD, either in their own office or at an affiliated facility. However, several participants – all of them GPs – did not have or use spirometers in COPD diagnosis. Some mentioned not using spirometry because they sent patients to a lab for other lung function tests or they referred patients to a respirologist for workup.

Patient education

The Physician's View

"Exacerbation is a teaching moment. You can get their attention because they don't feel well. The rest of the time they feel okay so they're less interested in what you say." – Respirologist

Physicians in the research sessions appreciated the importance of providing comprehensive patient education about COPD and its management, but several participants noted that short appointments and the need to focus on other co-morbid conditions often limited the amount of COPD education they were able to provide. Doctors found that patients were most receptive to learning about their disease and its management immediately following an exacerbation and that motivation declined as symptoms returned to a more normal level. This observation is consistent with the findings from the patient group, where patient motivation was driven primarily by a desire for relief of immediate symptoms and less so by concerns about minimizing the long-term impact of their disease.

When asked whether they discussed the role of inflammation in COPD symptoms and progression, physicians' responses varied. A number of participants reported that they did not raise the topic of inflammation because it was difficult to provide a simple and easily understood explanation. Others found that it was useful to compare and contrast lung inflammation with forms of inflammation elsewhere in the body that might be more familiar or visible – for example, a scratch on the skin or an infected cut might be an example of acute inflammation, while chronic inflammation could be compared to rheumatoid arthritis.

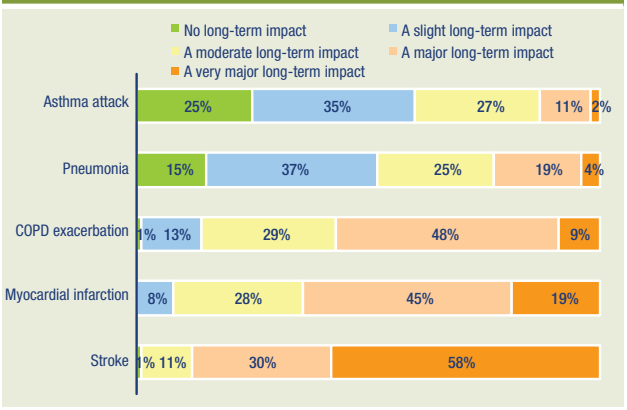
Exacerbations

The Physician's View

"Patients don't always report their exacerbations because either they don't think that it's important or something else is more important, or they minimize the symptoms. A lot of people feel a need to have a sense of control over themselves, and this is a loss of control." –GP

Although physicians had a better appreciation for the long-term consequences of exacerbations than patients did, in the Hidden Depths survey they still (incorrectly) ranked COPD exacerbations serious enough to require hospital admission behind myocardial infarction and stroke in terms of long-term impact (Figure 7).

Figure 7. Hidden Depths of COPD survey: Canadian physicians' perceptions of the long-term impact of serious exacerbations



Question: For the following list of conditions can you indicate how much you think an acute hospital admission impacts the long-term (12 months) health of a typical adult.
Population: All Canadian adults (100)

When it came to assessing and managing exacerbations, there were varying approaches among the physicians participating in the discussion groups. Participants' approaches were similar to those of reported study populations[15] in that only a minority had time to counsel patients on prevention strategies or action plans to be used in case of an exacerbation.

Unlike patients, physicians classified the severity of an exacerbation much as it is classified in clinical studies, that is, according to the measures required to treat it. The main criterion for defining an exacerbation as "severe" was the need for hospitalization, oxygen or oral steroids, while a "moderate" episode was one that required additional treatment beyond the patient's normal regimen (e.g., antibiotics).

Physicians in the research groups noted that their strategy for follow-up treatment after a recent exacerbation depended on the severity and/or frequency of episodes. The first step that most physicians reported was to check for the correct use of the patient's existing medications, for example, by asking the patient to demonstrate how he or she used the inhaler. If medications were being used correctly but were still insufficiently effective, the next step was to intensify the patient's existing medications.

When asked how many exacerbations they saw in a typical COPD patient in a year, most physicians in the research sessions mentioned numbers in the range of three to four. However, there was a general sentiment that the actual number was likely much higher but that patients were not reporting all their episodes. For example, patients may forget to mention an urgent care visit when they next see their regular physician, or they may deliberately withhold information for fear of being judged because their disease is not under control. Patients may also under-report their exacerbations because they do not realize what their frequent "chest colds" signify, or because they feel that other co-morbid conditions are a more pressing concern and they do not want to burden their doctor with an episode that happened weeks or months ago. Several physicians expressed frustration at having to make management decisions that would likely lead to suboptimal outcomes because they were based on incomplete information.

Measures of treatment success

Physicians' definitions of successful COPD treatment tended to be clinically oriented, and included:

- Patient complies well with medications and other management strategies
- Patient stops smoking
- Disease progression is halted (pulmonary function stabilizes) or slowed
- Number and severity of exacerbations are reduced
- Fewer courses of antibiotics are required

One significant finding was that physicians' measures of success were largely based on clinically observable signs and symptoms and did **not** focus on more wide-ranging measures of overall well-being such as quality of life and ability to exercise. Although physicians' typical success metrics do not fundamentally contradict the patients' criteria, which did focus more on symptoms and quality of life, the differences in priorities could potentially lead to communication difficulties. This is especially true in the matter of disease progression, where patients may think that treatment has been successful because they are accustomed to their symptoms and do not perceive the worsening, while the physician may observe that pulmonary function is continuing to decline and therefore decide that treatment has not been effective.

Patient and physician perspectives: Care and communication gaps in COPD

The following topics were identified as significant areas of differing perspectives between patients and physicians in the group research sessions and the Hidden Depths survey.

Slow disease progression and late diagnosis complicate education and management

One of the particular challenges with patient education in COPD is the insidious, slowly progressing nature of the disease. As previously discussed, physicians reported that patients were most receptive to education immediately following an exacerbation, with interest waning as symptoms decline. This tendency highlights the need for patients and physicians to work together to ensure better tracking of COPD symptoms in order to provide a true picture of disease progression. Combined with GP reticence to use spirometry, this also explains why diagnosis is happening in later stages of the disease and why diagnosed prevalence is thought to be half of the overall prevalence of the disease.

Patients and physicians have differing educational approaches

Overall, there was a difference in expectations about patient education in COPD. Several doctors said that their approach was to try not to overwhelm patients with too much information; however, some patients felt that their doctors were "not telling the whole story" and that they were left to fill in information gaps on their own. This is of particular concern given that understanding the importance of controlling chronic inflammation is key for patient adherence and optimal outcomes in clinical presentations (e.g., chronic bronchitis) linked to chronic inflammation.

The smoking cessation discussion creates barriers to honest communication

A significant disconnect was observed between patients and physicians with regard to discussions of smoking cessation. Most doctors felt that they were sensitive enough to patients' concerns and that they approached the issue of cessation in a constructive way. However, many patients – particularly those who had continued to smoke past their diagnosis of COPD – reported that

they felt their doctors were often judgmental and unsympathetic, and said that they sometimes felt there was a wall of mistrust that hindered effective communication.

Therefore, it is vital that physicians approach the smoking cessation discussion in a way that acknowledges these patient attitudes and needs. This is particularly important in the earlier stages of the disease, when patients may be less concerned about the consequences of continuing to smoke, but when smoking cessation may have a larger impact on long-term outcomes.

Long wait for referrals, little continuity

Patients and physicians agreed that it can be difficult to find enough time to provide effective patient education. In general, doctor visits were thought to be too short and too infrequent to be able to pursue in-depth education about COPD, particularly in light of the many common co-morbid conditions that may take precedence at any given visit. Patients tended to be appreciative when doctors acknowledged this time pressure and did the best with the limited time they had available, providing further trusted resources (e.g., preferred websites, brochures) for the patient to consult on his or her own time.

Patients reported frustration at the difficulty of getting specialist referrals and the long waiting period for appointments. They also mentioned that it was challenging to access other support resources such as certified respiratory educators and pulmonary rehabilitation programs that could potentially reduce the need for specialist care. In general, patients felt that they were not well enough informed about what to expect from the medical system in terms of which healthcare professionals they should see, which resources are available to them and how long wait times would be.

From the physician perspective, one of the most significant barriers to providing effective care within the existing system was a lack of continuity. The participants' concern was that patient visits to walk-in clinics or ERs for urgent care of exacerbations were not always reported back to the treating physician, leading to gaps in the patient's clinical record and an underestimation of the true number of exacerbations suffered by the patient.

Patients and physicians have different perceptions of the importance of exacerbations

The Patient's View

"I didn't get a flu shot last year. Every other year I've had the flu shot but not last year. I ended up being diagnosed with H1N1, and ended up in the hospital for 10 days, in isolation. It was pretty serious. But I think if I had gotten the flu shot – and my GP feels the same way – I probably would not have been as sick as I was." –Todd

There was also a significant disconnect in terms of patient and physician perspectives about the implications of COPD exacerbations. Physicians were familiar with the mortality statistics associated with lung attacks and COPD-related hospitalizations, but patients were less well informed about the data and their implications. Many patients, particularly those with other significant co-morbidities, acknowledged being concerned about their COPD but felt that "something else would get them in the end". When patients were given statistics showing that lung attacks can be as serious as or more serious than heart attacks, they were surprised and felt this changed their minds about where lung attacks fit into their priorities versus other diseases.

In the qualitative research sessions, patients were introduced to the term "lung attack" to describe an exacerbation, and asked their opinions of it. Some disagreed with the parallel to the more widely understood concept of a heart attack, because of the perceived absence of acute pain and long-term complications in lung attacks. However, when presented with the similar mortality statistics, patients agreed that the term painted an appropriate picture of lung attacks' urgency. This revealed a significant educational opportunity, since many patients seemed to be unaware of the high mortality and significant long-term effects of exacerbations.

One of the most significant findings was that for patients, the motivation to avoid exacerbations was mainly driven by concern about their symptoms and the immediate impact on quality of life. Patients were less motivated to consider the long-term consequences of exacerbations for their overall health.

There is an opportunity to reduce the economic and social burden of repeated exacerbations by enhancing patient education on how to avoid exacerbations through regular flu shots, handwashing and optimal medication. The challenge for physicians, therefore, is to provide patient education about exacerbations that recognizes patients' attitudes and priorities while still underscoring the

longer-term importance of avoiding repeated lung attacks. Physicians rarely include exacerbation avoidance in their initial definitions of quality of life or in patient follow-up; for example, the COPD Assessment Test (CAT) questionnaire does not consider exacerbations.[20] The situation is further complicated by the under-reporting of exacerbations. One tool that could help bridge these gaps would be a screening questionnaire for GPs to use in practice to help uncover recurrent chest colds and other "mild" lung attacks, as these could represent "hidden exacerbations" with an increased risk for future events and mortality.

From the physician's perspective, the need for medical treatment is usually seen as the dividing line between a "severe" exacerbation and a less severe one. That is, an episode where the patient was able to self-manage through bedrest and/or on-hand medications, while important to report as a marker of risk, would likely not qualify as severe from a physician's perspective. On the other hand, an exacerbation that eventually requires antibiotics or hospitalization (i.e., one a physician would describe as severe) can often have a more gradual onset that does not cause a similar level of alarm for the patient. This lack of a common language for describing the severity and implications of exacerbations is another important barrier to optimal communication and management.

Another important challenge is to give patients a clear indication of what should be done in the event of an exacerbation. Many patients did not appreciate the necessity of seeking prompt medical care; they tended to "wait until the last minute" and "try to ride it out" before going to a walk-in clinic or ER, often several days after the onset of symptoms. Given the serious long-term consequences of repeated severe exacerbations, there is a need for physicians to provide better patient education about the triggers for seeking medical care and how quickly patients should act on them. For some patients, a written action plan may be valuable in helping guide self-management and use of the healthcare system.

Equipping patients in this way with the information and resources for effective self-management of exacerbations is a neglected area where COPD management could be improved. There is considerable evidence that the duration of COPD exacerbations and their adverse consequences can be reduced by early treatment. One means to ensure that treatment is timely is to equip patients with a self-management plan, a well-known strategy in other disease areas; it has been successful in reducing asthma morbidity, for example. Several early studies have suggested that patients with COPD can be taught to recognize their symptoms early so that they can administer their own supplies of antibiotics, with or without oral steroids.[21] The Hidden Depths survey and research groups revealed no consensus on use of such self-management plans. When patients reported adjusting their treatment when they had a lung attack, they referred to taking more of their quick-relief medications, using breathing techniques and contacting their physicians. Physician participants reported that it was fairly uncommon for them to pre-equip their patients with antibiotic or other therapy that might allow for early intervention while still at home (with or without a telephone consultation with the physician's office). This seems an area in need of further research and clarification for both patients and their physicians.

Important communication and care gaps

Patient education and engagement	• Differing expectations about appropriate level of information – patients want to know more than doctors have time to provide • Lack of patient motivation and awareness regarding long-term implications of COPD and lung attacks – more education by GPs would heighten patient urgency to report and prevent lung attacks and accelerated progression • Difficulty of approaching smoking cessation discussion in a mutually constructive manner – physicians must use a non-judgmental approach • Challenge of tracking disease progression when patients become accustomed to their symptoms – physicians needs to probe beyond symptoms for unreported exacerbations and functional measures of disease progression
Exacerbations/ "Lung attacks"	• Patient perception that exacerbations/ lung attacks are "not as serious as heart attacks" – more education by GPs would heighten patient urgency to report, prevent and treat to elevate Canadian patients to the global standard • Lack of patient awareness of long-term effects of repeated exacerbations • Under-reporting of exacerbations • Differing definitions of exacerbation severity • Tendency of patients to delay seeking care for exacerbations

What can be done to begin to address management gaps?

Given the substantial gap between Canada and the global standard when it comes to accessing healthcare services in the event of a lung attack and the resulting impact on mortality, morbidity, and quality of life, it is evident that this represents the most urgent and substantial opportunity to improve healthcare outcomes. Earlier diagnosis of "frequent exacerbators" and more effective management and prevention of COPD lung attacks would not only improve patients' lives, but could also help ease the burden that COPD places on the Canadian medical system. Our recommendations for addressing gaps in COPD care are as follows.

Earlier recognition of "frequent exacerbators"

Steps should be taken to improve screening for exacerbations. Physicians should identify patients at a greater risk of exacerbations (e.g., cough and sputum, exacerbations in the past, etc.) in their practice and proactively ask or probe about "sick days" or "bad days" lasting longer than 48 hours, "chest colds", changes in sputum colour or thickness, visits to walk-in clinics and other indicators of potentially undiagnosed episodes, to assess the patients' "true" frequency of exacerbations.

Improved communication

Physicians and patients alike would benefit from improved two-way communication about COPD. Physicians should focus on helping patients understand:

- The definition of exacerbation/lung attack and how to recognize one when it occurs
- The importance of preventing exacerbations; the short-term and long-term effects of repeated exacerbations on disease progression and quality of life
- What should be done in the event of a lung attack
- The importance of reporting all exacerbations to one's treating physician
- The uses of and differences between short-acting medications for acute episodes (e.g., inhaled bronchodilators) and long-acting medications that fight chronic underlying causes (e.g., anti-inflammatories)
- Appropriate technique for using short-acting and long-acting COPD medications (e.g., video showing correct inhaler use)
- Available options and resources for smoking cessation

An important barrier to communication that was noted by both physicians and patients was the lack of time that doctors and patients have together to fully explore the implications of COPD and its management. Although there is unfortunately no easy way to relieve the financial and time pressures on the Canadian medical system, strategies could be put in place to help patients and doctors make the most of the limited time they do have together. An exacerbation screening tool and counselling tools on lung attacks and COPD in general should be developed to help both sides ensure that their questions and concerns are being appropriately addressed. Multidisciplinary programs such as the Chronic Disease Self-Management Program currently in use in British Columbia[22] could also help patients and physicians coordinate the various holistic measures that patients can take to improve their overall health.

Better continuity of care

Continuity of care is of great importance in any chronic condition, but particularly so in COPD, where patients with serious exacerbations often seek urgent care (e.g., walk-in clinic, ER) that may not be reported back to their GP and/or specialist. Patients should be encouraged to ensure that their treating physicians are informed about all of the patients' COPD-related interactions with any part of the healthcare system. Additionally, collaborative planning by agencies, patient groups and decision makers should be undertaken to improve communication and continuity within the healthcare system. Some key areas to focus on include:

- In the absence of an electronic medical record system that would update primary care physicians with information on possible exacerbations, more regular screening of COPD patients for exacerbation history, perhaps through the use of a simple screening tool
- Better access to smoking cessation programs and pulmonary rehabilitation
- Multidisciplinary care that treats the "whole" patient by addressing other issues (e.g., nutrition, co-morbidities, exercise) and enhancing the involvement of a variety of healthcare practitioners (e.g., pharmacists, nurses, nutritionists)
- Access to effective treatments, with reliable communication among the different members of the healthcare team about which medications have been tried and their effects

Recommendations for addressing care gaps	
More complete diagnosis	• Earlier and more effective diagnosis of COPD • Better profiling of exacerbation risk (i.e., identification of "frequent exacerbators")
Improved communication	• More extensive patient education, particularly regarding exacerbations • Tools to make better use of short physician visits • More consistent terminology for symptoms, disease severity and treatment success
Better continuity of care	• better appreciation by patients of the need to report all exacerbations to their treating physician • Collaborative planning to improve access to pulmonary rehabilitation, multidisciplinary care and effective treatment options • Better resources and education for patients to facilitate self-management of exacerbations where possible

In summary, these initiatives and others show that much more should be done to reduce the impact of COPD and exacerbations on the lives of Canadian patients. There is a significant opportunity to improve outcomes in this under-diagnosed and under-appreciated disease if all the relevant stakeholders can collaborate to improve awareness and support for programs that improve communication, continuity of care and access to effective management options.

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Appendix 1: Research methodology

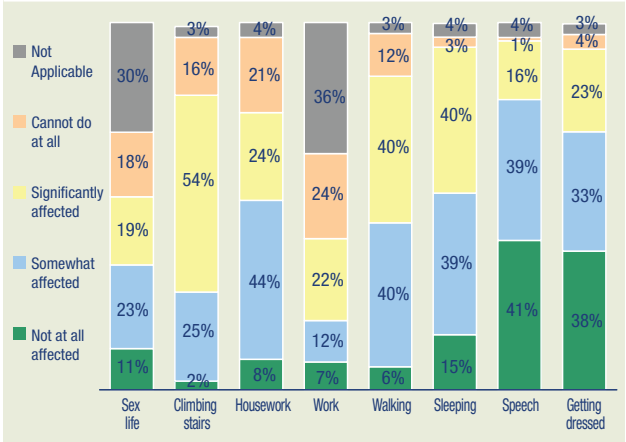
Qualitative research groups: Two sessions were conducted in October of 2010 – one in Toronto and one in Montréal. The groups included patients with moderate to severe COPD, as assessed by their physicians' diagnosis and their use of certain prescription medications.

Each session was divided into three phases designed to identify gaps in understanding. First, six physicians (two respirologists and four GPs) were asked a series of questions about their experience diagnosing and managing COPD. The physicians then stood behind a one-way mirror and observed the patient group answering a similar set of questions. Then, the doctors joined the patients and the two groups discussed the issues together, particularly those relating to gaps in care or communication.

Global survey: The Hidden Depths of COPD survey involved over 2000 patients and 1400 physicians in 14 countries; participants answered a questionnaire about COPD and its impact between July and September of 2010. Canadian participation in the survey was 100 physicians and 150 patients. All levels of COPD severity were represented among the patient population; some data analyses were stratified according to disease severity. The main objective of the survey was to highlight key differences in perception, attitude and opinion between the physicians who treat COPD and the patients themselves.

Appendix 2: Additional data

Hidden Depths of COPD survey: Effect of COPD on activities of daily living



Question: From the following list can you indicate to what extent your ability to undertake or participate in these activities or pastimes are directly affected or restricted when you are experiencing one of these attacks?
Population: All respondents who have ever experienced a worsening of at least one symptom of their Chronic Bronchitis/Emphysema/COPD - Canadian (101)

Appendix 3: In their own words – Patient and physician perspectives from the qualitative research sessions

Patients' comments

Quality of Life

"I'm not as active. I have grandchildren and it reduces the physical activities I can do with them, and they look at me and they say, 'You can't, Grandma?' And that breaks my heart."
–Denise

"At work I have to avoid being around people; I'll work alone if I can. Because of the coughing, I'm embarrassed that people will think I have something contagious. Socially, I stay away from large crowds because of the cough. I find myself spending more and more time alone."
–Todd

"I handed in my driver's license 6 years ago because I was driving and I saw a yellow light but I didn't see the rest. I started having a spasm and I passed out. I woke up in the intersection with cars on either side. So I went back home and I signed my driver's licence and sent it back. Killing somebody else, I wouldn't have wanted to do that."
–Normand

"I used to travel a lot by plane. But now the insurance doesn't want to cover me anymore. I used to go at least on a flight once a year and I haven't been on one for 2 years."
–Denise

Education

"We have to create a link of confidence between the patient and doctor. If he trusts his doctor, he'll follow what the doctor says. If the patient feels judged, he'll leave the office annoyed and angry."
–Daniel

Smoking Cessation

"The problem that I see with my doctor, he sees COPD everywhere. Like if my leg hurts, he'll say, 'We'll solve the COPD first.' My back hurts, he says, 'We'll deal with the COPD first.' That gets on my nerves. I tell him but it doesn't sink in, he just fixates on getting me to quit smoking. I think that doctors have the impression that we just want to cause trouble by continuing to smoke."
–Normand

"I feel sometimes he judges me, and it puts up a barrier. Because I don't even want to talk about COPD. Because he automatically

goes into a lecture about smoking. I know he's right – if I quit smoking it would lessen the impact. But I'm 44 years old, and I don't need to be treated like a child, either. I need for him to understand how difficult it is to quit smoking."
–Todd

"The healthcare system is flooded with smoking-related diseases, COPD being one of them. And it costs the taxpayer millions and millions of dollars every year to treat smoking-related illness. But there's not enough available for people like myself who desperately would love to quit smoking but can't."
–Todd

Disease Management
"Trying to use an inhaler during an attack – sometimes it's like you're drowning and someone is throwing you a lifeline and you can't reach it."
–Joanna

Physicians' comments

Education
"I tell them that it's a progressive disease caused by smoking. It's mostly the word 'progressive' that I insist on, to say that it's never too late to quit. Everybody progresses, so if you think that you're not that bad right now then it's time to stop."
–GP

"Sometimes instead of saying COPD we say emphysema. Patients might not know exactly what emphysema is but it rings a bell. They think it's much more serious. It's someone in a wheelchair with oxygen up his nose. You see the cemetery. In one word, it's clear."
–Respirologist

"As physicians we do need to do a better job of educating the public. Everybody is very concerned about the risk of heart attack, and they have a good idea of the seriousness of it, that they'll probably be admitted to the hospital. But an acute lung attack is very comparable in terms of morbidity and mortality, and many physicians are not very keen on passing on that knowledge to the patient."
–Respirologist

"It's an amazing thing. Patients know that continuing to smoke is going to damage their lungs, but just because you know something, it doesn't mean you're going to change your behaviour. It's really mind-boggling – why can't the guy stop if he knows it's going to kill him?"
–GP

Disease Management
"I think there are actually a lot of people who think that they're well-controlled, and they're really not at all. It's long-standing disease with a lot of symptoms, but they've gotten used to those and they're doing what they want to do. So they don't really realize what they're missing."
–GP

COPD Canada

Family Physician Airways Group of Canada

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