AN INTERPRETIVE DESCRIPTION OF HEALTH EQUITY IN CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD) CLINICAL PRACTICE GUIDELINES

By

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Abstract

Health equity is an increasing global phenomenon of interest among health care professionals (HCPs), researchers, and decision-makers. Clinical practice guidelines (CPGs) serve to promote standardized care and may have implications relative to health equity. Health care professionals rely on evidence including CPGs to be accountable, provide optimal care, and to advance advocacy efforts for people with chronic lung disease. However, CPGs for COPD may unintentionally exacerbate health inequities and health disparities experienced by those living in northern or rural areas where there may be decreased access to supports such as spirometry, pulmonary rehabilitation, and specialist care. The purpose of this study was to conduct an interdisciplinary analysis of COPD CPGs to understand the contribution and implications of these guidelines to health equity for individuals living with COPD. Different perspectives and representations of health equity across the guidelines may have problematic implications and challenges for patients, HCPs and decision-makers. The research question guiding this study is *how do CPGs for COPD explicitly or implicitly address health equity?* The study design, interpretive description, was guided by critical social theory. Using purposive sampling, publicly available international, national, and provincial English language CPGs for COPD were selected. Concurrent data collection and analysis was informed by five items of The Equity Lens instrument and the four items of Domain 5, outlined in the Applicability of the Appraisal of Guidelines for Research & Evaluation II (AGREE II) Instrument. The four stages of content analysis are decontextualization, recontextualization, categorization, and compilation. The results offer opportunities to engage multiple interdisciplinary knowledge users in dialogue about the implications of CPG adoption to move toward health equity and to best service individuals with COPD in Northeastern Ontario.

Keywords: chronic obstructive pulmonary disease, COPD, health equity, clinical practice guidelines, interpretive description, social determinants of health

Epigraph

Health equity is created when individuals have the fair opportunity to reach their fullest health potential. Achieving health equity requires reducing unnecessary and avoidable differences that are unfair and unjust. Many causes of health inequities relate to social and environmental factors including: income, social status, race, gender, education and physical environment. (Public Health Ontario, 2023)

Dedication

This thesis is dedicated to my mentor and dear friend, the late Dr. Patricia (Pat) Hill Bailey (1947–2017). Pat was a tremendous force and contributed greatly to the discipline of nursing and through her scholarly work, to the lives of individuals living with chronic obstructive pulmonary disease (COPD). As a young and naïve undergraduate nursing student, Pat took me under her wing and graciously introduced me to people and experiences in the world of respiratory care. Her unwavering willingness to share her passion with me served as the impetus for my evolving career and my own passion for respiratory care and education. In 2003, Pat and along with my brilliant colleague Sharolyn Mossey served as my incredible supervisory team as I embarked on my Master of Science in Nursing (MScN) degree. Pat was always supportive and expected that I would one day complete my PhD. Pat was presented the Queen's Golden Jubilee Medal, awarded to persons who have made significant contributions to Canada, to their community, or to their fellow Canadians. Her professional accomplishments and tremendous contributions to advancing knowledge and understanding of chronic lung disease will never be forgotten. I am honoured to dedicate this work to her. This "kid" hopes to continue to make her proud. She is always in my thoughts.

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"Whatever makes you uncomfortable is your biggest opportunity for growth."—Bryant McGill

I am proud to have completed this work amidst life's challenges including the global COVID-19 pandemic and the insolvency of Laurentian University. When I undertook this PhD work in 2018, I knew that it was going to challenge me personally and professionally. I am grateful I had the opportunity to study and complete this PhD work in my home community. While engaged in this work, I was able to work, raise my children, and support my family. I have had the opportunity to learn from supportive interdisciplinary program faculty and PhD students through the unique and diverse lens that is rural and northern health.

I would also like to express gratitude to my colleagues in the School of Nursing: Dr. Craig Duncan and Julie Duff-Cloutier. I appreciate your long-standing support and friendship. I stand on the shoulders of giants. I would not be where I am today both personally and professionally without the mentorship of the late Dr. Patricia Hill Bailey and Sharolyn Mossey. I am indebted to Sharolyn Mossey. She was the one who gave me the subtle yet powerful nudge to put my dreams into action and apply to the PhD program. Sharolyn, you continue to be a tremendous support and mentor to me, and I am grateful.

To my supervisory committee led by Dr. Philippa Spoel with Dr. Phyllis Montgomery and Dr. Mika Nonoyama, I thank you all for your mentorship, guidance, support, and patience. You have been so generous with your time, energy, and expertise. I cannot say thank you enough. You have helped me achieve my goals. I am forever grateful.

To my extended family and my wonderful in-laws, thank you for your encouragement and support. To my mom and dad. Words cannot express how incredibly thankful I am for you. You have provided me with guidance and opportunities. You have taught me what it is to work

hard, persevere, to do everything with heart and to contribute in meaningful ways. You were the first to introduce me to health care and I enjoy our conversations about the complex challenges and how they may be addressed. I am honoured to be your daughter.

To my two incredible children, Elliott and Finley. You are my biggest cheerleaders. You always support me and put things into perspective. You are both wise beyond your years and incredibly gifted. You are the top of mind in everything I do. In part, I do this for you. I want to make you proud. I want you to know that anything is possible if you have passion, drive, work hard and never give up. Elliott and Finley, I love you more than you will ever know. I am so proud of you both and I am honoured to be your mom. Always remember, “You must do the thing you think you cannot do.” –Eleanor Roosevelt.

Last but certainly not least, my husband Tim. Thank you for everything. For supporting our household and making sure the kids and I eat, when I am immersed in my work, and for taking the kids camping so I can spend quiet weekends at home writing. You have been behind me every step of the way. With you by my side, I know that anything is possible. Special thanks to our miniature schnauzer Chester, who continues to be a joyful, calming, and loyal companion.

I am incredibly grateful for all those mentioned above. This work is a compilation of many years of dedication to continued education, evidence-informed practice, nursing education, and improving the quality, accessibility, and equity of health care for those living in northern and rural environments.

“We don’t grow when things are easy; we grow when we face challenges.”—Joyce Meyer

Co-Authorship Statement

I led the first paper included in this thesis document, as outlined in Chapter 3, as a PhD student in 2018 in collaboration with three PhD student colleagues; Zoe Higgins, Celisse Bibr, and Nabina Sharma. I was responsible for the conceptualization and leading the draft and subsequent revisions, and publication of this paper by the Northern Health Policy Institute in 2020. I drafted another paper included in this thesis, as outlined in Chapter 4, with comments and edits provided by the co-authors, Dr. Philippa Spoel, PhD Supervisor, and committee members, Dr. Phyllis Montgomery, Dr. Mika Nonoyama. Kyle Montgomery was also co-author on this paper. This paper was published in 2022 in the Journal of Nursing Scholarship.

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List of Abbreviations

BPG, best practice guideline
CanCOLD, Canadian Cohort Obstructive Lung Disease
CFHI, Canadian Foundation for Healthcare Improvement
CIHI, Canadian Institute for Health Information
CIHR, Canadian Institute of Health Research
COPD, chronic obstructive pulmonary disease
CPG, clinical practice guideline
CTS, Canadian Thoracic Society
GOLD, Global Initiative for Chronic Obstructive Lung Disease
HCP, health care professionals
ICES, Institute for Clinical Evaluative Sciences
LHF, Lung Health Foundation
LHIN, Local Health Integration Network
LU, Laurentian University
LUREB, Laurentian University Research Ethics Board
MOHLTC, Ministry of Health and Long-Term Care
NE, North East
NW, North West
TCPS2, Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans
OLA, Ontario Lung Association
ORCS, Ontario Respiratory Care Society
PHSD, Public Health Sudbury and Districts
RNAO, Registered Nurses Association of Ontario
SDoH, Social Determinants of Health
SDHU, Sudbury and District Health Unit (SDHU)

Chapter 1

Introduction and Rationale

I will begin by positioning myself as an individual and situate myself within my thesis work. I am a Canadian, with a mother born in Loreto, Italy and father from Verdun, Quebec.

In 1952, at three years-old, my mother immigrated to Canada from Italy with her mother, father, and two brothers. She went on to graduate from the Sudbury Regional School of Nursing (formerly the St. Elizabeth School of Nursing) and began her nursing career in 1970 at the Sudbury General Hospital in the Pediatric Ward. For over 5 decades she worked in various health settings and continues to serve the community as a Registered Nurse.

My father, who was born just outside of Montreal, Quebec, attended Loyola College in 1961 despite incredible personal odds. In 1964, he graduated with a Bachelor of Science from the University of Montréal. He went on to study medicine at McGill University from 1965–1970. Upon graduating with his medical degree, he completed an Internship at McMaster University from 1970–1972. He then came to Sudbury, Ontario in 1972 to practice as a General Physician where he served the community for over 40 years.

I was born, raised, and educated in Northeastern Ontario. Following high school, I pursued a Bachelor of Science in Nursing (BScN) degree, followed by a Master of Science in Nursing (MScN) from Laurentian University. My Masters work investigated the meaning of disability for individuals living with chronic obstructive pulmonary disease (COPD).

Drawing on my professional and experiential experience of evidence-informed practices for COPD and the health disparities experienced by residents of rural and Northern Ontario, I proposed a study that explored how clinical practice guidelines (CPGs) for COPD explicitly or implicitly address health equity. The impetus for this work really began when I was a Masters student. As a long-standing member of the Ontario Respiratory Care Society (ORCS), now the Lung Health Foundation (LHF) and Chair of the Northeastern Ontario Region of the ORCS for 13 years, I developed a substantive understanding of lung health issues, particularly for individuals living in Northern Ontario. These issues are frequently linked to health inequities (i.e., how health services and providers are distributed, organized, and structured across the province). Likewise, my prior experience in 2005 as a member of the development panel for the Registered Nurses Association of Ontario (RNAO) Best Practice Guideline (BPG) for COPD, which was updated in 2010, has been formative in my selection of CPGs for COPD as the data for my study. This focus allowed me to bring together my interest in the issue of lung health equity for Northern Ontario residents with my professional knowledge of CPGs in this field. The path I chose in my academic and professional career, ultimately led me to pursue my PhD in the Rural and Northern Health program at Laurentian University.

Health care professionals as well as policy and decision-makers rely on sound empirical evidence to make fiscally responsible and clinically appropriate decisions about the allocation of health resources and health service delivery for lung health. Since my time as a panel member on COPD guidelines, I appreciate that guidelines too have evolved in their development. There is now an abundant body of scholarly evidence and CPGs about the diagnosis, treatment, and management of COPD and the experiences of individuals with COPD, which are intended to provide health care professionals with clear evidence-based guidelines to draw upon when providing care to individuals living with COPD. CPGs provide recommendations that aim to standardize care (Gupta et al., 2009; Kredo et al., 2016; Schunemann, Zhang & Oxman, 2019; Weisz, Cambrosio, Keating, Knaapen, Schlich & Tournay, 2007; Woolf, Grol, Hutchinson, Eccles & Grimshaw, 1999), with an implicit goal of achieving equity of care among diverse populations. Murad (2017) suggested that developers of CPGs must be careful not to exacerbate inequity when making recommendations. To date, however, no systematic analysis has been undertaken to determine the extent to which CPGs for COPD do—or do not—address health equity. From the perspective of knowledge translation, this research is important because CPGs and quality standards for COPD may have unintended consequences associated with their uptake (or lack thereof) for those in northern and rural communities. For example, they may inadvertently exacerbate health inequities and health disparities experienced by those living in northern or rural areas (i.e., lack of health services and challenges associated with receiving comprehensive treatment).

Analyzing how heath equity is addressed (or not) in CPGs has implications for their uptake by HCPs in Northeastern Ontario who may struggle with the feasibility, relevance, attainability, and applicability of recommendations within a northern context that may experience structural and service variations of health services. For example, if CPGs propose actions that require resources that are not readily available in the North, they are more challenging to implement. As such, individuals living with COPD in Northeastern Ontario continue to require expensive health care services but may not receive the appropriate care where and when they need it. Thus, although well intentioned, CPGs may contribute to and/or perpetuate health inequities.

The purpose of my study was to conduct an interdisciplinary analysis of CPGs to understand how these guidelines represent health equity for the care of individuals living with COPD. The research question guiding my study was *how do CPGs for COPD explicitly or implicitly address health equity?* Different perspectives and representations of health equity across the guidelines may have implications and challenges for clinicians and decision-makers in the uptake of CPGs. An analysis concerning the ways evidence informed guidelines and health equity intersect may offer a new perspective on the tensions that exist in the adoption of CPGs in Northeastern Ontario practice settings. Through my analysis, I aim to contribute to the dialogue about how to improve health equity for individuals living with COPD in Northeastern Ontario and those who care for them.

My study design was interpretive descriptive (Thorne, 2008, 2016), an established qualitative applied research approach that focuses on the generation and meaning of knowledge for practice (Bove, Lavesen, Jellington, Marsaa & Herling, 2018; Jensen, Vedelo, & Lomborg, 2013; Thorne, Kirkham & MacDonald-Emes, 1997; Thorne, 2008, 2016). A purposive sample of ten publicly available international, national, and provincial English language CPGs for COPD were analyzed, guided by elements of two separate instruments: The Equity Lens (Dans et al., 2007); and the Appraisal of Guidelines for Research & Evaluation II Instrument (AGREE II, 2017), Domain 5-Applicability. Collectively, the set of elements from each instrument assess multiple dimensions of CPGs and health equity relative to the posed research question.

In summary, the findings reveal that there is much variation in the way that international, national, and provincial CPGs address equity considerations as identified in the literature. In relation to Section 1 of the analysis framework that deals with population relevance, six of the ten CPGs clearly identify the COPD population that each guideline addresses while four of the ten somewhat address this. Only one CPG clearly articulates if any groups are excluded from the guideline while five somewhat address this item and four do not address this at all. Four of the CPGs clearly identify groups at high risk for COPD while one somewhat addresses this item, three poorly address this, and two do not address this item at all. Perhaps the most enlightening findings of all are the results of Section 2 of the analysis framework concerning The Equity

Lens. None of the ten CPGs address the first three criterion of The Equity Lens (*Do the recommendations in the guideline address a priority problem for disadvantaged populations? Is there reason to anticipate different effects of interventions in disadvantaged and privileged populations?).* Only one guideline was assessed to poorly address criterion four (*Is specific attention given to minimizing barriers to implementation in disadvantaged populations?),* whereas the remaining nine do not address this criterion at all. Only two CPGs poorly address criterion five (*Do plans for assessing the impact of the recommendations include disadvantaged populations?),* whereas the remaining eight do not address this criterion at all.

Finally, findings of Section 3 of the analysis framework concerning guideline development and application processes, including Domain 5-Applicability of the AGREE II Instrument, revealed that all ten CPGs included experts in COPD in the guideline development group. None of the ten CPGs included an expert in health equity in the development guideline group, had any evidence that the design of the literature review search strategy could identify studies relevant to COPD and disadvantaged populations, nor was there any evidence of consultation with people living with COPD and/or their carers representative of diverse contexts and regions in the development or implementation of the guideline. Only two of the ten CPGs somewhat addressed facilitators and barriers to their application, where four poorly addressed this item and four did not address this item at all. Only one guideline somewhat addressed the item pertaining to whether the CPGs provide advice and/or tools on how recommendations can be put into practice, five poorly addressed this, and four did not address this item at all. Eight of the CPGs did not address potential resource implications of applying recommendations at all and two poorly addressed this item. One CPG was assessed to have clearly addressed monitoring and/or auditing criteria, while five poorly addressed this item and four did not address this item at all.

This thesis is organized into chapters. Each chapter is followed by references specific to the chapter. The introductory chapter provides an overview of the dissertation and rationale for the work. Chapter 2 introduces COPD and discusses health service utilization associated with this chronic disease in Northern Ontario and the health policy considerations relative to the diagnosis and management of COPD for individuals living in Northern and rural Ontario. Chapter 3 is an article that was published in 2020 as a commentary for the Northern Policy Institute that examines the management of chronic disease in Northern Ontario and addresses the unique needs of Northern Ontarians in access to and delivery of effective chronic disease care. Chapter 4 presents an integrative literature review that discusses how health equity is represented in the health literature in relation to CPGs. Chapter 5 discusses the theoretical underpinnings and methods of this work. My findings as a result of my analysis of COPD CPGs are presented in Chapter 6. In Chapter 7, I present my discussion followed by Chapter 8 as a conclusion.

My study demonstrates that there is indeed an opportunity to evolve CPG processes to include a more purposeful and deliberate focus on health equity. It is critical that CPGs are embedded within an equity perspective and consider not only the implications of recommendations on systemically and structurally disadvantaged populations but throughout the CPG development process as well. Further work is required to be more inclusive of systemically and structurally disadvantaged populations and health equity. Doing so may result in recommendations that are more meaningful and appreciate the context and social determinants of health. This may have a greater positive effect at the practice, educational, and organizational and policy level. It may also increase their uptake, which could in turn see a reduction in health service utilization and increased quality of life for systemically and structurally disadvantaged individuals living with COPD. My study findings and discussion are translatable across all CPGs and other health policy documents. My study serves as a spark to initiate awareness, discussion, and reflection on how we may evolve CPG development processes and associated evidence and strive for a more equitable and healthy society. Future work must be done to gain additional insight into how to address the political, social, and economic factors that contribute to health inequity and adversely affect the health of systemically and structurally disadvantaged populations.

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Chapter 2

Background: Health Equity and COPD in Rural and Northern Ontario

The purpose of this chapter is to provide a background explanation of the definitions of rural and northern within the province of Ontario and an explanation of health equity in rural and Northern Ontario, chronic obstructive pulmonary disease (COPD), and health service utilization for individuals living with COPD in Northern Ontario. It also introduces socioeconomic status and rural residence as risk factors for COPD. It also includes a brief discussion of the use of technology as an attempt to mitigate health disparities and inequities experienced by individuals living with COPD.

Definitions of Rural and Northern

The definition of rural is variable and dependent upon orientation, perspective, and discipline (i.e., geography, politics, health, from those living in such communities). Further, how rurality is understood is dependent upon who is attempting to define it and for what purpose(s). Definitions of rural contain elements of geography and are often dichotomized as urban or rural (MOHLTC, 2010; Vanderboom & Madigan, 2007). Some scholars have suggested, however, that the definition of rural and concept of rurality go beyond geographical boundaries (Bourke et al., 2013; Malatzky & Bourque, 2016; Malatzky & Bourque, 2018). In Ontario, from a governmental standpoint, The Ontario Ministry of Health and Long-Term Care Rural and Northern Health Care Framework/Plan Stage 1 Report (2010) proposed a definition of rural and Northern Ontario.

The Rural and Northern Health Care Framework (2010) defined rural as communities in Ontario that have a population of less than 30,000 and that are greater than 30 minutes away in travel time from a community with a population of more than 30,000 people. The report recognized that communities with more than 30,000 people tend to have a broader scope of available health services, including specialty hospital services and expanded community-based programs in comparison to smaller communities. While some communities are indisputably rural, others may have a "gradation of rurality" (p. 8).

The Rural and Northern Health Care Framework (2010) adopted the same definition of northern as defined by the government of Ontario's planning parameters; Parry Sound and north comprises northern, inclusive of both the North East (NE) and North West (NW) Local Health Integration Networks (LHINs). As such, Northern Ontario is:

> comprised of 10 territorial districts (145 municipalities): Kenora, Rainy River, Thunder Bay, Cochrane, Algoma, Sudbury, Timiskaming, Nipissing, Manitoulin, and Parry Sound. This area covers over 800,000 square kilometers, representing nearly 90 percent of the Province of Ontario's land area. It extends across two time zones, from the southern boundary of the District of Parry Sound, north to Hudson Bay and James Bay, and westerly from Quebec to the Manitoba border. (p. 8)

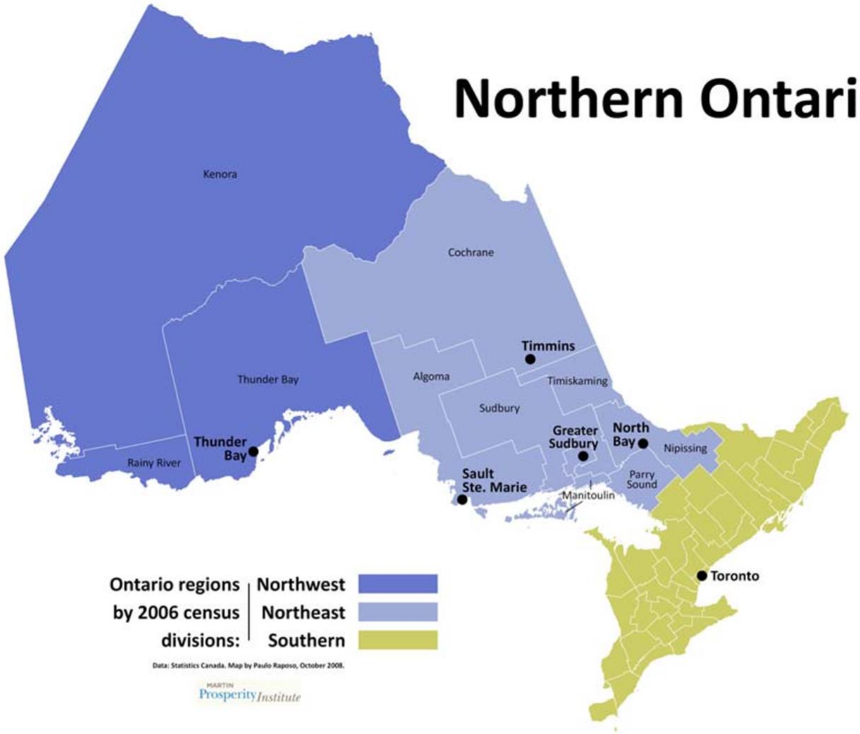
Political and geographical definitions of rural and northern, like those above, fail to acknowledge the heterogeneity and diversity that exists among northern, rural, and remote communities (Bourke, Taylor, Humphreys & Wakerman, 2013). Northern and rural communities are not homogeneous; there is no "one size fits all" approach to them. It is helpful to understand how government defines rural and northern communities as these represent politicized definitions that may not be shared by citizens or communities themselves.

Health Equity in Rural and Northern Ontario

The North West and North East LHINs are the first and second largest LHINs in Ontario (Ontario LHIN 2014a). Although this area is large (the North makes up 91% of the province's landmass, see Figure 2-1), it hosts only approximately 6% of the population (Health Quality Ontario (HQO), 2018; NWLHIN 2018; Ontario LHIN 2014b). Regional variation exists relative to the unique health needs of those living in rural and Northern Ontario. The population density in these regions varies from sparse communities to areas that are more densely populated. Citizens of Northern Ontario experience specific issues relative to access to timely, quality, and comprehensive health services (Kulig & Williams, 2012). Moreover, they experience higher disease incidence, prevalence, morbidity and/or mortality (HQO, 2018; Kulig & Williams 2012; NELHIN, 2016) and health service utilization (Kulig & Williams, 2012; NELHIN, 2016).

Figure 2-1

Ontario Regions by 2006 Census Divisions: Northern Ontario (Hall & Donald, 2009)



Many international scholars have discussed the concept of rurality and rural health and the challenges relative to accessing health services and health care providers (Bourke et al., 2012ab; Bourke et al., 2013; Farmer, Munoz & Threlkeld, 2012; Fitzpatrick, Perkins, Luland, Brown & Corvan, 2017; Kulig & Williams, 2012; Malatzky & Bourque, 2016; Malatzky & Bourque, 2018). Differences in health status, access to health service challenges, and definitions and theories of rural health are commonalities across this work. Rural and northern communities also experience health inequities, leading to health disparities as a result of issues related to access to health services and health care providers. It is well documented that issues related to both a lack of and maldistribution of health human resources exist within the context of Northern Ontario (Ontario LHIN 2014b; RNAO, 2009; 2015ab). This suggests an imbalance between where services are offered and where the target population resides. Given this reality, and an appreciation of how the population of Northern Ontario is distributed across a wide geographic land mass, challenges regarding access to comprehensive, coordinated, and appropriate health services exist.

Individuals living in rural and northern settings experience poorer health outcomes than their urban counterparts because of decreased access and inequitable distribution of health services and health human resources (HQO, 2018; MOHLTC, 2010; Ontario LHIN 2014b). The question is, how do you improve the situation? In order to attempt to address these complex issues, many health organizations within the province, including the NELHIN and the Northern Ontario Health Equity Strategy, strive to illuminate the unique context of Northern Ontario (HQO, 2018; NELHIN, 2016). For example, Health Quality Ontario outlined a Northern Ontario Health Equity Strategy (HQO, 2018). The goal of this strategy is to improve the health of citizens in Northern Ontario. The report suggests that in order to improve health of residents with the greatest health disparities, it is essential to address social determinants of health (SDOH) and equitable access to high quality and appropriate health care services. A key recommendation in this strategy is the creation of a Northern Network for Health Equity to provide a means for active involvement of individuals and organizations from many sectors (i.e., public health, municipalities, Indigenous organizations and authorities, community health centers and organizations, educational and research institutes, Francophone organizations, and provincial and federal ministries). Such a network will support the current movement towards greater collaboration to advance health equity in Northern Ontario so that barriers are removed and health is improved.

COPD Health Service Utilization in Northern Ontario

Historically, COPD has been defined as a common preventable and treatable progressive debilitating disease characterized by persistent respiratory symptoms and airflow limitation and progressive airflow obstruction, not fully reversible, with symptoms of dyspnea, cough, and sputum (Chapman, Bourbeau & Rance, 2003; GOLD, 2022, 2023; O'Donnell et al., 2003; Petty, 2005). Most recently, in their work, Celli et al. (2022) suggested a revision to the definition of COPD to now be understood as "a heterogeneous lung condition characterised by chronic respiratory symptoms (dyspnea, cough, sputum production) due to abnormalities of the airways (bronchitis, bronchiolitis) and/or alveoli (emphysema) that cause persistent, often progressive airflow obstruction" (p.5). The 2023 International GOLD strategy as outlined by the Global Initiative for Chronic Obstructive Lung Disease (GOLD, 2022, 2023) has adopted this most recent definition. COPD is a major cause of disability, morbidity, mortality, and health care spending (Celli et al., 2017; Crighton et al., 2015; Ehteshami et al., 2016; Gershon et al., 2013b; Gershon et al., 2017; GOLD, 2022, 2023; Halbert et al., 2006; Mannino et al., 2015; Roldan et al., 2012; Verma, 2017). An estimated 3.9 million Canadians aged 35 to 79 years have a lung function score indicative of COPD (Evans et al., 2014; Statistics Canada, 2017). Similarly, the Ontario Lung Association reports that an estimated 1.6 million Canadians live with COPD and one million Canadians have COPD and do not even know it (OLA, 2019). Provincial data suggest that approximately 850,000 Ontarians are living with COPD (Gershon, Hasanaj & Diong, 2013), affecting between 10% and 12% of adult Ontarians (Crighton et al., 2015; Gershon et al., 2017; WHO, 2018). COPD is under-diagnosed (Gershon et al., 2018; Labonté et al., 2016; Statistics Canada, 2017), suggesting that the documented incidence and prevalence of the disease are estimates at best.

Lung disease, along with cancers, cardiovascular disease, and diabetes, are responsible for 79% of all deaths in Ontario (OLA, 2018). COPD accounts for the most hospitalizations of all chronic diseases (CFHI, 2018). COPD patients are frequent and high users of health services; often admitted to hospital for acute exacerbations (Chapman et al., 2003, Chechulin, Nazerian, Rais, Malikov, 2014; CIHI, 2014, CIHI, 2017; Crighton et al., 2015; Gershon et al., 2013b; Gershon et al., 2017, Mannino et al., 2015; Mittmann et al., 2008; Roldan et al., 2012). COPD is the third leading cause of death and the number one cause of hospitalization in Canada (OLA, 2019). The annual health care cost of COPD is $12 billion (accounting for more than 6% annually in Canada), and is the leading cause of hospitalization (OLA, 2018). The costs associated with COPD are due to its progressive nature and increasing incidence of acute exacerbations requiring cyclical utilization of both acute and community health services. Unscheduled care visits accounted for almost 60% of the total direct cost of COPD (Chapman et al., 2003). In Ontario for 2011, the direct health care costs for lung disease alone (asthma, COPD and lung cancer) were 5.1 billion dollars; COPD alone accounted for 3.9 billion dollars (Smetanin et al., 2011).

ICES researchers Gershon and colleagues (2017) reported that the rate of new cases of COPD has been decreasing over time in all parts of Ontario, except in the North East, where the prevalence continues to rise. Between 1996/97 and 2014/15, the incidence rate for COPD per 1000 individuals had an overall decline in all Local Health Integration Networks (LHINs) in Ontario, with the exception of the North East LHIN (NELHIN) where it increased by 11.1% from 13.5% to 15%. They found that the largest increase in prevalence rate was among residents in the North East (71.3% from 8.7% to 14.9%) (Gershon et al., 2017). In 2014/15, the NELHIN had the highest mortality rates for COPD. As the incidence and prevalence of COPD increase, the numbers of health services being used are also increasing. This is an indication that the burden of COPD on the health care system is likely to worsen before it improves. In Northeastern Ontario, between 2002/03 and 2014/15, the NELHIN had the second highest COPD hospitalization rates and the highest COPD emergency department visit rates (52.5 per 1000 people). The LHIN with the highest COPD ED visit rate was the North East, five times higher than the lowest of all the LHINs and the largest increase of COPD emergency department visits (42.7% from 36.8 to 52.5 people). The cost of exacerbations in COPD has not been well studied (Mittmann et al., 2008), and there is a lack of data on the impact of the disease on primary health care resource utilization and the economic burden of the disease (Chapman et al. 2003).

COPD Hospitalization and Readmission

One in four of all hospital and ED visits in Ontario are individuals living with COPD (Gershon et al., 2013a). COPD patients account for the highest volume of readmission to hospital (HQO, 2017); in part attributed to fragmented care between acute care, community, and home settings. Readmission rates are a predictor of poor prognosis. An estimated 19% of patients with COPD in Canada are readmitted to acute care within 30 days of a previous hospitalization (CIHI, 2012; OLA, 2019) and 18% of people with COPD have two hospitalizations per year; and 14% are hospitalized three times annually (CIHI, 2008). Twenty-five to 40% of patients with COPD die within one year following hospitalization for an acute exacerbation event (HQO, 2017). In a longitudinal population cohort study using Ontario data, Gershon et al. (2013b) found that 853,438 people with COPD were responsible for 24% of hospitalizations, 24% of ED visits, 21% of ambulatory care visits, filled 35% of long-term care places, and used 30% of home care services. Furthermore, people with COPD had rates of hospital, ED, and ambulatory care visits that were respectively, 63%, 85%, and 48% higher than the rest of the population, while rates of long-term care and home care use were 56% and 59% higher (Gershon et al., 2013b).

Diagnosis Conundrum

Health services are utilized not only by those with COPD who are correctly diagnosed but also by individuals who are both undiagnosed and incorrectly diagnosed with COPD (Gerhson et al., 2018; Labonté et al., 2016). In both Ontario and Canada, COPD is underdiagnosed more so than overdiagnosed (Gershon et al., 2018, Labonté et al., 2016). Moreover, undiagnosed individuals are susceptible to exacerbation-type events that consume health care services and resources (Labonté et al., 2016) and have higher rates of hospitalization than those without COPD (Gershon et al., 2018). Misdiagnosed COPD was fivefold more common than COPD that was correctly diagnosed, suggesting a significant burden of disease that may be prevented with correct diagnosis (Gershon et al., 2018). Labonté et al. (2016) conducted an analysis of data from a large data set, the Canadian Cohort Obstructive Lung Disease (CanCOLD) study, in order to compare exacerbation-like respiratory events, event prevalence, and odds of using medication and health services between those with diagnosed and undiagnosed COPD. Results indicated that although undiagnosed subjects were less symptomatic and functionally impaired and had been prescribed less medication than those with a diagnosis of COPD, they had an increased severity of airflow obstruction and exacerbation-like events.

Health service use for exacerbation events was similar in both the undiagnosed and diagnosed group. Suffice it to say, many people with COPD in Canada and Ontario remain undiagnosed, yet they use a similar amount of health services for exacerbation of illness events (Labonté et al., 2016). As such, the overall health system burden in those with undiagnosed COPD is substantial.

Transition from Hospital to Community

In an Ontario population-based cohort study, Gruneir et al. (2018) found that from their sample of 701,527 older adults over the age of 65 years, 88,305 of them (12.6%) were readmitted to hospital within 30 days. Findings revealed that those who returned to the community with home care or to long-term care had a greater risk of readmission. In a population-based cohort study using Alberta data, Sin and colleagues (2002) examined the relation between follow-up office visits after emergency discharge and the risk of emergency readmission within 90 days in patients with asthma and COPD who did and did not have an office follow-up within the first 30 days. Findings revealed that follow-up visits were associated with a significant reduction in the 90-day risk of a readmission via the ED and inversely related to repeat emergency visits, yet only 7829 (31%) of people within the study population of 25,256 had an office visit within 30 days of their emergency encounter. Findings of a systematic review conducted by DeRegge et al. (2017) revealed that hospitals could play a vital role in transitional care interventions by taking the lead in integrated and coordinated chronic care programs.

Based on the analysis largely based on administrative health claims data, clearly the incidence, prevalence, and health service utilization in Northern Ontario are higher than in the rest of the province. These findings from the analysis of big data suggest areas for health policy priorities relative to those living with COPD in the North. However, although this information is useful, it does not tell the whole story. Presented data in this case do not consider the complex contextual factors as to why this may be (i.e., mining and occupational exposures in the North, smoking rates). To create a more comprehensive picture of what is going on in the North, it would be important to complement this data with additional sources of evidence (i.e., qualitative evidence about patient experiences in the North, and critical analysis of health equity concepts such as the social determinants of health). A complementary approach could provide further insight into how to best attempt to address these complex issues. Doing so can inform health policy in rural and Northern Ontario contexts. Furthermore, there is a compelling case to be made about where health policy efforts could and should be focused. For example, this may include a provincial lung health policy strategy, a COPD screening strategy, and policies aimed to improve care transitions. Utilization of administrative health claims data illuminates instances and geographic locations (i.e., Northern Ontario) where health disparities exist. Conversely, this presentation of findings from big data analysis does not consider the social determinants of health that may be at play for citizens of rural and northern communities.

The Missing Million

The practice of using administrative claims data to inform policy captures those who use a health service with an identified diagnosis. This approach does not capture those who use a health service without a formal diagnosis or those who do not access service at all due to complex challenges experienced by residents in rural and northern communities. Approximately two million Canadians are identified as living with COPD, and as many as an additional one million may suffer from the disease while remaining undiagnosed and untreated (OLA, 2019). The OLA (2019) published a white paper to gain a better understanding of how to treat individuals who are properly diagnosed with COPD and to scrutinize why individuals are not diagnosed sooner. Based on the evidence, those who are undiagnosed with COPD are using health services; however, they are not being formally captured or coded as such through administrative health claims data. Knowing that there are access challenges to health care providers in Northern Ontario raises a very important critical question: How many of those missing million are individuals living in rural and northern communities? The white paper outlines what needs to be done to ensure that those “missing million” are diagnosed. In this case, the analysis of administrative health claims data is limited because it assumes that all individuals who access health services have a verified diagnosis of COPD from a health care provider. The same can be said relative to the incidence, prevalence, and mortality associated with COPD. This is simply not the case as there is a substantial population of individuals who are undiagnosed yet use health services that are then not accounted for in these large data sets. As such, the scope of this issue may not be fully realized. The OLA white paper suggests that the one million Canadians living with undiagnosed or diagnosed COPD need improved access to diagnosis, treatment, and support (i.e., access to family physicians and specialists, access to spirometry). Any action taken on the part of advocacy groups or government to address this must ensure the rural and northern voice is included.

Socioeconomic Status and Rural Residence: Risk Factors for COPD

Evidence suggests that where one resides and one’s socioeconomic status are both risk factors that lead to poorer health outcomes for individuals with COPD; this means that contextual factors such as place of residence and socioeconomic status should inform intervention strategies targeting individuals living with COPD (Abayateye, 2022; Galiatsatos et al., 2020; Grigsby et al., 2016; Raju et al., 2019; Sugarman, Stukel, Li, Guan, & Gershon, 2023). Raju and colleagues (2019) conducted a study that aimed to understand the impact of rural-urban status, poverty, and other factors (i.e. type of heating in home, community poverty) on COPD -

prevalence in the United States and among never-smokers. They used a nationally representative sample of adults in the National Health Interview 2012-2015 and linked neighbourhood data from the U.S Census's American Community Survey with data from the National Center for Health Statistics Urban-Rural Classification Scheme to examine COPD prevalence. Their findings revealed that rural residence and poverty were risk factors for COPD, even among those who have never smoked. Living in a rural area and both individual socioeconomic status and community poverty were predictive for COPD prevalence. They also found that coal was used as a heating source in those who were poor and living in rural areas and that this was a risk factor for COPD, including for those individuals who had never smoked. Further, this study demonstrates an association between living in a rural environment and the development of COPD, even when controlling for socioeconomic factors and exposures more commonly found in rural areas (i.e. heating with solid fuels, agriculture and mining occupations).

Furthermore, Galiatsatos and colleagues (2020) explored whether neighbourhood disadvantage was associated with COPD-related health outcomes, and whether this relationship is independent of individual level socioeconomic status. This work was part of a larger multicenter prospective cohort study that enrolled geographically diverse patients with COPD, along with smokers without COPD and non-smokers across 12 sites in the United States. Their findings indicated that those participants who lived in the most-disadvantaged neighbourhoods had 56% higher rate of COPD exacerbation, 98% higher rate of severe COPD exacerbation, and a 1.6-point higher COPD Assessment Test (CAT) score. They further found that these individuals had 3.1 points higher St George's Respiratory Questionnaire (SGRQ), a validated questionnaire for measuring quality of life in individuals with COPD, and 24.6 meters in a less six-minute walk distance compared with those who lived in the least disadvantaged neighbourhoods. These authors concluded that individuals living with COPD who lived in more disadvantaged neighbourhoods had worse COPD outcomes as compared to those who lived in less-disadvantaged neighbourhoods.

Mitigating COPD Health Disparities through Technology

Given the health disparities experienced by those living with COPD in Northern Ontario as described above, this section briefly discusses the implications of virtual care and the range of technological advances in mitigating health disparities for individuals living with COPD. Lundell and colleagues (2020) explored perceptions of the use of a home telemonitoring system among patients with COPD. Their findings revealed that participants transitioned from being insecure and experiencing technical concerns to acquiring technical confidence and improving the management of their disease. New technology was seen as an important complement to health care but the importance of maintaining a human contact in real life or through the telemonitoring system was emphasized. They concluded that further research is needed on how telemonitoring contributes to equity in health. I would add that considering how this translates to systemically and structurally disadvantaged populations who may lack access to the technological infrastructure and resources to participate effectively in virtual care, especially within rural and remote contexts.

It is noteworthy to state that the global COVID-19 pandemic indeed illuminated and exacerbated health inequities experienced by systemically and structurally disadvantaged populations around the world. At the same time, the pandemic likely helped to propel virtual care innovations forward as one way to address health disparities and health inequities. Sculley, Musick, and Krishnan (2021) conducted a review to describe the evidence base supporting the use of telehealth for COPD prior to the COVID-19 pandemic, to discuss barriers to implementing telehealth during the pandemic, and to share their insight about the future of telehealth in COPD. Their findings revealed that the effectiveness of telehealth interventions compared to in-person usual care on clinical outcomes is inconclusive. They stated that experiences during the pandemic indicated that telehealth may increase access to healthcare and satisfaction with care when delivered in addition to usual in-person care. However, they also found that several patient, provider, and health-system barriers to implementation of telehealth remain. Nouri and colleagues (2020) discussed how health systems have adopted telemedicine with remarkable speed not only for COVID-19 related care, but also for chronic disease management. These authors also warned, however, that without proactive efforts to ensure equity, the current wide-scale implementation of telemedicine may actually increase health disparities in systemically and structurally disadvantaged populations. They discussed four key actions for clinicians and health system leaders to employ to ensure that the current telemedicine implementation does not exacerbate health disparities. These include proactively exploring potential disparities in telemedicine access, developing solutions to mitigate barriers to digital literacy and resources needed, removing health system-created barriers to accessing video visits, and advocating for policies and infrastructure that facilitate equitable access to telemedicine.

In addition to telemedicine, artificial intelligence continues to rapidly evolve as does interest in its applications, particularly in relation to health care (Estépar, 2020). Estépar (2020) conducted a review that discussed opportunities, challenges, and limitations of AI applications in the context of COPD. He addressed many aspects whereby AI can be applied to COPD for example, in pulmonary function testing, diagnosis and outcome prediction, and COPD progression and trajectory. He concluded that the COPD community can benefit from novel approaches offered through AI as it offers a new paradigm for data integration in COPD with potential long lasting effects. It would be interesting to further explore these ideas with those living in under-resourced areas who are systemically and structurally disadvantaged.

Technology may be used as a means to support the screening, diagnosis, and management of various chronic diseases (Estépar, 2020; Nouri et al., 2020; Sculley et al., 2021). Given this, I now circle back to the discussion in Chapter 3 about the need for comprehensive chronic disease management, in which CPGs can play a role. The COVID-19 pandemic also required the shifting and pivoting of health resources to areas where needed most in the acute management of the virus. Wright et al. (2020) argued that chronic disease management including prevention, screening, monitoring, and treatment for chronic disease was largely neglected during COVID-19. In the context of COPD, Flegel and Stanbrook (2018) contended that to keep patients with COPD out of hospital, we must look at the co-morbidities experienced by these individuals. This is difficult to do at the best of times let alone during a global pandemic. Layering the COVID-19 pandemic on top of complex issues regarding chronic disease management for individuals with complex social needs (Goodridge et al., 2019) and a large majority of systemically and structurally disadvantaged populations without access to primary care (Kiran, 2022) presents tremendous challenges. CPGs for COPD as a way to standardize care for COPD are challenging at the best of times for HCPs to implement in under-resourced areas and with systemically and structurally disadvantaged populations let alone during a global pandemic. This underlines how much work needs to be done to address health disparities and inequities.

Conclusion

This chapter introduced equity in rural and northern Ontario, COPD, and health service utilization associated with this chronic disease in Northern Ontario and the health policy considerations relative to the diagnosis and management of COPD for individuals living in Northern and rural Ontario. It also introduced socioeconomic status and rural residence as risk factors for COPD. It also discussed the use of technology as an attempt to mitigate health disparities and inequities experienced by individuals living with COPD.

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The proceeding Chapter represents the first publication of my PhD work. To uphold the accuracy and integrity of this work, this article is reproduced as it originally appeared as published by the Northern Policy Institute (NPI) in 2020. This piece explores the unique and diverse health needs of those living in Northern Ontario, especially those with chronic lung disease. The paper outlines health policy considerations for chronic disease management in Northern Ontario as a priority and suggests changes are needed to our current health system. Although the intention of this completed work is not to make recommendations about Medicare reform, this work is complementary to the overall PhD work about health equity considerations in clinical practice guidelines pertaining to chronic obstructive pulmonary disease. Given that the doctorate degree that I am working toward obtaining is in interdisciplinary rural and northern health, this work is an important piece of the foundation that serves as an introduction to the context of this thesis.

Chapter 3

Spinning Our Wheels? Chronic Disease Management as a Health Policy Priority for Northern Ontario

Boyles, C.M., Higgins, Z.E., Bibr, C.O., & Sharma, N. (2020). Spinning our Wheels? Chronic Disease Management as Health Policy Priority for Northern Ontario. Northern Policy Institute, 38, 1–22. Available at: https://www.northernpolicy.ca/upload/documents/publications/commentaries-new/boyles-higgins-bibr-sharma-chronic-disea.pdf

Executive Summary

The health care needs of Canadians are evolving. Indeed, in 2019 the Ontario government announced that the province's health care system would be transformed into one that is more efficient and appropriate for all residents. As with any policy reform, however, not all regions of the province are alike, and Northern Ontario has needs and priorities that differ from those elsewhere. In that context, this paper examines the management of chronic disease in Northern Ontario and discusses reforms to the health care system that address the unique needs of Northern Ontarians in access to and delivery of effective care. One promising approach to chronic obstructive pulmonary disease (COPD) is INSPIRED, for **I**mplementing a **N**ovel and **S**upportive **P**rogram of **I**ndividualized care for patients and families living with **RE**spiratory **D**isease, which has been shown to reduce the number of unnecessary visits to health care providers by those with COPD. Although this approach has been implemented in other areas of Ontario and elsewhere in Canada, it has not yet been tried in Northern Ontario. The paper concludes that the medicare model requires much-needed changes — as the health needs of Northern Ontarians change, so too should the system. Implementing policy that is targeted and

continues to prioritize effective chronic disease management is essential for quality health care in Northern Ontario.

Introduction

Chronic disease is a predominant health issue, and the management of chronic disease must be a health policy priority for Northern Ontario. The region cannot continue to be the poor cousin to its southern counterpart. This paper is intended to draw the attention of provincial policymakers to the unique characteristics of Northern Ontario and to the inequities and health disparities its citizens face. We critically examine the medicare model and the need for an evolution of its delivery and funding to ensure it meets the needs of Canadians, especially those living with chronic disease in northern communities. Despite efforts to mitigate its effects, those living with chronic disease continue to be high users of health services. Unless fundamental changes are made to how our health care system is funded and delivered, we could be stuck spinning our wheels when it comes to chronic disease management in Northern Ontario.

Background

Medicare in Canada is a pillar of our national identity and a sense of pride for many Canadians (Armstrong and Armstrong 2010; Coletta 2018; Martin 2017; Picard 2017). The medicare system has been effective in covering hospital and physicians' costs; however, this narrow scope has produced gaps in coverage and challenges in terms of ensuring equitable access (Marchildon 2013, xxi). These issues are exacerbated within the northern and rural context for many reasons, including sparse and widely distributed populations, lack of health care providers and specialists, distance and the need to travel for services, lack of services, and variations in the social determinants of health. In recent years, concerns have arisen regarding the comprehensiveness and fiscal sustainability of the Canadian health care system (Advisory Panel on Healthcare Innovation 2015; Marchildon 2013, xv). Canada's federal system of government has shaped the development of medicare (Martin 2017, 23): the delivery of health care services lies with each province and territory, while the federal government is responsible for providing monetary support of health care in these jurisdictions (Marchildon 2013, 21; Martin 2017, 24). Knowing this, both the federal and the Ontario provincial governments have implemented strategies to address complex issues. Specifically, the Ontario government has proposed the priorities of improving access, connecting health services, informing Ontarians, and protecting the universal public health care system (Hoskins 2016a, 2016b; Ontario 2015b, 9).

Where one lives affects access to health care, and the experience of individuals living in Northern and rural Ontario is very different from that of their southern counterparts. In particular, residents of Northern Ontario face issues regarding (1) access to timely, quality, and comprehensive health services (Kulig and Williams 2012, 6); (2) specific population health needs, such as higher disease incidence, prevalence, morbidity, and/or mortality (Health Quality Ontario 2018, 25; Kulig and Williams 2012, 2; NELHIN 2016, 8–9); and (3) health service utilization (Kulig and Williams 2012, 60; NELHIN 2016, 8–9). Knowing this, it is vitally important that provincial goals be considered within the context of Northern Ontario.

The North West Local Health Integration Network (NWLHIN) and the North East Local Health Integration Network (NELHIN) are the first- and second-largest LHINs, respectively, in Ontario (Ontario LHIN 2014a, para. 1). Although Northern Ontario is huge, accounting for 91 per cent of the province's landmass, it hosts only 6 per cent of its population (NWLHIN 2018, 18; Ontario LHIN 2014b, 6). This equates to a population density of 2 per square kilometre in the Northeast and 0.5 per square kilometre in the Northwest, compared with the provincial average of 14.8 per square kilometre (Statistics Canada 2017a, 2017b). In addition, 30 per cent of the population covered by the NELHIN and 34.2 per cent by the NWLHIN live in rural areas, compared with Ontario's average of 14 per cent (NELHIN 2016, 9; NWLHIN 2017, 7). The Northern Ontario Health Equity Strategy, as outlined by Health Quality Ontario, brings health inequities experienced by Northerners to the forefront. This strategy outlines recommendations for action, including the creation of a Northern Network for Health Equity, "developed in the North, by the North, for the North" (Health Quality Ontario 2018, 1).

Provincial health disparities and inequities, when it comes to chronic disease management, are exacerbated by the maldistribution of health care resources in the North. For example, although Ontario boasted 26,502 physicians in 2017, only 4.6 per cent of those were outside of Census Metropolitan Areas (CMAs) or Census Agglomeration regions (Statistics Canada 2015).[1] This was the lowest distribution percentage in Canada, and well below the national average of 8.2 per cent (Canadian Medical Association 2018). In 2017, in the two CMAs in Northern Ontario, there were 382 physicians (general physicians and specialists) in Sudbury and 334 physicians in Thunder Bay (Canadian Medical Association 2017). This is compounded by a paucity of medical specialists such as respirologists, gerontologists, neonatologists, cardiologists, and infectious disease specialists (*CBC News* 2014) — in 2013, for example, 200 specialist vacancies were reported in Northern Ontario (Ontario LHIN 2014b, 8). Although the Ontario government has attempted to address the shortage of physicians in the North by offering incentives to recruit and retain health professionals in the region (Ontario 2013, para. 1), the issue of access to care in the region remains challenging. It is important to

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[1] CMAs are defined as areas surrounding an urban core with a population of at least 100,000, of which at least 50,000 live in the urban core. Census Agglomeration regions are defined as regions surrounding an urban core with a population of at least 10,000 (Statistics Canada 2015).

note, however, that, since 2011, 94 per cent of graduates from the Northern Ontario School of Medicine have set up practices in the North (*CBC News* 2017).

Issues related to both the lack of and the poor distribution of health human resources in Northern Ontario are well documented (Ontario LHIN 2014b). There is an imbalance between where services are offered and where the target population resides, leading to challenges regarding access to comprehensive and coordinated health services for chronic disease management. This is, in part, due to the distribution of health care professionals in Northern Ontario. Professional isolation, increased client caseloads, and decreased access to continuing education opportunities are just some of the challenges Northern health professionals face (Ontario LHIN 2014b, 10). As a result, health care professionals tend to choose to work in larger centres, such as Sudbury or Thunder Bay.

Although interprofessional models of health care (such as Family Health Teams) can reduce some of the detrimental effects of this imbalance (Donato 2015), these models are often adapted to local situations in a non-standardized approach. This can affect coordination of care between health centres, a vital aspect of Northern health care. The patchwork nature of service distribution in the region, in combination with sheer distance across the North, mean that individuals often need to travel to receive the care they need (Statistics Canada 2015). Travel in the North can be unsafe and onerous, however, due to weather and road conditions, especially for individuals in ill health. This adds another barrier to care, and often results in individuals' deciding to forgo seeking needed health services (Statistics Canada 2015).

Provincial initiatives such as the Ontario Telemedicine Network attempt to mitigate the need to travel for health care, but these require financial resources for the community (Ontario Telemedicine Network 2015). However, equipment costs and challenges associated with the use of technology can be barriers to receiving optimal comprehensive care. Northern Ontarians are not always able to see their health care provider when needed, and instead might use hospital emergency departments. In the North, as much as 60 per cent of visits to emergency departments by individuals with a primary care provider could have been avoided if the provider had been available (Health Quality Ontario 2017b, 40). This demonstrates lack of improvement in follow-up visits after hospitalization and the need for further improvement in the transition between acute and community care. Since chronic conditions "have complex care needs, involving primary care, home care, hospitals, and specialists…[e]stablishing smooth transitions between these areas of care is critical to managing [them]" (Health Quality Ontario 2013, 5). Overall, the barriers Northern Ontarians experience in both location and time contribute to the fragmented nature of care and, ultimately, to a disparity in health care relative to their counterparts in Southern Ontario.

The obstacles Northern Ontarians face have been acknowledged, and initiatives have begun to mitigate them. One such promising example is the introduction of Family Health Teams (Ontario 2016, para. 1). Despite the lack of coordination among centres, as noted earlier, Family Health Teams reduce barriers by providing interdisciplinary and after-hours services in a coordinated effort to meet the needs of their community. Family Health Teams reduce barriers of both location and time, as access to a variety of local health care professionals might reduce the need to travel. In addition, access to services after-hours might prevent unnecessary visits to emergency departments. Due to Northern Ontario's size and the region's small, scattered population, it is difficult for such initiatives to be as effective as possible. This is especially important for complex conditions where individuals need prolonged interdisciplinary care, such as in the case of chronic disease management.

Chronic Disease Management

Canadians are generally living longer and healthier lives; however, many are also living with multiple chronic diseases (Health Council of Canada 2007; Morgan, Zamora, and Hindmarsh 2007; Ploeg et al. 2019). This is in part due to medical advances that “convert acute life-threatening diseases into chronic illnesses” (Morgan, Zamora and Hindmarsh 2007, 7). Because of this shift from acute to chronic disease, patients with one or more illnesses that are chronic require a substantial amount of costly health services. If the ever-increasing number of people living with chronic illnesses is not well managed in the community, these patients often “bounce in and out of hospital and [emergency departments] for every exacerbation of their illness” (Health Council of Canada 2007, 9; Martin 2017, 36). This is neither sustainable for the health care system nor does it positively affect the quality of life of those living with chronic illnesses. The factors contributing to this revolving door include lack of access to an appropriate health care provider and services, not having their underlying issues fully addressed, or simply not having anywhere else to go. The main reason for this situation is the manner in which the Canadian health care system is delivered and funded. Established in the 1950s and deliberately designed to treat patients with acute, episodic needs (Picard 2017; Verma et al. 2014), this reactive approach to health care does not align with proactive approaches to health care, such as public health and other suggestions to evolve the health system that we discuss below.

Cancer, diabetes, cardiovascular disease, and respiratory disease are four chronic diseases that account for 79 per cent of all deaths in Ontario (Lung Association – Ontario 2018). The Ontario Ministry of Health and Long-Term Care is interested in high-cost users of services and resources because this small fraction of Ontarians accounts for a substantial amount of health care spending. It is estimated that 39,000 Ontarians consume 30 per cent of all hospital and home care costs (CIHI 2014). In fiscal year 2018/19, health care spending in Ontario was $61.3 billion, up from $59.3 billion in the previous year (Financial Accountability Office of Ontario 2019). These data suggest that approximately $20.4 billion in health care spending goes to just 0.3 per cent of the population, and the amount is expected to rise as the number of Ontarians living with chronic disease increases. Another study suggests that, in 2013, 5 per cent of health care users consumed 61 per cent of hospital and home care funding (Rais et al. 2013). In 2011, direct health care costs for lung disease alone in Ontario was approximately $5.1 billion (Smetanin et al. 2011). In 2010, the direct health care costs for diabetes was $4.9 billion, while the direct and indirect costs for cardiovascular disease in 2009 and cancer in 2011 were $22 billion and $7 billion, respectively (OCDPA 2014), and these costs are likely increasing. In short, chronic disease costs the health system an exorbitant amount of money. From a national perspective, the population of seniors in Canada is expected to increase from less than 15 per cent of the total at the start of this century to more than 25 per cent by the middle of the century (Clemens and Velhuis 2018), and seniors are the largest consumers of health care spending.

Individuals with chronic diseases are classified as high-cost users, as they frequently access health services and require a significant amount of resources. In the NELHIN area, the incidence, prevalence, rates of hospitalization, and emergency department visits are among the highest in the province for certain chronic diseases, including chronic obstructive pulmonary disease (COPD) (Gershon, Mecredy, and Ratnasingham 2017), diabetes (Booth et al. 2012), and stroke (Hall et al. 2018). Health Quality Ontario reports that, in the NWLHIN region, 24.5 per cent of people reported having two or more chronic diseases, while in the NELHIN area, it was 25.3 per cent; the overall provincial rate sat at 19.7 per cent (Health Quality Ontario 2017a, 24).

First Nations and Métis individuals are also more likely to have chronic conditions, which can be caused by socio-economic conditions, as well as limited options for physical activity (Health Quality Ontario 2017a, 24; 2018, 25). It is reported that around 21 per cent of First Nations individuals live with diabetes, while the average provincial and Northern Ontario rates sat between 10 and 13 per cent (Health Quality Ontario 2018, 25).

Finally, the NWLHIN area has the highest rates of readmission within one year for COPD, diabetes, and chronic heart failure (NWLHIN 2018, 20). Given the higher incidence and prevalence of chronic disease and rates of health service utilization by those living in Northern Ontario, this further highlights the health disparities and inequities experienced by those in the North. It also further substantiates that changes are needed in chronic disease management for northern residents. As such, a comprehensive focus on chronic disease management would bring more balance to health expenditures in Ontario.

Discourse about improving continuity and coordination of care aims to smooth patient transitions, decrease fragmentation, and improve consistency of services, regardless of location in the province (Health Quality Ontario 2018, 7; Hoskins 2016b; NELHIN 2016, 18). Wagner's (1998) Chronic Care Model is frequently referred to in the literature as an example of a combination of multipronged strategies to improve chronic disease care. Barr et al. (2003) have enhanced the model to include elements of population health promotion and prevention efforts, as well as recognition of the social determinants of health and enhanced community participation. Chronic disease management should also take an upstream approach that addresses the root causes of or contributing factors to illness in an attempt to avert illness while accounting for the effects of social determinants of health such as income, housing, education, food security, race, and gender (Barr et al. 2003; Marchildon 2013; Martin 2017). This way of thinking about chronic disease management demonstrates clear associations between the health care system and the community. It also focuses on many aspects of chronic care, including delivery system design, self-management, and building healthy public policy. This approach also encourages us to think about “reorienting health services beyond the provision of clinical and curative services to an expanded mandate that supports individuals and communities in a more holistic way” (Barr et al. 2003, 78).

A focus on chronic disease prevention and management (CDPM) would transform the health care system and help to ensure its sustainability (Morgan, Zamora, and Hindmarsh 2007, 7). Currently, the health care system does not enable physicians and other allied health providers to provide coordinated and comprehensive CDPM for reasons that include the manner in which the system is designed, the delivery of highly fragmented care, and the lack of clinical information systems where information for effective clinical decision-making can be appropriately shared (8). Furthermore, in order to address the CDPM deficit, there should be a focus on population-based and patient-centric models of care[2] that encompass health promotion and disease prevention strategies (9). This should be done in conjunction with addressing the needs of individuals who are currently living with chronic illness in terms of disease management and to ensure they are receiving timely, coordinated, continuous, and appropriate care across all sectors of the health care system.

A focus on CDPM and community-based outreach would reduce costs by ensuring greater continuity of care. Challenges of access to services in Northern Ontario result in fragmented care among health sectors; this directly affects those living with chronic conditions,

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[2] A population-based model focuses on a particular group of individuals, while, in a patient-centric model, not only is care provided based on an individual’s health needs, but the patient plays an active role (Iowa 2016; OneView 2015).

as evidenced by their increased health service utilization. Efforts on the part of LHINs across the province via the Community Health Links initiative (NELHIN 2016, 17) aim to provide coordinated, consistent, and effective care for people with complex conditions. A specific example of how this is enacted is through community paramedicine programs designed to help seniors and high-needs patients at home to avoid emergency department visits and hospital admissions (Ontario 2014). So far, these programs are underway in both Sudbury and Thunder Bay and areas they service (City of Greater Sudbury n.d.; City of Thunder Bay n.d.; NWLHIN n.d.; Tbnewswatch.com Staff 2016). In 2017, the Ontario government invested $771,200 in community paramedicine programs in the NELHIN area including: Cochrane, Manitoulin-Sudbury, Algoma, Nipissing, and Parry Sound (Ontario 2017). In the NWLHIN area, as of January 2017, community paramedicine and telehomecare projects were underway in Thunder Bay and had expanded into the District of Thunder Bay subregion (NWLHIN n.d.). There is potential to build upon this initiative with the fiscal goal of decreasing unnecessary health service use and costs. These programs also provide chronic disease self-management training for patients. It remains to be seen, at this point, exactly what will happen to initiatives such as these as a result of the changes to health services that the Ontario government has recently announced. We discuss these changes and their implications relative to chronic disease management later in this paper.

The Canadian Foundation for Healthcare Improvement (Verma et al. 2014) supports efforts that focus on CDPM. A comprehensive community-based outreach approach that supports those living with chronic illnesses would decrease unnecessary use of emergency and acute care services and readmissions. This approach would provide access to a health care team that would address individuals’ health needs in their home or community and intervene appropriately, preventing unnecessary use of health services, thus decreasing health care costs. Chronic care management and the transition between acute care and the community thus should be a continuing priority in Northern Ontario.

The evidence regarding health service utilization, hospitalization, and emergency department visits in Northern Ontario reveals the need to address the issue of continuity of care between acute and community care settings. One approach that has been sporadically adopted both provincially and nationally, with documented benefits and evidence of reducing the revolving-door effect that those living with COPD often experience, is called INSPIRED, an acronym for Implementing a Novel and Supportive Program of Individualized care for patients and families living with REspiratory Disease (CFHI 2017, n.d.b; Marciniuk et al. 2010; O'Donnell et al. 2008; Picard 2018).

Since 2014, the INSPIRED approach for COPD — a quality improvement collaborative partnership between the Canadian Foundation for Healthcare Improvement (CFHI) and Boehringer Ingelheim (Canada) Ltd. — has provided funding, training, coaching, and resources for a network of 19 interprofessional health care teams across Canada. Each team has received $50,000 in seed funding to adapt and implement the program. This approach has reduced emergency department visits, hospital admissions, and days in hospital by 60 per cent at the Queen Elizabeth II Health Sciences Centre in Halifax, for example (CFHI n.d.a). Although seven health care teams and associated facilities have implemented the INSPIRED approach for COPD in Ontario, none is in Northern Ontario or in any other rural or remote area in the North (CFHI n.d.b). This might be due in part to the unique and diverse challenges that smaller and more rural areas in Northern Ontario face relative to geography, infrastructure, and health human resources. That is not to say that larger centres such as Sudbury and Thunder Bay could not implement this approach. This program is a facility-to-home clinical initiative that, through improved care transitions, self-management, and engagement in advanced-care planning, has demonstrated a significant reduction in health care utilization and costs (Gillis, Demmons, and Rocker 2017). In an interview with the CBC News program *The Current*, health reporter and *Globe and Mail* columnist André Picard stated that, in Canada, "we deliver excellent health care but not because of the system but in spite of the system" (quoted in Hoath 2017, para. 11). He went on to suggest that Canada's biggest single problem was not scaling up its successes. There are many examples of great initiatives that are being implemented in pockets across the country, even within Ontario, relative to chronic disease management that have not been expanded or "scaled up", largely due to the federal and provincial jurisdictional aspects of health care delivery. Picard has further suggested that "innovation is stifled by the structure and administration of the health system, and by a dearth of leadership" (Picard 2017, 39). On the leadership point, Everett (2019, 12) notes that, for Northern Ontario, there is the challenge of senior administration and board leadership capacity in relation to talent and training gaps, succession planning, and the like, which can affect the ability to carry out innovation. Given these challenges, the INSPIRED approach is an example that Northern Ontario should look to as a model that could address chronic disease management.

The INSPIRED approach has already significantly decreased readmission rates and emergency department visits in various Ontario communities. According to the CFHI (n.d.b), if the INSPIRED COPD Outreach Program were implemented across Canada, it would have its biggest effect in Ontario, as preventable health care costs in the province represent 39 per cent of all projected health care savings in Canada. INSPIRED programs cost around $1,000 annually per COPD patient to implement, but within five years such a program would net $263 million in health care savings in Ontario, and $1 spent on this approach would prevent $21 in health care costs (CFHI n.d.b). These types of approaches to chronic disease management ensure that individuals receive appropriate care when they need it while reducing unnecessary health care costs. In order to scale up innovative approaches to chronic disease management such as this, a system needs to be created that focuses on chronic disease management through funding and delivery models.

Prioritizing chronic disease management requires emphasizing that care needs to be provided in the right place at the right time (Health Quality Ontario 2017b, 62; Ontario 2015b, 12). It also aligns with Bill 41, the *Patients First Act, 2016* (see Hoskins 2016b), as it aims to smooth the transition of patients between sectors and improve consistency of services regardless of location in the province. Due to the substantial health care costs required by high-cost users, interventions for this population not only improve patient outcomes and health-related quality of life, but also reduce overall health care spending (Chechulin et al. 2014; Health Council of Canada 2007). As such, chronic disease management, which includes coordinated and continuous transitions from acute to community care, remains a substantial health policy priority, particularly in the unique context of Northern Ontario.

Discussion

Fragmented access to coordinated care is the common theme that runs through this paper. This patchwork nature of services distribution exacerbates the disparities experienced by Northern Ontarians, especially those with chronic conditions. Canadians are increasingly in need of community-based outpatient and ambulatory care services; however, medicare’s historical focus on hospital-based and physician services neglects the use of such approaches. This focus makes it difficult for the Ontario health care system to keep up with contemporary needs. In

Better Now: Six Big Ideas to Improve Health Care for All Canadians, Dr. Danielle Martin suggests that “the disconnect between the primary care universe and the hospital universe is an ongoing source of difficulty for patients and irritation for providers” (Martin 2017, 72). Lack of continuity of care and ineffective communication between primary care providers and the rest of the system leads to wasted time and money and inappropriate use of health services and resources. Recognizing the limitations imposed by medicare and the complex nature of chronic disease management, it is vital to consider the ethical, moral, legal, social, and political implications of initiatives put forth to address them. Potential sources of tension include reallocation of health care dollars within the system, redistribution of health human resources, and reconfiguration of how and where health services are delivered. Although addressing these priorities might not deliver either immediate or explicit benefits, both short- and long-term benefits can arise from such actions. These recommendations thus should be viewed as an investment in the future and as a way to ensure the health not only of Northern Ontarians, but of all Ontarians.

In consideration of the Northern Ontario Health Equity Strategy (Health Quality Ontario 2018), one of the top priorities for Northern Ontario health policy is to address the patchwork nature of health human resources and services by facilitating coordination and communication between centres in order to ensure access to coordinated care and smooth transitions via innovative approaches to chronic disease management. Recently, the Ontario government announced a strategy to transform health care by the merging and consolidation of 20 health agencies, including Cancer Care Ontario, eHealth Ontario, the Trillium Gift of Life Network, Health Shared Services, Health Quality Ontario, and Health Force Ontario Marketing and Recruitment Agency into one super agency that will establish local health teams for coordinating care (Crowe 2019, para. 2; Jeffords and Jones 2019, para. 1). With this announcement, the government intends to address system fragmentation by providing seamless access to all health services. As well, the province estimates that there will be "an annual savings of $200 million by 2021–22" by amalgamating the Ontario health units (Langlois 2019). On the other hand, according to Agnes Grudniewicz, a health systems researcher from the University of Ottawa Telfer School of Management, there is no evidence that centralizing the health care delivery system will actually improve care and reduce costs (cited in Payne 2019, para. 12). Similarly, Dr. Bob Bell, former Ontario deputy minister of health worries that the current government's plan to transform health care will fix things that are not broken or break things that are still working — for example, Cancer Care Ontario, the province's highly regarded cancer service agency, is to be absorbed by the new superagency (Crowe 2019, para. 20). Overall, since the announcement, there has been scepticism over whether these changes will be beneficial, but until the plan is finalized, predicting the exact savings or improved appropriateness and efficiencies of care will be hard to pin down.

Furthermore, the Ontario government has set the funding of public hospitals to less than the rate of inflation and population growth, depriving people of needed health care (Ontario Health Coalition 2019, para. 1). As people with chronic illness are among the most frequent users of hospital services, they will be the most affected. The government has also announced changes to the manner in which public health services will be organized throughout the province, and its intention to cut the public health budget by almost one-third. This will lead to a reduction in the number of health units in the province from 35 down to 10, and to a cut and restructuring of ambulance services that will lead to 10 giant regions as opposed to the previous 59 (Ontario Health Coalition 2019, para. 1). These government-level cuts and changes have the potential to affect proactive health approaches and chronic disease management in the province—particularly access to timely, quality, and comprehensive health services in Northern Ontario (para. 14). This approach does not coincide with a focus on community and public health services that include efforts to promote health and prevent disease. Moreover, this particular announcement is counterintuitive to a CDPM model.

Since the announcement of the strategy, many stakeholder groups have added their perspective to the public narrative about its implications. Despite this, it remains to be seen how the transformation of the health care system and the associated legislation, put forth by the current Ontario government, will unfold or what effects it will have on chronic disease management in Northern Ontario. What is clear is that chronic disease management should remain a health policy priority, particularly in the diverse context of Northern Ontario. Where health disparities exist and lack of attention persists, they should be challenged. It is also unclear how the proposed changes will address the unique needs of Northern Ontario and how they will mitigate the health disparities and inequities experienced by its residents. Given that the responsibility for health care delivery and organization lies within provincial jurisdiction, decisions and policies that are enacted or repealed are substantially influenced by the manner in which health care is funded through the Canadian medicare model.

The Need for Medicare Evolution

There is no doubt that Canadians value their iconic health care system, which allows them to obtain health care services based on need, not on ability to pay. The system, however, is not without its challenges and does have imperfections. There are aspects of the system that work and those that do not. The need for medicare evolution has been discussed for the better part of two decades (Clemens and Veldhuis 2018; Marchildon 2013; Martin 2017; Picard 2017;

Romanow 2002). Arguably, the impetus for this discussion was spearheaded by the foundational work of Roy Romanow who, in 2001, was appointed to head the Commission on the Future of Health Care in Canada and tasked by the federal government with inquiring and undertaking dialogue with Canadians on the future of Canada's public health system. He was also requested to recommend policies and measures, respectful of jurisdictional power, that would be required to ensure the long-term sustainability of a publicly funded health system that is universally accessible and offers quality services. In his detailed report, Romanow (2002) proposed a multitude of recommendations relative to how to improve access and ensure quality, investing in health care providers, primary health care and prevention, home care, and prescription drugs. He also specifically addressed the need to address disparities in health and access to care for rural and remote communities. The work of the Commission is seminal to discussions about Canada's health system, and has direct implications for chronic disease management.

What, however, has been done since the Romanow report? Have any changes been made based on his extensive recommendations? In 2012, ten years after the report's release, the Canadian Association for Health Services and Policy Research hosted a one-day retrospective/prospective on the Commission (Adams 2012). The main message was the repeated call for federal leadership in order to move the Commission's recommendations forward. In the years since Romanow, the documented ebb and flow of federal health care dollars has provided insight into the health priorities of various governments of the day (Adams 2012; Fuller 2017; Lewis 2013; Marchildon 2013). In his review of the Canadian health system, Marchildon (2013) suggested that there had been no major effort focused on rural or remote health care and no major initiative on the part of the federal, provincial, and territorial governments or Indigenous organizations to work together to address Indigenous health care, and that medicare remained unchanged. As Lewis (2013) suggests, however, it is easy to call for change with respect to Canadian health policy but much harder to implement.

More recently, discussion about the need to reform and redesign medicare has continued (see, for example, Clemens and Veldhuis 2018; Fuller 2017; Martin 2017; Picard 2017). Fuller (2017) suggests that an expansion of Canada's publicly funded health care system is exactly what is needed now. She goes on to state that there is a need to bring community-delivered services under medicare and to establish a national pharmacare program. Martin underscores the "need to address the challenges in health care that build on what's good about what we already have in place" (2017, 5), noting that Canadians are deeply committed to medicare and that this is, or should be, the foundation for change (15). In recent years, there has been a paucity of pan-Canadian health reform initiatives, yet, as Marchildon (2013, xx) points out, individual provinces and territories have reorganized their respective health systems, attempting to improve patients' experiences and the quality and timeliness of primary, acute, and chronic care.

In his book, *Matters of Life and Death: Public Health Issues in Canada*, André Picard discusses the need to drag medicare into the twenty-first century. This notion is particularly relevant to chronic disease management. Picard suggests that Canada's "medicare model is a relic" (2017, 17). In fact, in its setup, organization, delivery, and funding medicare has not significantly evolved over the past 70 years. Picard goes on to state that, although Canadians celebrate Tommy Douglas's role in shaping medicare, in fact "medicare was designed to meet the needs of 1950s Canada" (17) through hospital-based physician services. The health care needs of Canadians in the 1950s were mainly for acute care, however, and people did not live as long as they do now. Since people are living longer as a result of many factors, including technological advances, the care needs of Canadians have shifted to management and treatment of chronic disease. Despite this knowledge, the model for the delivery and funding of health care has not yet adapted to current reality.

A revolutionary shift in the model of medicare would support the manner in which chronic disease is managed and how it is experienced by patients, families, and health care providers alike. It also has the potential to reduce expenditures. In order even to begin addressing this issue, critical and difficult discussions need to take place regarding the fundamental methods of delivery and funding. In terms of delivery, the focus of medicare should be primary care — including a medical home base that enables centralized care coordination and electronic medical records — and the extension of universal health coverage to include prescription drugs, home care, and aspects related to the social determinants of health (Fuller 2017; Lewis 2013; Martin 2017; Picard 2017). With respect to funding, a major pitfall of the medicare model is that it fails "to define clearly what is covered by public insurance and what is not" (Picard 2017, 19). In addition, we should recognize that, in this case, universal does not mean unlimited; rather, while expanding areas that medicare covers, coverage should be restricted, across the board, to essentials (Picard 2017).

Picard suggests that the public-private debate over the health care system is a "false dichotomy" — that every health system has a mix of private and public delivery and funding, and that "the question is not whether or not we have private and public care; it's getting the mix right" (2017, 20). Canada has a two-tiered health system, but the split is not private-public but urban-rural (27), as clearly demonstrated in the statistics relative to the health status of Northrern versus Southern Ontarians. Continued dialogue and discussions should take place that are appropriate, relevant, meaningful, and "have teeth" that address this gap and system reform, and subsequent policies and strategies should be developed and implemented with this split in mind.

Clearly, this is easier said than done. Although changing the manner in which the historical model of medicare is based might seem unfathomable, it is not impossible. There is no such thing as a perfect health care system in any country, but there are numerous international examples from which Canadian reformers might take lessons and inspiration. As Picard notes (2017, 41–2), in his book *In Search of the Perfect Health System*, Mark Britnell discusses the strengths and weaknesses of the health systems of 25 countries and the various traits that are important to consider in creating a good health system. In terms of health equity, Raphael (2012) discusses the health systems of seven wealthy developed countries — Canada, the United States, Australia, Britain, Northern Ireland, Finland, Norway, and Sweden — and analyzes their differing approaches to health inequalities. He suggests that Canada is not addressing health inequalities successfully, and could learn from other nations that are doing so, such as Finland (Raphael 2012, chap. 6) and Norway (chap. 7).

Clemens and Veldhuis (2018) suggest that rising health care costs amid constrained public finances, changing demographics (including the increasing number of seniors), increasing support for reform by average Canadians, middling performance, and/or a court case (Vancouver physician Brian Day’s case making its way to the Supreme Court of Canada) could all be catalysts for genuine health care reform. Picard states that changing the historical model of medicare in Canada will require courageous leadership, political will to learn from others, and the will of the people: everyone has a role to play, and “we need a debate about structure and funding and priorities” (2017, 21). This notion, however, might not align with the historical and current understanding and implementation of medicare in Canada. Canadians are increasingly in need of community-based outpatient and ambulatory care, but the *Canada Health Act* and its focus on hospital and physician care makes it “legislatively challenging” to adapt to contemporary needs (Verma et al. 2014, 5). “Rising costs are real, but what matters more than what we spend is what we get for it,” and there is a need to improve the health care system’s performance with respect to chronic, long-term problems (Martin 2017, 38). Martin argues that medicare is part of what it means to be Canadian, and that we should be committed to delivering high-quality, accessible services in an equitable way — that means thinking about how to deliver services better and making medicare a social program worthy of its iconic status (14). As Picard (2017, 21) declares, “It’s time to stop talking and start acting.”

Conclusion

The recommendations and considerations in this paper would indeed be challenging to undertake from a governmental and administrative perspective. They might require the reallocation of health care dollars within the system, a redistribution of health human resources, and a reconfiguration of how and where health services are delivered. Between 2003 and 2018, the previous Ontario government commissioned many reports and initiatives that currently inform health care directions and priorities. The current Ontario government has outlined its platform of health priorities, some of which align with and others potentially deviate from those of the previous government. Tension also might exist between the current federal government and the Ontario government in terms of health care priorities and future directions. There might also be ethical, moral, legal, social, and political implications to consider relative to each of the priorities we have identified. Careful consideration of chronic disease management models of care has the potential to ensure greater continuity between acute care and community care services with an integrated care approach. This would reduce readmission rates and use of acute and emergency care services. As we have noted, the INSPIRED approach is one consideration for Northern Ontario.

Finally, our recommendations might not deliver immediate explicit benefit — both short- and long-term benefits could arise out of actions taken to address the identified priorities. Accordingly, these recommendations should be viewed as an investment in the future to ensure the health of all Ontarians, regardless of where they reside.

Chronic disease management in Northern Ontario and the manner in which health services are organized and delivered must continue to be a priority for policymakers. We need to ensure that provincial goals relative to health care are adapted to the Northern Ontario context. The barriers Northern Ontarians face in both location and time contribute to the fragmented nature of care and, ultimately, to health disparity in the region. Chronic disease management care provided in the right place at the right time will not only improve patient outcomes and health-related quality of life, but also reduce overall health care spending. Comprehensive, coordinated care between health sectors is vital. Meaningful policy discussions and development should not occur in silos, but engage a variety of ministries across the provincial government that play a role in health and social policies specifically in relation to the social determinants of health. Ultimately, the nature of appropriate chronic illness management and the pace at which it evolves will be determined by Canadian voters and their influence with elected government officials of all levels (Health Council of Canada 2007, 3). Finally, discussions about health policy and its development should take place in a manner that considers and addresses the diverse context and health disparities of Northern Ontario. Now is the time for the federal government to engage in discussions with the provinces about how to evolve the Canadian medicare system in a way that aligns with contemporary needs and places chronic disease management at the forefront of health policy discussions. Only then will we stop spinning our wheels.

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Chapter 4 is an integrative review of how health equity is discussed in the health care literature. It serves as a comprehensive review of the literature to assist in understanding two very important concepts of this doctoral work, health equity and clinical practice guidelines. This integrative review was published in the Journal of Nursing Scholarship in 2022. Since its publication, some content has been added and is reflected in this chapter that provides additional information.

Chapter 4

Representations of clinical practice guidelines and health equity in health care literature: An integrative review

McMillan Boyles, C., Spoel, P., Mongomery, P., Nonoyama, M., & Montgomery, K. (2022). Representations of clinical practice guidelines and health equity in health care literature: An integrative review. *Journal of Nursing Scholarship* doi: 10.1111/jnu.12847

Abstract

Aim: This paper reports an integrative review of international health literature that discusses health equity in relation to clinical practice guidelines (CPGs).

Background: Health care professionals (HCPs), policymakers, and decision-makers rely on sound empirical evidence to make fiscally responsible and appropriate decisions about the allocation of health resources and health service delivery. CPGs provide statements and recommendations that aim to standardize care with an implicit goal of achieving equity of care among diverse populations. Developers of CPGs must be careful not to exacerbate inequity when making recommendations. As such, it is important to determine how equity is discussed within the context of CPGs.

Design: This integrative review was conducted according to integrative review methods as outlined by Whittemore and Knafl (2005), and Toronto and Remington (2020). These authors outlined a systematic process for the identification of relevant literature across health disciplines to examine the state of knowledge pertaining to a phenomenon such as health equity.

Search methods: The computerized databases PubMed, CINAHL, Cochrane, Embase, Medline, and Web of Science were searched using a combination of keywords. Search parameters included international peer-reviewed published, full text, English language articles, editorials, and reports over the last decade (January 2011 to February 2022). A reference search of included articles was conducted to identify any additional articles. Dissertations and theses were not included.

Search outcome: A total of 139 peer-reviewed English language articles were identified.

Results: Findings of this review revealed five main ways in which health equity is in context of CPGs including if they target or exacerbate inequity among disadvantaged populations, equity and CPG development, implementation, and evaluation, and checklists and tools to assist developers and users of CPG to consider equity. Although critical appraisal tools exist to assist users of CPGs assess and evaluate how well CPGs address issues of equity, the definition of equity and how CPG development panels should incorporate and articulate it remains unclear and haphazard. As such, recommendations intended to be implemented by HCPs to optimize health equity remain diverse and unclear.

Conclusion: The way equity is discussed within the reviewed health literature has implications for their uptake by and utility for HCPs. The ability of HCPs to implement CPGs may be hindered without an appreciation and integration of equity considerations across the various phases of CPG conceptualization, development, implementation, and evaluation, and their relevance and appropriateness to diverse geographic and socio-economic contexts with variable access to health human resources and services. This situation could be improved if equity were more clearly articulated within all aspects of the CPG process.

Keywords: health disparities, quality of care, evidence-based practice, health policy, policy development/policy-making, health of specific populations, equity, clinical practice guidelines, integrative review

Clinical Relevance: Understanding how equity is discussed in the literature relative to CPGs has implications for their uptake by and utility for HCPs in their goal of providing equitable health care. Successful implementation of CPGs with consideration equity could be improved if equity was more clearly articulated within all aspects of the CPG process including conceptualization, development, implementation and evaluation.

Introduction

An abundant body of international clinical practice guidelines (CPGs) exist for an array of chronic diseases. CPGs are systematically developed, evidence-based documents that provide guidelines and recommendations to health care clinicians, educators, and decision-makers about the care of patients with various health conditions. They aim to standardize and optimize care and improve patient outcomes with an implicit goal of achieving equity of care among diverse populations (American Academy of Family Physicians [AAFP], 2022; Brignardello-Petersen, Carrasco-Labra, & Guyatt, 2021; Graham, Mancher, Wolman, Greenfield, Steinberg, & Institute of Medicine, 2011; Guerra-Farfan, 2022; Garcia-Sanchez, Jornet-Gibert, Nunez, Balaguer-Castro, & Madden, 2022; Gupta et al., 2009; Kredo et al., 2016; Nakase et al., 2021; Schunemann, Zhang & Oxman, 2019; Shekelle, 2022; Slade, Kent, Patel, Bucknall, & Buchbinder, 2016; Weisz, Cambrosio, Keating, Knaapen, Schlich, & Tournay, 2007). As such, CPGs may help to promote health equity and reduce health inequities, which are priority issues for health researchers (Browne et al., 2012; Greenwood et al., 2018; Pinto et al., 2012; Raphael, 2010; Reutter & Kushner, 2010).

However, developers of CPGs must be careful not to inadvertently exacerbate inequity when making recommendations (Murad, 2017; Shi et al., 2014). To better understand how health equity may be considered across the continuum of CPG development, implementation, and evaluation, this paper reports an integrative review of health literature that discusses health equity in relation to CPGs. From the perspective of knowledge translation, this review is important because CPGs may have unintended consequences associated with their uptake (or lack thereof) by HCPs including inadvertently exacerbating health inequities and health disparities. Understanding how equity is addressed in CPGs has implications for their uptake by HCPs who may struggle with the feasibility, relevance, attainability, and applicability of recommendations within contexts that experience structural and service variations in health systems. As background for the main integrative review, the paper begins with a brief explanation of CPGs and of the concept of health equity.

Background

Clinical Practice Guidelines

Clinical or best practice guidelines (CPGs/BPGs) are systematically developed evidence-informed documents about a specific health condition or issue (AAFP 2022; Alonso-Coello et al., 2010; Brignardello-Petersen et al., 2021; Field & Lohr, 1990; Graham et al., 2011; Guerra-Farfan et al., 2022; Jun, Kovner & Stimpfel, 2016; Nakase et al., 2021; Sabharwal et al., 2013; Schunemann, Zhang & Oxman, 2019; Shekelle, 2018; 2022). Guidelines are designed for HCPs and policymakers to assist them in their decision-making for quality health services. They are helpful in that they have the potential to diminish the gap between research and practice (Grol, Cluzeau & Burgers, 2003). According to Woolf (1992), the development of CPGs began in the 1970s. While early guidelines were based mainly on expert opinions derived from clinical practice (Guerra-Farfan et al., 2022), more recent guidelines are based on systematic searches of peer-reviewed research and evidence (Murad, 2017).

Over time, the production of guidelines and extensive research on their methods have proliferated (Alonso-Coello et al., 2010; Grol et al., 2003; Kredo et al., 2016; Murad, 2017). During this time, CPGs have evolved in terms of their development methods and they have become a significant component of health care delivery (Blake & Green, 2019; Grol et al., 2003; Guerra-Farfan et al., 2022; Murad, 2017). In 2000, many different guideline systems existed with varying degrees of quality, which was confusing for various vested interest groups. To address this issue, in 2003 the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) approach was developed to provide a framework for rating the quality of evidence on which guidelines are based as a means to advance guideline methodology and to improve the quality of guidelines (Murad, 2017).

As a genre, CPGs have basic recurring features. There are variations in form of CPGs, as they can range from 7–165 pages. CPGs that are longer in length tend to include a table of contents as they typically cover a wider range of topic areas (see Figure 4-1).

Figure 4-1

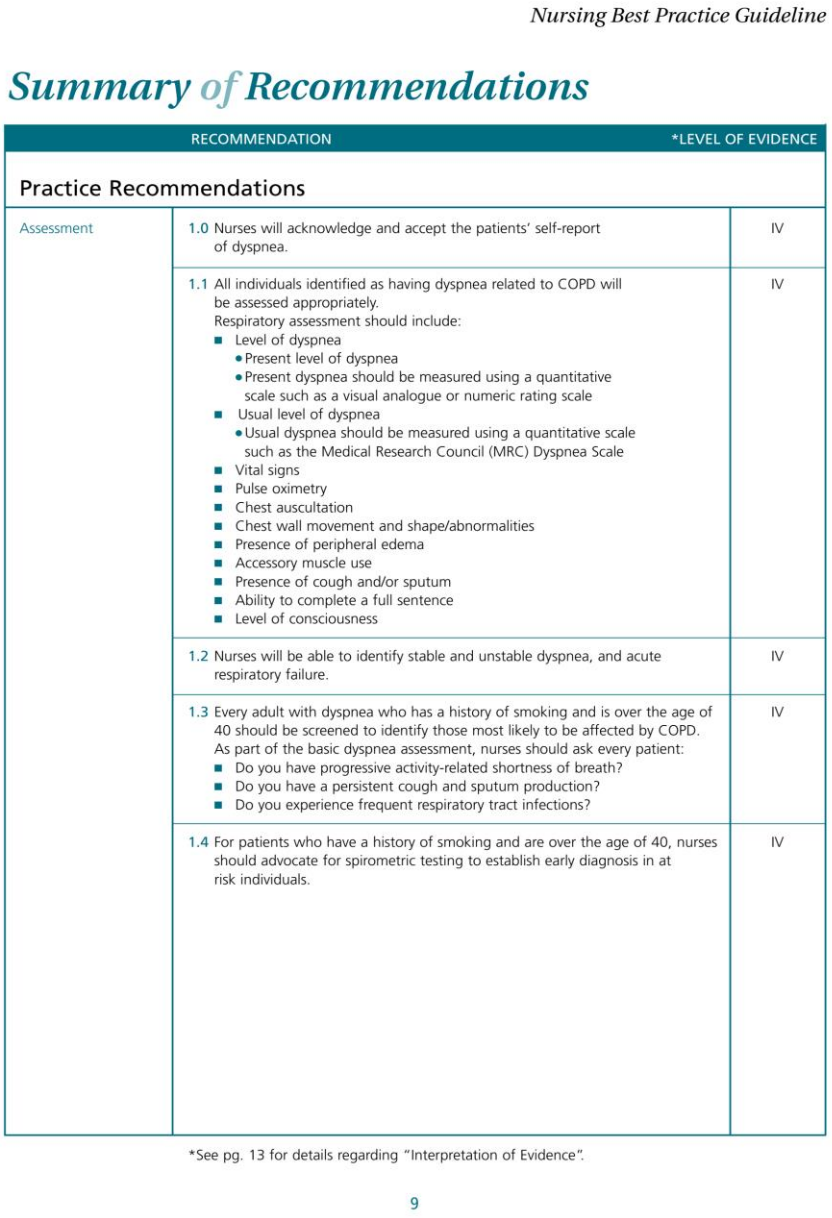
Excerpt from RNAO (2005) COPD CPG-Table of Contents

Table of Contents

They also tend to have a greater depth of information relative to the development process and methodology, address diverse topic areas, and include a summary of recommendations (see Figure 4-2).

Figure 4-2

Excerpt from RNAO (2005) COPD CPG-Summary of Recommendations



Nursing Best Practice Guideline

Summary of Recommendations

	RECOMMENDATION	*LEVEL OF EVIDENCE
Practice Recommendations		
Assessment	**1.0** Nurses will acknowledge and accept the patients' self-report of dyspnea.	IV
	1.1 All individuals identified as having dyspnea related to COPD will be assessed appropriately. Respiratory assessment should include: ■ Level of dyspnea • Present level of dyspnea • Present dyspnea should be measured using a quantitative scale such as a visual analogue or numeric rating scale ■ Usual level of dyspnea • Usual dyspnea should be measured using a quantitative scale such as the Medical Research Council (MRC) Dyspnea Scale ■ Vital signs ■ Pulse oximetry ■ Chest auscultation ■ Chest wall movement and shape/abnormalities ■ Presence of peripheral edema ■ Accessory muscle use ■ Presence of cough and/or sputum ■ Ability to complete a full sentence ■ Level of consciousness	IV
	1.2 Nurses will be able to identify stable and unstable dyspnea, and acute respiratory failure.	IV
	1.3 Every adult with dyspnea who has a history of smoking and is over the age of 40 should be screened to identify those most likely to be affected by COPD. As part of the basic dyspnea assessment, nurses should ask every patient: ■ Do you have progressive activity-related shortness of breath? ■ Do you have a persistent cough and sputum production? ■ Do you experience frequent respiratory tract infections?	IV
	1.4 For patients who have a history of smoking and are over the age of 40, nurses should advocate for spirometric testing to establish early diagnosis in at risk individuals.	IV

*See pg. 13 for details regarding "Interpretation of Evidence".

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It is also noteworthy to state that in some guidelines, CPG developers use the terms "suggest" and "recommend" depending on the grade or quality of the evidence on which the statement is based. If the evidence is of lower quality, the term "suggest" is used, whereas if the statement is based on higher quality evidence, the term "recommend" is used. Guidelines that focus on one aspect of, for example, chronic disease management, like pharmacological management tend to be shorter in length and do not contain a table of contents or summary of recommendations. CPGs typically begin with a listing of development panel members, acknowledgements. Most CPGs outline the purpose and scope of the CPG and define and discuss the epidemiology of a disease (in this case COPD), some may discuss risk factors, burden of illness, and include a discussion of levels of evidence (see Figures 4-3 and 4-4).

Figure 4-3

Excerpt from CTS (2007) COPD CPG-Levels of Evidence

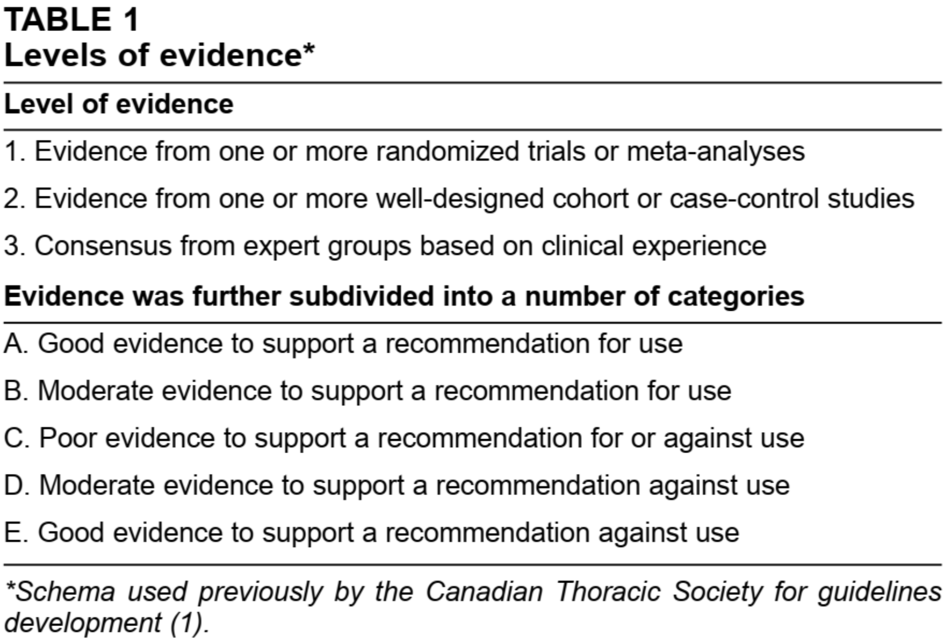


TABLE 1
Levels of evidence*

Level of evidence
1. Evidence from one or more randomized trials or meta-analyses
2. Evidence from one or more well-designed cohort or case-control studies
3. Consensus from expert groups based on clinical experience
Evidence was further subdivided into a number of categories
A. Good evidence to support a recommendation for use
B. Moderate evidence to support a recommendation for use
C. Poor evidence to support a recommendation for or against use
D. Moderate evidence to support a recommendation against use
E. Good evidence to support a recommendation against use

**Schema used previously by the Canadian Thoracic Society for guidelines development (1).*

Figure 4-4

Excerpt from CTS (2011) COPD CPG-Strength of Evidence

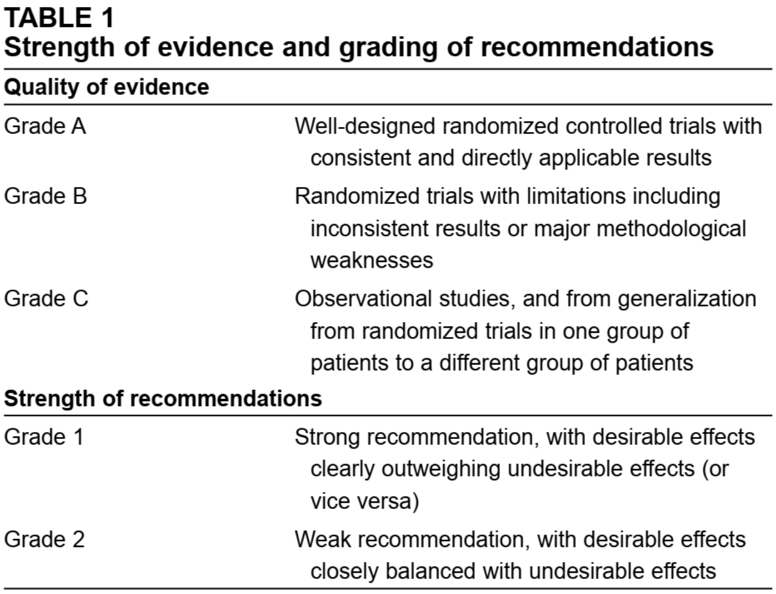


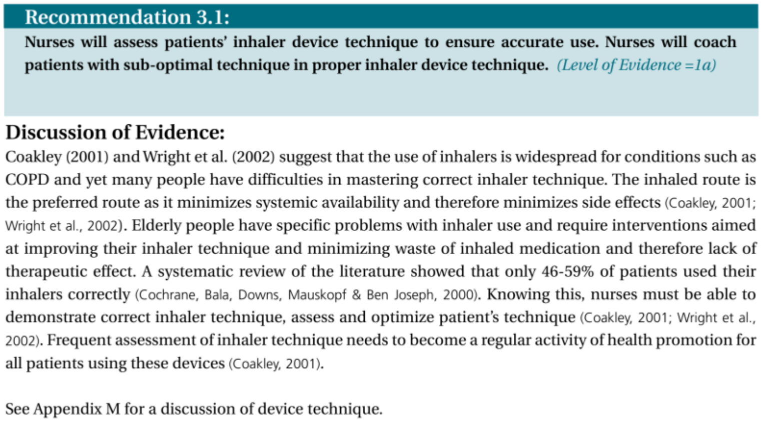
TABLE 1
Strength of evidence and grading of recommendations

Quality of evidence	
Grade A	Well-designed randomized controlled trials with consistent and directly applicable results
Grade B	Randomized trials with limitations including inconsistent results or major methodological weaknesses
Grade C	Observational studies, and from generalization from randomized trials in one group of patients to a different group of patients
Strength of recommendations	
Grade 1	Strong recommendation, with desirable effects clearly outweighing undesirable effects (or vice versa)
Grade 2	Weak recommendation, with desirable effects closely balanced with undesirable effects

Although most CPGs discuss practice, education, organizational and policy recommendations, the format of how this information is presented varies. A discussion of the evidence and an indication of the level of evidence of which the recommendation is based either precedes or follows each section of recommendations (see Figures 4-5 and 4-6).

Figure 4-5

Excerpt from RNAO (2005) COPD CPG-Recommendation and Discussion of Evidence



Recommendation 3.1:

Nurses will assess patients' inhaler device technique to ensure accurate use. Nurses will coach patients with sub-optimal technique in proper inhaler device technique. *(Level of Evidence =1a)*

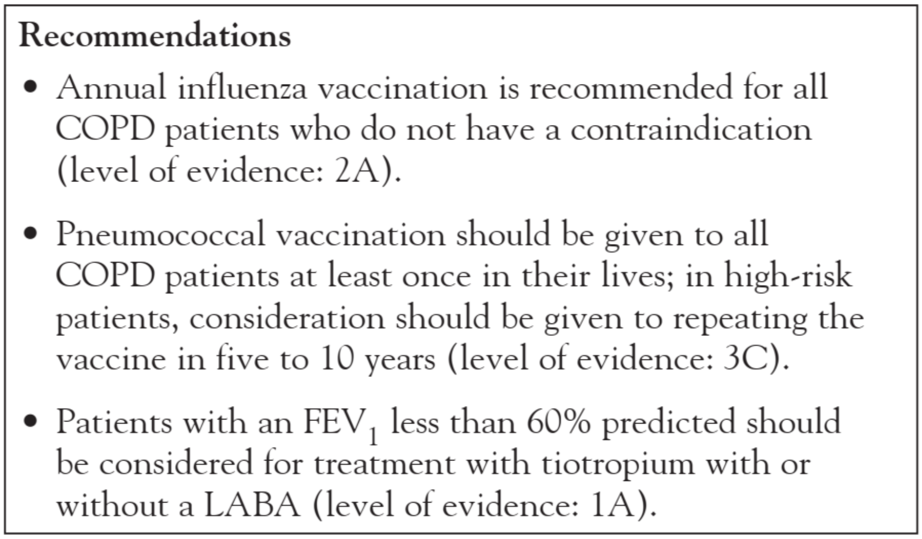
Discussion of Evidence:

Coakley (2001) and Wright et al. (2002) suggest that the use of inhalers is widespread for conditions such as COPD and yet many people have difficulties in mastering correct inhaler technique. The inhaled route is the preferred route as it minimizes systemic availability and therefore minimizes side effects (Coakley, 2001; Wright et al., 2002). Elderly people have specific problems with inhaler use and require interventions aimed at improving their inhaler technique and minimizing waste of inhaled medication and therefore lack of therapeutic effect. A systematic review of the literature showed that only 46-59% of patients used their inhalers correctly (Cochrane, Bala, Downs, Mauskopf & Ben Joseph, 2000). Knowing this, nurses must be able to demonstrate correct inhaler technique, assess and optimize patient's technique (Coakley, 2001; Wright et al., 2002). Frequent assessment of inhaler technique needs to become a regular activity of health promotion for all patients using these devices (Coakley, 2001).

See Appendix M for a discussion of device technique.

Figure 4-6

Excerpt from CTS (2007) COPD CPG-Recommendations



Recommendations

- Annual influenza vaccination is recommended for all COPD patients who do not have a contraindication (level of evidence: 2A).
- Pneumococcal vaccination should be given to all COPD patients at least once in their lives; in high-risk patients, consideration should be given to repeating the vaccine in five to 10 years (level of evidence: 3C).
- Patients with an FEV_1 less than 60% predicted should be considered for treatment with tiotropium with or without a LABA (level of evidence: 1A).

Benefits of CPGs. According to Kredo et al. (2016), high quality, evidence-informed CPGs provide a way to bridge the gap between policy, best practice, local context, and patient choice. CPGs attempt to improve outcomes at both an individual and a system level. They are designed to improve quality of care, reduce variation in practice, and ensure effective and efficient evidence-based care is delivered (Boivin et al., 2010; Brignardello-Petersen et al., 2021; Fischer, Lange, Klose, Greiner, & Kraemer, 2016; Grol et al., 2003; Guerra-Farfan et al., 2022; Shekelle, 2022; Woolf, Grol, Hutchinson, Eccles & Grimshaw, 1999). In doing so, they have the potential to reduce morbidity and mortality, improve efficiency, contain costs, and ensure consistency in practice and points of reference for HCPs (Fischer et al., 2016; Giugliano, Lloyd-Jones, Camargo Jr, Makary & O’Donnell, 2000; Guerra-Farfan et al., 2022; Woolf et al., 1999).

CPGs amalgamate a large amount of evidence in “one place”, which is beneficial to clinicians who may not have time to search various resources for evidence to guide their practice. According to Woolf et al. (1999), CPGs can improve quality of clinical decisions, clarify which interventions are supported by evidence and which are not, reinforce critical appraisal, and call attention to wasteful, ineffective, and dangerous practices. Furthermore, they support quality improvement initiatives that highlight gaps in evidence and areas for future research and other investigations.

CPGs also influence the allocation of clinical and financial resources in health care (Lacasse, Ferreira, Brooks, Newman & Goldstein, 2001). Guidelines make it more likely that patients will be cared for in the same manner regardless of where or by whom they are treated (Woolf et al., 1999). As such, CPGs may support improvements in health care processes and structures (Lugtenberg, Burgers & Westert, 2009). CPGs also can influence public policy as they often bring attention to under-recognized health problems, clinical services, and preventative interventions and to neglected patient populations and high-risk groups (Woolf et al., 1999). As such, they can promote distributive justice by advocating for better delivery of service for those in need.

Criticisms of CPGs. Despite the many possible benefits of CPGs, over the years a growing body of critical discussion about CPGs has emerged (Alonso-Coello et al., 2010; Grilli, Magrini, Penna, Mura & Liberati, 2000; Grol et al., 2003; Murad, 2017; Guerra-Farfan et al., 2022; Netsch & Kluesner, 2010; Qaseem, Snow, Owens & Shekelle, 2010; Shekelle, 2018; Sekercioglu et al., 2017; Shaneyfelt, Mayo-Smith & Rothwangl, 1999; Woolf et al., 1999). The late 1990s saw increasing concern regarding variations in guideline recommendations, their quality, reliability, and independence (Grilli et al., 2000; Shaneyfelt et al., 1999). More recently, Guerra-Farfan and colleagues (2022) suggested that depending on how the reliability of CPGs is measured, up to 50% of guidelines can be considered untrustworthy. Despite the plethora of guidelines that have been developed and the many manuals on how to develop CPGs, several scholars have suggested they lack methodological quality (Alonso-Coello et al., 2010; Netsch & Kluesner, 2010). Grol et al. (2003) suggested that without an accounting of how evidence is interpreted and translated into practice, there may be difficulties in implementing guideline recommendations.

Moreover, the needs of patients may not be the only priority in making recommendations (Woolf et al., 1999). Within some guideline development programs, patient preferences and situated needs are not considered (Grol et al., 2003; Guerra-Farfan et al., 2022). Another criticism of CPGs is that they may impede clinician critical thinking because they dictate how clinicians ought to do their job (Holmes, Murray, Perron & McCabe, 2008; Weisz et al., 2007). Holmes et al. (2008) suggested that if guidelines are not constructed on sound evidence, evaluating patient and service outcomes is challenging. Further, the variation among guideline recommendations for a specific health condition contributes to confusion among HCPs (Grilli et al., 2000; Grol et al., 2003; Shaneyfelt et al., 1999; Shekelle, 2018). Perhaps most scathing is the criticism that describes the creation and development of the Registered Nurses Association of Ontario (RNAO) CPGs as “part of an ideological agenda that is scientifically, socially, politically, and ethically unsound” (Holmes et al., 2008, p. 394). These authors argued that guidelines symbolize ready-made tools and rules that impede critical thinking and reflection within practice and that they produce an illusion of scientific and ethical truth that cannot be translated into the real world of practice.

CPG Uptake. Guidelines are often underutilized by HCPs due to various barriers and challenges that preclude their uptake and implementation (Duncombe, 2018; Eslava-Schmalbach et al., 2017; Fischer et al., 2016; Graham, Harrison, Brouwers, Davies, & Dunn, 2002; Jun et al., 2016; Pereira, Pellaux & Verloo, 2018; Radwan, Sari, Rashidian, Takian, Dagga & Elsous, 2017; Radwan, Sari, Rashidian, Takian, Elsous & Dagga, 2018; Schaefer & Welton, 2018; Slade et al., 2016; van der Weijden, Boivin, Burgers, Schunemann & Elwyn, 2012). For example, in an integrative review, Jun et al. (2016) appraised the current literature on the barriers and facilitators in the use of CPGs by registered nurses. Results showed that nurses who believed that CPGs supported their practice and improved patient outcomes were more likely to use them. In contrast, nurses who perceived that CPGs impeded their clinical autonomy were reluctant to use them. In addition to the internal factors (i.e., attitudes, perceptions, knowledge), there were also external factors (i.e., format, usability, resources, leadership, and organizational culture) that were described as either barriers or facilitators to the use of CPGs in clinical practice. Similarly, a scoping review conducted by Fischer and colleagues (2016) revealed barriers to CPG implementation can be differentiated into personal factors (i.e., knowledge, attitude, behaviours), guideline-related factors (i.e., level of evidence, credibility, plausibility), and external factors (i.e., organizational resources).

Inadequate resources and lack of institutional support and leadership in creating an environment that fosters evidence-based practice also have been identified as substantial barriers to using CPGs in practice (Duncombe, 2018; Jun et al., 2016; Schaefer & Welton, 2018). Unlike formal policy, these guidelines are recommendations that self-regulated and autonomous HCPs can choose to utilize in their practice to varying degrees if at all. Despite efforts of clinicians, researchers, and policymakers alike to create clinical guidelines that are grounded in sound evidence, their uptake hinges upon how this evidence is valued and understood by institutions, organizations, and HCPs (Duncombe, 2018; Pereira et al., 2018). Finally, guideline recommendations also may be challenging to implement in contexts where inequities and/or structural vulnerabilities impede the delivery of and access to quality services (i.e., lack of infrastructure, diagnostic services, and specialized HCPs). For example, these resources are readily available in more urban settings but sparser within northern and rural communities (Bourke, Taylor, J, Humphreys & Wakerman, 2013; Kulig & Williams, 2012; Malatzky & Bourque, 2016; Malatzky & Bourque, 2018; MOHLTC, 2010; NELHIN, 2016).

Health Equity

Health equity is an increasing global phenomenon of concern among HCPs, researchers, and decision-makers. Its definition, however, varies. Lane, Sarkies, Martin, and Haines (2017) included 74 health reports in a systematic review of health equity's explicit or implicit attributes to yield an operational definition. Despite the incongruities among the numerous definitions, these researchers identified 21 common attributes of equity, which include equalization of opportunity to access service, use of service, and potential for wellness. In specific relation to health care access, Lane et al. (2017) conceptualized equity as the availability of services, in terms of both quantity and quality, at a responsible cost for individuals and groups. Nonetheless, despite the diversity of health equity definitions, there are organizations and scholars whose definitions of health equity are often cited within the literature.

Expanding on the World Health Organization (WHO)’s 1986 definition of health equity, Whitehead (1992) defined health inequalities as unjust and avoidable differences in health care access, quality, and outcomes. Braveman et al. (2011) contributed to the debate on the meaning of health equity by using the term health disparities, which they defined as systemic, reasonably avoidable health differences of disadvantaged groups because of determinants of health such as race/ethnicity, geography, and socioeconomics. A shared feature of these definitions is reference to service specific attributes which have become a fundamental aspect of equity relative to the just distribution of multiple yet finite health resources (Almond, 2002; Ahluwalia, Damberg, Silverman, Motala & Shekelle, 2017; Scott & Rawal, 2018). Braveman (2014) suggested that even though the definitions of health inequity, health disparity, and health equity may overlap, these concepts should be distinguished to avoid misdirection of resources and that health disparities can be conceptualized as tangible measures of health differentials relative to well-defined public health indicators as a means to assess progress towards health equity (Braveman et al., 2011). From Braveman's perspective, *health equity* is synonymous with social justice in health. That is, "no one is denied the possibility to be healthy for belonging to a group that has historically been economically/socially disadvantaged" (Braveman, 2014, p. 7). Braveman et al. (2011) suggested that health equity could not be defined without defining social disadvantage, which she defined as follows:

> Social disadvantage refers to the unfavorable social, economic, or political conditions that some groups of people systematically experience based on their relative position in social hierarchies. It means restricted ability to participate fully in society and enjoy the benefits of progress. Social disadvantage is reflected, for example, by low levels of wealth, income, education, or occupational rank, or by less representation at high levels of political office (p.S151).

Health equity is social justice in health, and social justice affects the health and wellbeing of people (Abu, 2020; Benjamin, 2015; Braveman et al., 2011; Trinh-Shevrin, Nadkarni, Park, Islam & Kwon, 2015). Abu (2020) asserted that social justice in health:

> refers to equitable distribution and redistribution of resources for positive health outcomes, recognition and removal of social and political barriers that impinge on health and promoting parity of participation in decision-making for the allocation and utilization of health resources. These are situations that relate to practices, policies, and systems that

> create and perpetuate poverty, unemployment, homelessness, discrimination, lack of education….. (p. 1).

More recently, the WHO (2020) has defined equity as the absence of avoidable, unfair, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically. In simpler terms, health equity or equity in health affords each individual a just opportunity to achieve their full health potential through appropriate services and resources. Public Health Ontario (2020) and the Canadian Institute of Health Information (2018) echo the WHO's understanding of health equity. In their definitions, *health equity* focuses on the mitigation and absence of unjust, unfair, and avoidable differences in health care access, quality, or outcomes to fulfill health potentials across diverse determinants of health.

The Review

Integrative reviews are a method of knowledge synthesis that explore a health phenomenon by examining both theoretical and empirical literature (Toronto & Remington, 2020; Whittemore, Chao, Jang, Minges & Park, 2014; Whittemore & Knafl, 2005). This systematic approach involves the identification, analysis, appraisal, and synthesis of literature framed by a focused question. This study's integrative steps were guided by methods as outlined by Whittemore and Knafl (2005) and, more recently, Toronto and Remington (2020). The steps begin with problem identification followed by a search and appraisal of relevant literature before extracted data are synthesized and analyzed.

Aim

The aim of this review was to explore how equity is discussed in the health literature in relation to CPGs and has been reported according to the Preferred Reporting Items for Systematic Review and Meta-analyses (PRISMA) statement (Moher et al., 2009).

Literature Search and Appraisal

A literature search was conducted to identify relevant articles using the electronic databases PubMed, CINAHL, Cochrane, Embase, Medline, and Web of Science. Search terms were developed relevant to each database such as ((“clinical practice guideline*) AND (“health equity”)), AND (barrier* OR facilitator*). Search parameters included international peer-reviewed published, full text, English language articles, over the last two decades (between January 2011 and February 2022). Only sources that discussed the concept of equity within the context of CPGs were included in this review. Dissertations and theses were not included. The search was conducted by two authors (CMcB and KM) and screening of the articles and data extraction was undertaken by the first author (CMcB). A reference search of included articles was conducted to identify any additional articles.

According to Whittemore and Knafl (2005), evaluating quality of sources in an integrative review is complex. For this review, articles were assessed for quality using the Critical Appraisal Skills Program (CASP) tool (2021). Because of the diversity of the included research and theoretical literature, articles were evaluated based on methodological quality, informational value, and representativeness. Sources of evidence with low theoretical or methodological quality, low informational value, or lack of representativeness were excluded.

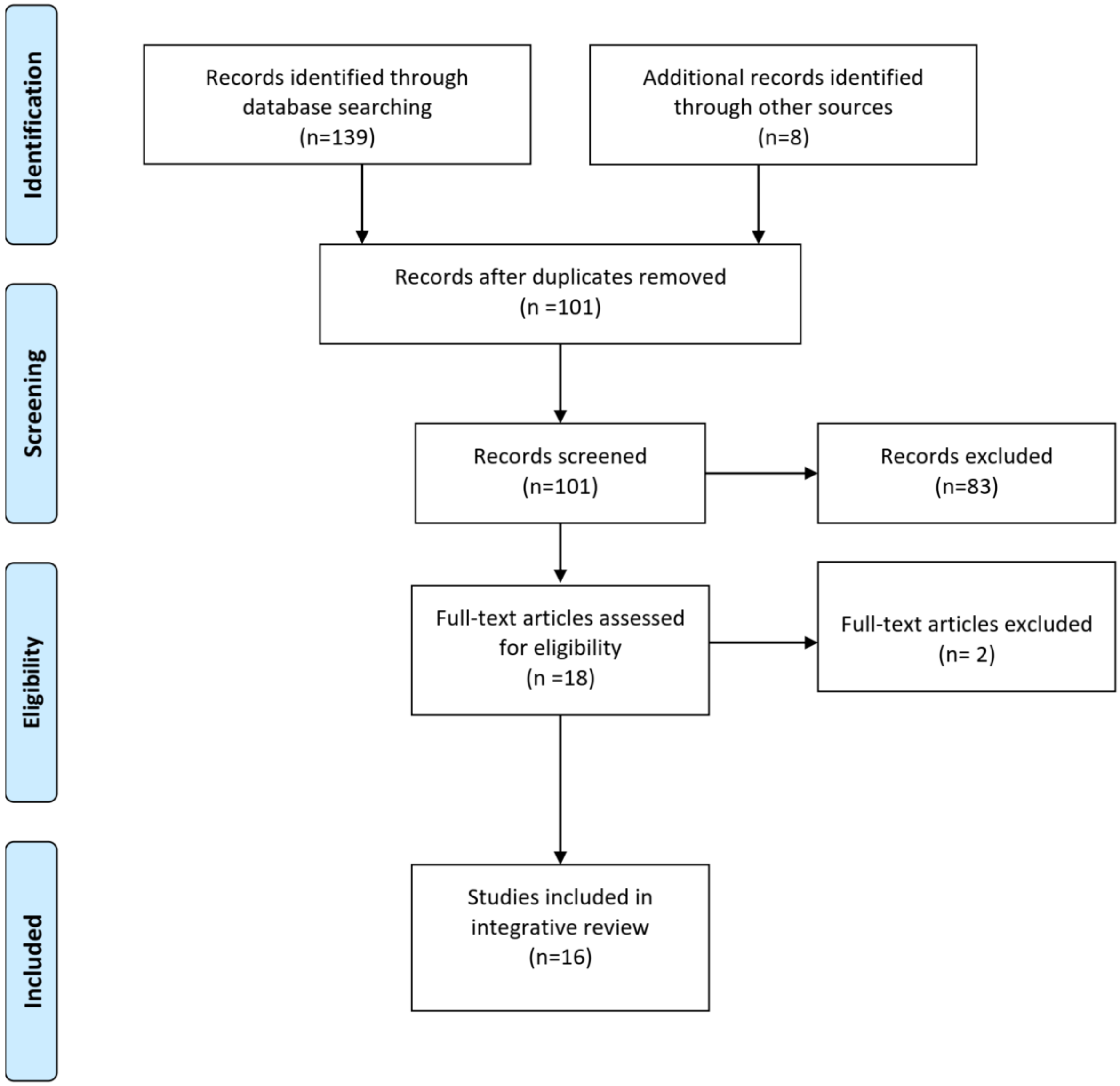
Results

Search Outcome

A total of 147 English language peer-reviewed articles from authors around the world published between January 2010 and February 2022 were identified (Figure 4-7).

Figure 4-7

Flow Diagram of Literature Search and Selection Process (Moher et al., 2009)



Several of the same citations were identified across the various databases searched. Of the 147 articles identified, 46 of them were identified as duplicates across two or more databases. Of the 101 citations remaining, 83 of them were identified as not relevant to the aim of the review. Two were excluded as they were not relevant to the aim of the review following further analysis of the full text. As such, sixteen theoretical and empirical articles met the inclusion criteria and were therefore included in this review (Table 4-1).

Table 4-1

Literature Included in Integrative Review n=16

Lead author Year Country	**Design/Method**	**Aim(s) of study/purpose/objective**	**Findings**
Kahn & Beauchemin (2021) USA	Review Theoretical	This review focuses on the pediatric and young adult vulnerable populations who trail behind on survival curves. It also highlights where inequities may occur, especially those that affect minority and low-income patients. This review suggests that improving health equity requires wide dissemination and uptake of guidelines to ensure best care for all patients.	This review accompanied the 2021 NCCN Guidelines for Pediatric Hodgkin Lymphoma and suggested that systemic inequities in cancer care disproportionately affect minority and low-income children, adolescents, and young adults, and directly contribute to observed disparities in cancer-related outcomes. It proposed that the first step toward reducing disparities is large-scale dissemination of guidelines, because equity is best achieved when treatment approaches are clear, comprehensive, and standardized across all clinical practice settings.
Magwood et al. (2020) Canada	Mixed-method	To identify determinants of guideline implementation from the perspective of patients and practitioner stakeholders for a health guideline on homelessness.	Stakeholder concerns and perceptions about fragmented services and social stigma serves as a barrier to health care. Practitioners were reluctant to provide care and called for improved training to increase knowledge of patient needs and preferences. Several knowledge translation strategies that may improve implementation of guidelines for marginalized populations were identified.
Petkovic et al. (2020) International	Multi-stage project Study Protocol First stage: conduct a series of four systematic reviews	To develop guidance on how to equitably and meaningfully engage multiple stakeholders in guideline development and implementation.	Overall goal of this proposed study is to improve the development of guidelines through meaningful and equitable multi-stakeholder engagement, and subsequently to improve health outcomes and reduce inequities in health by conducting 4 systematic reviews to develop draft guidance recommendations and broad feedback from guideline developers and external stakeholders. Finally, an invited group of representatives from all stakeholder groups will consider all of the above and come to a consensus on final guidance.
Prescott et al. (2020) Canada	Assessment of a nursing guideline using The Equity Lens	To conduct an assessment of the nursing CPG, *Sexually Transmitted Infection Assessment Decision Tool* using the health equity assessment tool by Dans et al. (2007).	Overall, the tool was useful in assessing the inclusion and omission of an equity focus in the guideline. However, there were several challenges: the identification of an appropriate health equity tool; the absence of an evaluation of the chosen tool; the

			tool’s focus on chronic disease versus communicable disease; and the difficulty of obtaining client perspectives.
Zamor et al. (2020) USA	Retrospective cohort study	To determine if a family’s preferred language of Spanish versus English was associated with differences in the management of bronchiolitis in the pediatric emergency department.	Children from families with a preferred language of Spanish who presented to the pediatric emergency department were more likely to receive diagnostic testing that did not align with the American Academy of Pediatrics bronchiolitis guidelines.
Akl et al. (2017) International	Literature review Theoretical	To provide guidance for guideline developers on how to consider health equity during the guideline development process.	Key stages at which guideline developers could consider equity are: setting priorities, guideline group membership, identifying target audiences, generating guideline questions, considering the importance of outcomes and interventions, deciding what evidence to include, searching for evidence, summarizing the evidence, wording of recommendations, evaluation, and use.
Eslava-Schmalbach et al. (2017) International	Critical appraisal of the literature Theoretical	This article describes nine steps that provide guidance for consideration of equity during guideline implementation using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) methodology for development of clinical, public health, and health system guidelines.	Nine-steps that were used to implement equity-focused GRADE recommendations: 1. Identification of disadvantaged groups, 2. Quantification of current health inequities, 3. Development of equity-sensitive recommendations, 4. Identification of key actors for implementation of equity-focused recommendations, 5. Identification of barriers and facilitators to the implementation of equity-focused recommendations, 6. Development of an equity strategy to be included in the implementation plan, 7. Assessment of resources and incentives, 8. Development of a communication strategy to support an equity focus, 9. Development of monitoring and evaluation strategies.
Pottie et al. (2017) International	Theoretical	To provide detailed guidance on how to incorporate health equity within the GRADE methodology.	Consideration of the impact on health equity may be required both in general guidelines and in guidelines that focus on disadvantaged populations. Two approaches to incorporate equity considerations include: 1. Assessing the potential impact of interventions on equity; 2. Incorporating equity considerations when judging or weighing each of the evidence to decision criteria.
Welch et al. (2017a) International	Theoretical	This article introduces the rationale and methods for explicitly considering health equity in the GRADE methodology.	The authors developed three articles on incorporating equity considerations into the overall approach to guideline development, rating certainty, and assembling the evidence base and evidence to decision and/or recommendation. Clinical and public health guidelines have a role to play in promoting health equity by

			explicitly considering equity in the process of guideline development.
Welch et al. (2017b) International	Theoretical	To describe a conceptual framework for how to consider health equity in the GRADE methodology.	Authors developed consensus-based guidance to help address health equity when rating the quality of evidence. When health inequity is determined to be a concern by stakeholders, the authors propose five methods for explicitly assessing health equity: 1. Include health equity as an outcome; 2. Consider patient-important outcomes relevant to health equity; 3. Assess differences in the relative effect size of the treatment; 4. Assess differences in baseline risk and the differing impacts on absolute effects; 5. Assess indirectness of evidence to disadvantaged populations and/or settings.
Schunemann et al. (2014) International	Theoretical	To systematically compile a comprehensive checklist of items linked to relevant resources and tools that guideline developers could consider, without the expectation that every guideline would address each item.	The authors developed a checklist with 18 topics and 146 items and a webpage to facilitate its use by guideline developers. The topics and included items cover all stages of the guideline enterprise, from the planning and formulation of guidelines, to their implementation and evaluation. The final checklist includes links to training materials as well as resources with suggested methodology for applying the items.
Shi et al. (2014) China/Canada	Qualitative synthesis	To qualitatively synthesise the methods for incorporating equity in CPGs.	Themes and processes on how to address equity issues in guideline development. 8 studies with 10 publications were included from 3405 citations. In total, a list of 87 questions/items was generated from 17 checklists/frameworks. After content analysis, questions were grouped into eight themes ('scoping questions', 'searching relevant evidence', 'appraising evidence and recommendations', 'formulating recommendations', 'monitoring implementation', 'providing a flow chart to include equity in CPGs', and 'others: reporting of guidelines and comments from stakeholders' for CPG developers and 'assessing the quality of CPGs' for CPG users). Four included studies covered more than five of these themes.
Lorenc et al. (2012) United Kingdom	Overview of systematic reviews	To understand which types of smoking ban interventions are likely to produce "intervention-generated inequalities" (IGIs) and which can reduce IGIs. To identify IGIs by socioeconomic status	Media campaigns and workplace smoking ban intervention types showed some evidence of increasing IGIs between socioeconomic groups. However, for many interventions, data on potential IGIs are lacking. Structural workplace interventions, provision of resources, and fiscal interventions showed some evidence of reducing IGIs.

Mizen et al. (2012) United Kingdom	Assessment of guidelines using equity lens developed by the International Clinical Epidemiology Network (INCLEN)	To examine CPGs address of inequities experienced by individuals living with intellectual disabilities.	Of 36 identified guidelines, 1 explicitly excluded persons with intellectual disabilities, 35 met the first equity lens criterion, 8 contained content on intellectual disabilities, 6 addressed the fourth equity lens criterion. No guidelines addressed the second, third, and fifth equity lens criteria.
Beauchamp et al. (2010) Australia	Review	To examine impact of cardiovascular disease prevention and treatment relative to socioeconomic gradient.	Only limited evidence was found for the effectiveness of the selected interventions among lower SES groups and there was little exploration of SES related barriers to their uptake. Social and environmental factors associated with disadvantage are a significant barrier to the effectiveness of interventions.
Dans et al. (2007) International	Theoretical	To identify a proposed lens for users to evaluate how well CPGs address issues of equity.	The five criteria of The Equity Lens include: 1. Do the public health recommendations in the guidelines address a priority problem for disadvantaged populations? 2. Is there a reason to anticipate different effects of intervention in disadvantaged and privileged populations? 3. Are the effects of the intervention valued differently by disadvantaged compared with privileged populations? 4. Is specific attention given to minimizing barriers to implementation in disadvantaged populations? 5. Do plans for assessing the impact of the recommendations include disadvantaged populations?

Study Characteristics

The 16 articles originated from several countries including Canada (Magwood et al., 2020; Prescott et al., 2020), the United States (Kahn & Beauchemin, 2021; Zamor et al., 2020), the United Kingdom (Lorenc et al., 2012; Mizen et al., 2012), and Australia (Beauchamp et al., 2010). Many of the articles were authored by teams of international and interdisciplinary scholars (Akl et al., 2017; Dans et al., 2007; Eslava-Schmalbach et al., 2017; Pottie et al., 2017; Petkovic et al., 2020; Schunemann et al., 2014; Shi et al., 2014; Welch et al., 2017a, b). This aggregated body of evidence situates the concept of equity within the context of disadvantaged groups (Beauchamp et al., 2010; Kahn & Beauchemin, 2021; Lorenc et al., 2012; Magwood et al., 2020; Mizen et al., 2012; Zamor et al., 2020). Disadvantaged groups included individuals who are marginalized due to homelessness (Magwood et al., 2020), socio-economic status (Beauchamp et al., 2010; Kahn & Beauchemin, 2021), and minority and language status (Kahn & Beauchemin, 2021; Zamor et al., 2020). A shared goal of the authors was to improve health outcomes and reduce health inequities for marginalized populations (Kahn & Beauchemin, 2021; Magwood et al., 2020; Petkovic et al., 2020). Included articles are listed in Table 1 and collated according to conceptual patterns of how equity is discussed within the context of CPGs.

Data Extraction and Synthesis

A narrative synthesis is an interpretive approach utilized in systematic reviews to synthesize textual content findings from the included articles (Toronto & Remington, 2020). This approach was used to summarize and describe findings related to how equity is discussed in the health literature within the context of CPGs. Textual content relevant to the aim of the review was extracted from articles and organized in a table to visually represent patterns of how equity was discussed in the included literature. This table allowed for the identification of similarities and differences in these representations. These synthesized patterns are discussed in the results of the integrative review.

Findings of this review revealed five main ways in which health equity is discussed in the health literature. The patterns identified included discussion of how CPGs, although intended to target inequity, may unintentionally exacerbate inequity among disadvantaged populations. The reviewed literature also discussed the various stages of the CPG process, including development, implementation, and evaluation, in which equity is considered as well as checklists and other tools that both developers and users of CPGs could utilize to consider equity (Table 4-2).

Table 4-2

Conceptual Patterns of Equity in Included Published Articles

Pattern	**Published Articles**
CPG and Disadvantaged Groups: Target or Exacerbate Inequity?	Kahn & Beauchemin (2021) Magwood et al. (2020) Eslava-Schmalbach et al. (2017) Shi et al. (2014) Lorenc et al. (2013) Mizen et al. (2012) Beauchamp et al. (2010) Dans et al. (2007) Zamor et al. (2020)
Equity and CPG Development	Petkovic et al. (2020) Akl et al. (2017) Pottie et al. (2017) Welch et al. (2017a) Welch et al. (2017b) Schunemann et al. (2014) Shi et al. (2014)
Equity and CPG Implementation	Kahn & Beauchemin (2021) Magwood et al. (2020) Zamor et al. (2020) Akl et al. (2017) Eslava-Schmalbach et al. (2017) Lorenc et al. (2012) Mizen et al. (2012) Beauchamp et al. (2010)
Equity and CPG Evaluation	Prescott et al. (2020) Akl et al. (2017) Mizen et al. (2012) Dans et al. (2007)
Equity and CPG Checklists and Tools	Prescott et al. (2020) Akl et al. (2017) Eslava-Schmalbach et al. (2017) Pottie et al. (2017) Schunemann et al. (2014) Dans et al. (2007) Welch et al. (2017a) Welch et al. (2017b)

CPGs and Disadvantaged Groups: Target or Exacerbate Inequity?

Authors perceive guidelines as simultaneously advantageous and disadvantageous in relation to health equity. CPGs aim to target inequity through standardized care approaches; however, an unintended consequence of CPGs is their potential to exacerbate inequity if services and resources outlined in CPG recommendations are not readily available or accessible. On one hand, CPGs can be used to target health inequities experienced by disadvantaged populations (Dans et al., 2007; Eslava-Schmalbach et al., 2017; Kahn & Beauchemin, 2021; Magwood et al., 2020; Mizen et al., 2012; Shi et al., 2014). On the other hand, guidelines may unintentionally increase health inequities (Beauchamp, Peeters, Tonkin & Turrell, 2010; Dans et al., 2007; Eslava-Schmalbach et al., 2017; Lorenc, Petticrew, Welch, & Tugwell, 2013; Mizen, Macfie, Findlay, Cooper & Melville 2012), particularly among disadvantaged groups (Lorenc et al., 2013), individuals with intellectual disabilities (Mizen et al., 2012), and individuals of lower socio-economic status (Beauchamp et al., 2010). For example, Beauchamp and colleagues (2010) conducted a review of evidence investigating the uptake of cardiovascular disease (CVD) primary and secondary prevention interventions among adults of lower socioeconomic status. The authors found that environmental and social factors associated with disadvantage (i.e., lower socioeconomic status, levels of education, health literacy, and social isolation) were significant barriers to the effectiveness of evidence-based treatments and preventions strategies for the management of CVD. They concluded that there are significant disparities in the uptake and delivery of key prevention and treatment strategies related to CVD, there is a paucity of evidence of their effectiveness among lower socioeconomic groups, and prevention strategies may be contributing to the widening socioeconomic-CVD gradient.

Khan and Beauchemin’s (2021) review focused on children and adolescent/young adults diagnosed with Pediatric Hodgkin lymphoma including minority and low-income individuals. This review outlined that the effects of social determinants of health may contribute to inequities experienced by these groups at various points in time along the cancer continuum (pre-treatment, treatment, post-treatment, survivorship, and long-term follow-up). These authors suggested that wide dissemination and uptake of CPGs is needed to improve health equity and to ensure optimal care for all patients. They concluded that vulnerable populations may benefit from national American CPGs given that equity is best achieved across all clinical practice settings via clear, comprehensive, and standardized treatment approaches.

This tension about CPGs usefulness in practice at supporting health equity is particularly underscored by their historical focus on systematic synthesis, effectiveness, and even cost-effectiveness as opposed to a focus on fostering equity in health care practices or systems. In light of this omission, Akl et al. (2017) and Shi et al. (2014) provided guidance for CPG developers on how to consider equity at key stages of the guideline development process while others considered equity during guideline implementation (Eslava-Schmalbach et al., 2017; Magwood et al., 2020; Mizen et al., 2012; Petkovic et al., 2020) and evaluation (Dans et al., 2007; Mizen et al., 2012). Lorenc et al. (2013) suggested that there is a need to understand which type of interventions are likely to produce intervention-generated inequalities (IGIs) and which can reduce inequalities. Although these papers mention equity, the actual definition of equity and how CPG development panels should go about incorporating it remain diverse and unclear.

Equity and CPG Development

The articles in this review discussed the concept of equity at various points of the CPG process from development through to implementation and evaluation. Akl and colleagues (2017) offered guideline developers a checklist for the integration of health equity during key stages of the development process. These stages include setting priorities, establishing the CPG group membership, delineating the CPGs' purpose, identifying the target audience, generating guideline questions, considering what evidence to include, summarizing the evidence, and establishing the wording of recommendations. Following publication of the CPG, developers may evaluate and monitor its use by the intended audience. Many scholars identified equity promoting strategies during the early stages of CPG development (Petkovic et al., 2020; Pottie et al., 2017; Welch et al., 2017ab; Schunemann et al., 2014; Shi et al., 2014). These include multi-stakeholder engagement in the literature search plan (Petkovic et al., 2020), the utilization of the GRADE evidence-to-decision framework (Pottie et al., 2017; Welch et al., 2017ab), and comprehensive guideline development checklists that aim to incorporate equity in CPGs (Schunemann et al., 2014; Shi et al., 2014).

What remains unclear, however, is how, in practice, to equitably and meaningfully engage multiple vested interest groups from development to implementation of a CPG. Petkovic and colleagues (2020) suggested that there is a lack of guidance on how to equitably and meaningfully engage multiple vested interest groups throughout the guideline development and implementation process. As such, they developed a study protocol which aims to develop guidance for CPG developers in relation to this problem through collaboration with diverse vested interest groups and by conducting four systematic reviews. The goal of their proposed study was to improve health outcomes and reduce inequities in health by improving guideline development to include meaningful and equitable multi-stakeholder engagement.

Equity and CPG Implementation

Other reviewed articles discussed equity in relation to the implementation phase of CPG recommendations, an emergent area of investigation (Akl et al., 2017; Beauchamp et al., 2010; Eslava-Schmalbach et al., 2017; Lorenc et al., 2012; Magwood et al., 2020; Mizen et al., 2012; Zamor et al., 2020). Language preferences of those receiving care was identified as an important aspect in the implementation of CPG recommendations. For example, in a retrospective cohort study, Zamor et al. (2020) found that children from families with a preferred language of Spanish who presented to the pediatric emergency department were more likely to receive diagnostic testing that did not align with the American Academy of Pediatrics bronchiolitis guidelines.

Within the literature, some scholars delineated conceptual frameworks and processes for incorporating health equity within GRADE and specifically addressed the implementation of equity-focused GRADE recommendations (Eslava-Schmalbach et al., 2017; Magwood et al., 2020; Pottie et al., 2017; Welch et al., 2017ab). Using the Grading of Recommendations Assessment, Development, and Evaluation Feasibility, Acceptability, Cost, and Equity Survey (GRADE-FACE) health equity implementation outcomes, Magwood and colleagues (2020) conducted a mixed-method study aimed at identifying determinants of equitable implementation of homeless health guidelines from patient and practitioner perspectives. These authors contributed to the growing body of international evidence on effective interventions for populations experiencing homelessness through its focus on the health equity concerns of guideline implementation, which are often excluded from the dialogue about implementation outcomes. They found that understanding stakeholder and end-user perceptions of contextual and population-specific enablers and barriers (i.e., fragmented services, social stigma) to guideline implementation provided the opportunity to better understand and put forward more effective ways for HCPs to implement recommendations into practice. Incorporating these perceptions can make recommendations more appropriate for addressing vulnerable populations and support greater uptake and sustainability. Based on the results of their study, these authors suggested greater health care provider training to increase knowledge of patient needs and preferences. They identified several knowledge translation strategies that may improve implementation of guidelines for marginalized populations.

Equity and CPG Evaluation

Some articles included in this review discussed The Equity Lens (Dans et al., 2007; Mizen et al., 2012). This conceptualization of equity was developed through an initiative known as the Knowledge Plus Project, which aimed to address the needs and challenges of health professionals and other groups with a vested interest provide evidence-informed, cost-effective, and equitable health care. Dans et al.'s (2007) concept of equity incorporates Evans and Brown's (2003) definition of disadvantaged populations: groups vulnerable to inequity by virtue of place of residence, race, occupation, gender, religion, education, socioeconomic status, and social network and capital. This is critically important to equity considerations given that disadvantaged populations experience health disparities and challenges related to access more than those who are in a place of privilege.

Within The Equity Lens, CPG developers are theoretically oriented to consider not just effectiveness and efficiency but also equity and local appropriateness through five critiquing questions. As such, developers can determine the significance and relevance of tailored interventions and expected outcomes situated in a disadvantaged rather than privileged population. Users of CPGs can also use the five questions to evaluate how well a CPG addresses equity issues. The Equity Lens tool has been employed by other researchers interested in assessing the inclusion or omission of an equity focus in CPGs (Eslava-Schmalbach et al., 2017; Mizen et al., 2012; Prescott et al., 2020; Shi et al., 2014). For example, Mizen and colleagues, who utilized The Equity Lens to evaluate how well CPGs consider equity, revealed that of 36 CPGs they identified, 35 CPGs met the first criterion of The Equity Lens (*Do the public health recommendations in the guideline address a priority problem for disadvantaged populations?*). However, none of the 36 guidelines addressed the second, third, and fifth Equity Lens criteria (*Is there reason to anticipate different effects of interventions in disadvantaged and privileged populations?, Are the effects of the interventions valued differently by disadvantaged compared to privileged populations?,* and *Do plans for assessing the impact of the recommendations include disadvantaged populations?)* and only six CPGs addressed the fourth equity lens criterion (*Is specific attention given to minimizing barriers to implementation in disadvantaged populations?*). Mizen et al. (2012) concluded that most CPGs do not meet the published equity lens criteria and thus, may be contributing to the health inequities experienced by individuals with intellectual disabilities and other disadvantaged groups.

Equity and CPG Checklists and Tools

The literature presents checklists and other tools like frameworks that provide guidance to CPG development panels about how they may incorporate considerations of equity (Akl et al., 2017; Dans et al., 2007; Pottie et al., 2017; Schunemann et al., 2014, Welch et al., 2017ab). This includes the internationally regarded *Grading of Recommendations Assessment, Development, and Evaluation (GRADE)* framework which is employed by more than 90 organizations to transparently and systematically summarize the confidence and quality of evidence and the strength of recommendations via well-established methods to advance guideline methodology and improve the quality of guidelines (Murad, 2017; Welch et al., 2017ab). In 2013, in a 15-part series about GRADE in the *Journal of Clinical Epidemiology,* authors acknowledged the importance of health equity yet provided no detailed guidance on how CPG development panels should go about incorporating equity considerations (Welch 2017a). More recently, in 2017, the same journal presented another series on GRADE equity guidelines (Akl et al., 2017; Pottie et al., 2017; Welch et al., 2017ab). This series began by introducing the rationale and methodology for explicitly considering health equity in the GRADE methodology (Welch et al., 2017a). Akl and colleagues (2017) subsequently provided guidance to the developers of CPGs on how to consider health equity at key stages of the development process. In the same spirit, Welch and colleagues (2017ab) described a conceptual framework for how to consider health equity in the development process. Finally, Pottie and colleagues (2017) provided detailed guidance on how to incorporate health equity within the GRADE evidence-to-decision process (which is a structured and transparent approach to support policy-making, informed by the best available research evidence).

Another important checklist is the *Guidelines International Network (GIN)-McMaster Guideline Development Checklist* (Schunemann et al., 2014), which was developed to guide developers' appraisal of CPGs' credibility inclusive of equity issues. This comprehensive checklist outlines 18 topics with a total of 146 items across each stage of CPG development. Topic 14, for example, is focused on the wording (i.e., syntax and formulations) of recommendations. This includes asking developers to address contextual details such as the targeted population, types of interventions, patients' preferences, and available resources to optimize the implementation, feasibility, and equity of recommendations. Thereby, developers of CPGs are reminded to integrate equity considerations when summarizing and judging the quality of evidence prior to formulating recommendations.

Discussion

Numerous CPGs exist that provide recommendations for the diagnosis and management of chronic diseases with the aim to reduce variation in practice, improve patient outcomes, and reduce health service utilization through more effective and efficient care. CPGs provide recommendations that aim to standardize care with an implicit goal of achieving equity of care among diverse populations. Although the intentions of CPG developers are admirable and judicious, the lack of clarity within the reviewed literature on how CPG development panels should go about incorporating health equity within guidelines is problematic. As a result, developers of CPGs must be careful not to inadvertently exacerbate inequity when making recommendations. To assist developers in how they may think about incorporating equity within CPGs, health researchers have created various resources including checklists and other tools.

These various recognized checklists and other tools (e.g., GRADE, GRADE-FACE, GIN-McMaster Checklist, The Equity Lens) are comprehensive, yet they are lengthy and can be potentially overwhelming to CPG developers which may affect their usability. It may also be challenging for developers of CPGs to consider how they integrate these various tools and checklists into their work. Finally, The Equity Lens tasks users of CPGs with the responsibility of conducting their own assessment of how well any given CPG considers equity. This is based on the assumption that users of CPGs know about this tool and how they may use it in practice. In addition, it may be unclear to users, who identify inequities or lack of consideration of equity within recommendations what the next steps are to address these problems. This may further contribute to challenges in implementing these recommendations in any given context or circumstance. Despite the existence of these various tools and checklists that consider equity, the literature articulates concern that the effectiveness of CPG recommendations and interventions are lower among individuals of lower socio-economic status, with little investigation being undertaken of socio-economic related barriers experienced by populations CPGs intend to serve and thus their uptake by HCPs.

The literature discusses equity at various stages of the CPG process including development, implementation, and evaluation as well as the role of CPG development teams, inclusion of relevant vested interest groups, and users of them. Much of the reviewed literature attributes responsibility for considering equity within the development phase to all members involved in CPG development. Some of the literature discusses consideration of equity after the fact, where the onus for equity considerations is on HCPs who are the users that attempt to incorporate CPG recommendations into their practice. This approach requires users of CPGs to consider how well a CPG addresses equity within specific practice situations and it may be viewed as “too little too late” if it occurs in isolation rather than as part of a comprehensive approach to equity considerations at all stages of the CPG process.

As mentioned, scholars and CPG developers acknowledge the importance of health equity, yet no detailed guidance on how CPG development panels should go about incorporating equity considerations is provided. Further, results of this integrative review indicate that there is a lack of guidance on how to equitably and meaningfully engage multiple vested interest groups within CPG processes. Given this lack of clarity about how to engage vested interest groups and incorporate equity within guideline recommendations, it may be challenging to systematically incorporate equity considerations throughout the CPG processes, leading to haphazard and inconsistent ways in which CGPs incorporate or address equity considerations.

Although tools exist to assist users of CPGs to assess and evaluate how well CPGs address issues of equity, the definition of equity and how CPG development panels should incorporate and articulate it within guidelines before making implementation recommendations remain unclear. The results of this integrative review illustrate that it is problematic for equity to be included as an after-thought once CPG recommendations have already been made that may or may not have considered equity within their initial creation. If guidelines address equity from the outset of the development process and throughout all facets, leading to the articulation of recommendations, they would be better positioned to identify those at greater risk of various health challenges and the contextual variables that contribute to this risk. This, in turn, could draw attention to the systemic and situational barriers that may impede HCPs assessment, diagnosis, and management of patients affected by equity-related health challenges. This consideration could enhance the relevance of CPGs to mitigating these barriers to help reduce health inequities.

Conclusion

How equity is discussed within the literature relative to CPGs has implications for their uptake by and utility for HCPs in their goal of providing equitable health care. The ability of HCPs to implement CPGs effectively may be hindered without an appreciation and integration of equity considerations across the various phases of CPG conceptualization, development, implementation, and evaluation. This also affects the CPG's relevance and appropriateness to diverse geographic and socio-economic contexts with variable access to health human resources and services. Although one aim of CPGs is to promote equity through a standardized way of approaching care, they also risk contributing to health inequity. This may occur through recommendations that require health human resources or services that are not available or accessible to individuals living in northern, rural, and remote communities or recommendations that are formulated without explicit consideration of vulnerable populations. Conversely, the relevance and appropriateness of CPGs may be optimized by HCPs and decision-makers across diverse geographic and socio-economic contexts with variable access to health human resources and services when considerations of equity are clear within all aspects of the CPG continuum.

Clinical Resources

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Addendum to McMillan Boyles et al. (2022) Integrative Review

Since we conducted our integrative review, Shaver and colleagues (2023) conducted a rapid scoping review that synthesized current practices for integrating health equity into guideline development and their advantages and disadvantages. This research complements our work, specifically the integrative review included in Chapter 4 (McMillan Boyles et al., 2022). Many of the publications included in their review are also included and discussed in our review. Our review aligns with that of Shaver and colleagues as it illuminates the ways that those who develop CPGs may consider health equity. Interestingly, like our work, Shaver and colleagues discuss many equity approaches and considerations including the INCLEN equity lens by Dans and colleagues (2007), the WHO-INTEGRATE evidence to decision framework (Rehfuess et al., 2018), and various works related to GRADE (Akl et al., 2017; Eslava-Schmalbach et al., 2017; Pottie et al., 2017; Welch et al., 2017ab). Shaver et al. (2023) outline the benefits and drawbacks associated with integrating health equity into guideline development. Their review discussed how health equity might be incorporated into 4 phases of CPG guideline development including guideline planning, evidence review, guideline development, and dissemination. Their discussion complements my own discussion as outlined in Chapter 7 about CPG development practice considerations, particularly within a neoliberalist context, the disconnect between evidence and practice, and the need to critically reflect upon the evidence that informs the development of CPG recommendations.

Consistent with the findings of my research as discussed in Chapter 7, Shaver and colleagues (2023) identified equity-related guidance for most stages of guideline development. They also found that some gaps in the knowledge base remain particularly in relation to a lack of equity-related guidance to identify or report conflicts of interest for those who produce CPGs due to potential vulnerability from industry influence. My work, although complementary to Shaver et al.'s (2023) review, illuminates something unique, specifically the first critical juncture that occurs before the CPG process development process even begins. I argue that this crucial juncture presents both an opportunity and challenge to CPG developers to consider how they will appraise and incorporate a given body of evidence that may be lacking equity considerations. Like Shaver et al. (2023), my work highlights and acknowledges the complex concept of health equity and how it is considered in CPG development processes. Through our respective research, we both argue that the uptake of health equity promoting practices in CPGs is slow and that CPGs developers should consider the use of guideline checklists and tools to assist them to implement health equity considerations throughout guideline development. Shaver et al. (2023) further suggest that organizations involved in CPG development must carefully consider the advantages and disadvantages of best practices. Similar to my discussion about a socially just approach to CPGs, I appreciate and align with their position that CPG developers should be conscious of important systemic health and social inequities in our health care system when implementing practices. Finally, my work is also consistent with their position that any equity framework or plan should be developed in partnership with experts in the field of health equity, health system stakeholders, including individuals with lived experience of COPD, and community organizations. I would argue that this approach is a must and not optional.

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Chapter 5

Theoretical Underpinnings and Methods

Research Purpose and Questions

As noted in the Introduction, the purpose of this study was to conduct an interdisciplinary analysis of CPGs to understand how these guidelines represent health equity for the care of individuals living with COPD. The research question guiding this study was *how do CPGs for COPD explicitly or implicitly address health equity?*

Theoretical Underpinnings

Critical social theory (CST), as described by Canadian nursing scholars Annette Browne and colleagues (Browne, 2000; Browne et al., 2012), offers a constructive framework for understanding the dynamic social, historical, and political features of health care knowledge and practice. Browne and Fiske (2001) argued that health and illness are underpinned by:

> power differentials and social conflict in health care, the capacity of people to undertake health-related activities and negotiate health sectors from which they are marginalized, and professional control of mainstream health services and their distribution. (p. 127)

Developed from Habermas' concept of emancipatory knowledge, CST aims to illuminate and address macro-level structural and meso-level institutional barriers and inequities within dominant health care systems. It is an approach used by health care scholars “interested in social justice and critically oriented praxis” (Browne, 2000, p. 43). As Browne (2000) explained, a critically oriented praxis in nursing inquiry means “the ability to link knowledge and theory development to practice-relevant social and political actions aimed at improving health, health care, and social conditions” (p. 42). CST thus provides an epistemologically and ideologically appropriate framework for this study's purpose of investigating how CPGs (a form of standardized, mainstream health care knowledge) address the social justice principle of health equity in relation to the socio-political and structural realities of COPD health care practices in Northeastern Ontario.

Numerous scholars have used a CST approach across a range of health equity inquiries (Bowleg, 2017; Browne et al., 2012; Greenwood, de Leewuw & Lindsay, 2018; Pauly, Shahram, Dang, Marcellus & MacDonald, 2017; Pinto, Manson, Pauly, Thanos, Parks & Cox, 2012; Plamondon, Caxaj, Graham, & Bottorff, 2019; Reutter & Kushner, 2010). Some scholars have examined the concept of equity relative to the development process of CPGs and/or the implementation of them. For example, Shi and colleagues (2014) conducted a content analysis of methodological publications to qualitatively synthesize the methods used for incorporating equity in CPGs. Their findings revealed seven themes for CPG developers to consider when including equity in the CPGs development process and one for CPGs' users. In addition, Dans et al. (2007) provided the users of CPGs with criteria to help them address inequities in guidelines. Further, Eslava-Schmalbach and colleagues (2017) studied health equity in relation to the implementation of evidence-based guidelines. They suggested that guidelines could be used to target health inequities but also may unintentionally increase them. Finally, Mizen and colleagues (2012) employed the work of Dans et al. (2007) to explore how CPGs contribute to health inequities experienced by individuals living with intellectual disabilities. They concluded that there is a need to systematically incorporate methods to consider disadvantaged population groups into the CPG development process. My study builds on and extends this existing research by examining how CPGs for COPD explicitly and implicitly address health equity.

Methods

Design

My study design is interpretive descriptive (Thorne, 2008, 2016). Interpretive description, an established qualitative applied research approach, focuses on the generation and meaning of knowledge for practice (Bove, Lavesen, Jellington, Marsaa & Herling, 2018; Jensen, Vedelo, & Lomborg, 2013; Thorne, Kirkham & MacDonald-Emes, 1997; Thorne, 2008, 2016). It integrates the methodological considerations of Glaser and Strauss (1967), Lincoln and Guba (1985), and Miles and Huberman (1994) for the systematic examination of practice-specific inquiries. As such, health researchers can investigate the "what", "why", and "how" of various phenomena to generate an interpretive research product that is more than the sum of its parts.

Health researchers characterize interpretive description as a flexible rather than a categorical approach to yield knowledge to inform practice and policy development. Interpretive description has been used to study patient care issues such as: home-based psychoeducation, access to palliative care, communication, pain management for advanced COPD, and assisted personal body care (Bove, Jellington, Lavesen, Marsa & Herling, 2019; Bove et al., 2018; Bove, Midtgaard, Kaldan, Overgaard & Lomborg, 2017; Jensen et al., 2013; Rocker, Young, Donahue, Farquhar & Simpson, 2012; Thorne et al., 2010). Further, interpretive description has also been used to study varied health services issues in Ontario. Topical examples are access to multiple sclerosis services, cancer-related Internet information, and rehabilitation services for people with acquired brain injury (Haase, Gifford, Holtslander, & Thomas, 2018; Panday, 2019; Petrin & Finlayson, 2020). This approach has also been used by Ontario policy researchers to understand the impact of policy for systemic changes to address the needs of vulnerable groups, stroke survivors and their caregivers, and persons living with mental health and addiction issues (Bullock & Abelson, 2019; Garnett, 2019).

Setting and Sample

As the lead researcher of this study, resident and health care professional in Northeastern Ontario, I can attest to the relevance of this topic for the area. Empirically and experientially, it is known that equitable access to health service and health care professionals (HCPs) in rural and northern communities is a challenge that is not easily remedied (Bourke, Taylor, Humphreys & Wakerman, 2013; Kulig & Williams, 2012; Malatzky & Bourke, 2016; Malatzky & Bourke, 2018; MOHLTC, 2010; NELHIN, 2016). It is important to consider equity and access when thinking about citizens of rural and northern Ontario where access to service and providers is a challenge (MOHLTC, 2010; RNAO, 2009; 2015ab). As a researcher situated in Northeastern Ontario, it is through this lens that I collected, analyzed, and interpreted the data.

Purposive sampling allows for the identification and selection of relevant, information-rich cases to inform the object of inquiry (Patton, 2002; Thorne, 2016). A purposive sample of textual documents, namely publicly available international, national, and provincial English language CPGs for COPD, was the focus of analysis. CPGs for COPD are understood as those commissioned by internationally, nationally, and provincially recognized professional bodies for uptake by respiratory health professionals. I identified the guidelines included in this study through my professional expertise and knowledge of publicly available interdisciplinary CPGs for COPD, both current and under review, that are widely recognized and referred to in current practice by HCPs in Canada and Ontario. Given the context of this work, specific to Northeastern Ontario, I felt it prudent to include guidelines from the Canadian Thoracic Society (CTS) as the authority for lung-related CPGs in Canada and the Registered Nurses Association of Ontario (RNAO) CPGs about COPD. I also included the international 2022 GOLD guideline (2021) as a renowned authority in terms of clinical practice and COPD used worldwide by health care professionals and which are referred to and inform other guidelines. No limits were placed on the date of publication. Position statements were excluded as they are not necessarily subject to the same methodological processes associated with CPG development. As such, the guidelines subjected to analysis were those CPGs produced by the CTS, RNAO, and Global Initiative on Obstructive Lung Disease (GOLD) Strategy.

The CPG search resulted in ten CPGs that met the inclusion criteria. The sample for analysis included one international, seven Canadian, and two provincial CPGs. The status of the guidelines revealed that three of the CPGs were current, five were under review, and for two of the CPGs, the status was not stated. The authoring organizations, titles, and dates of publication are listed in Table 5-1.

Table 5-1

Included Guidelines (n=10)

Guideline Title, Publication Year, Status
International
Global Initiative for Obstructive Lung Disease (GOLD) 2022 Report (2021) —Current
National
Canadian Thoracic Society (CTS) Guideline: Pharmacotherapy in patients with COPD (2019) —Current
CHEST-CTS Guideline: Prevention of Acute Exacerbation of COPD (2015) —Current
CTS Guideline: Alpha-1 Antitrypsin Deficiency (2012) —Under Review
CTS Guideline: Managing Dyspnea in Patients with Advanced COPD (2011) —Under Review
CTS Guideline: Optimizing Pulmonary Rehabilitation in COPD (2010) —Under Review
CTS (2008): Recommendations for Management of COPD-Highlights for Primary Care—Under Review
CTS (2007): Recommendations for Management of COPD-2007 update—Under Review

Provincial

Registered Nurses Association of Ontario (RNAO) Best Practice Guideline: Nursing Care of Dyspnea Guideline Supplement (2010) —Not Stated

Registered Nurses Association of Ontario (RNAO) Best Practice Guideline: Nursing Care of Dyspnea (2005) —Not Stated

Although not subject to analysis, I also explored relevant supporting documents that I deemed relevant to the contextualization of the CPGs that were subject to review. These supporting materials included documents such as the CTS guideline development process, RNAO guideline development process, CTS Patient/Public Involvement Process, and grading of evidence documents. These texts provided information about the contexts of the developed guidelines and possible perspectives about their health equity underpinnings. These documents developed my understanding of the health and social arena of a published guideline, and as mentioned, were not subject to data analysis.

Data Collection and Data Analysis

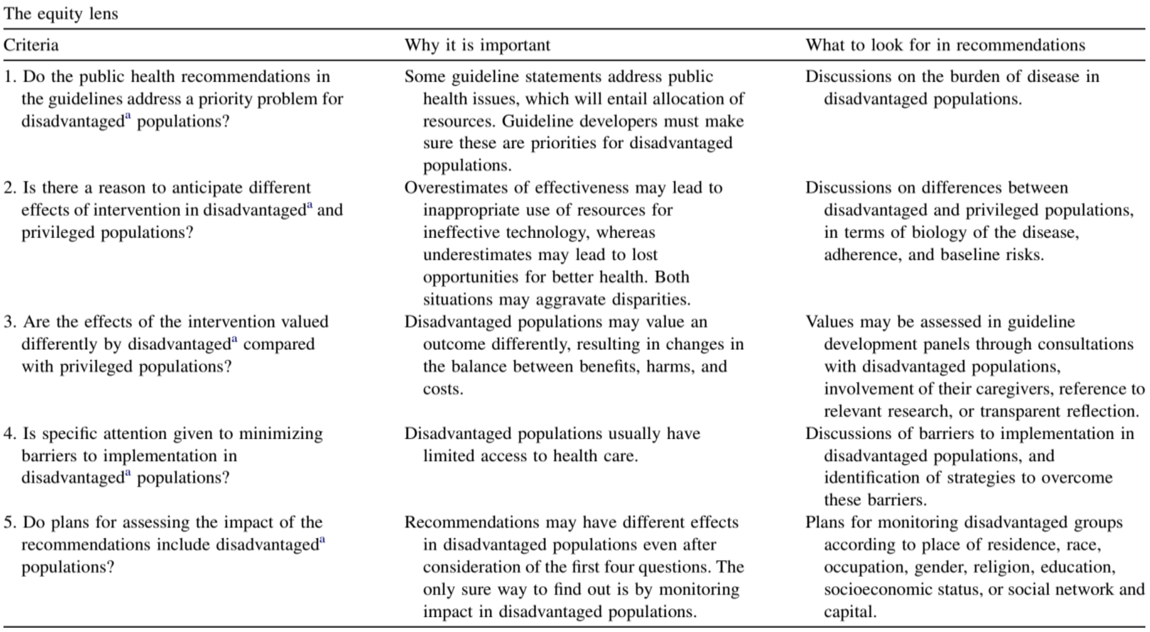
In keeping with the interpretive descriptive design, data collection and analysis were simultaneously performed. Data collection and analysis are considered iterative rather than linear. These processes interact to guide the inquiry towards new possibilities for consideration (Thorne, 2016; Thorne, Kirkham & O'Flynn-Magee, 2004). The study data subjected to analysis consisted of written text from publicly available international, national, and provincial COPD CPGs that are widely recognized and referred to in current practice by HCPs in Ontario, Canada.

For my study, data analysis was conducted using an analysis framework (Table 3) that I created as informed by Mizen et al. (2012), The Equity Lens (Dans et al., 2007), and the Appraisal of Guidelines for Research & Evaluation II (AGREE II, 2017) Instrument, Domain 5-Applicability. My analysis framework consisted of three sections: 1) Population relevance, 2) Guideline content, and 3) Guideline development and application processes. Section 1 of the analysis framework examined equity considerations about population relevance. Each CPG was analyzed relative to three key questions that were posed in this section including, *what COPD population does the guideline address? are any population groups excluded from the guideline? and are groups at high risk of COPD identified?* This section of the framework was informed by the work of Mizen et al. (2012) who conducted a study that utilized an equity lens to examine how well CPGs addressed inequities experienced by individuals with intellectual disabilities. I included Section 1 dealing specifically with relevance to the population because such questions provided context to understanding the target population of each CPG. It also provided insight into groups that each CPG excluded. These questions extended beyond that of the International Clinical Epidemiology Network (INCLEN) Equity Lens as outlined in Section 2 of the analysis framework and added context in the attempt to examine how CPGs consider equity.

Section 2 of the analysis framework also draws upon the work of Mizen et al. (2012) and the International Clinical Epidemiology Network (INCLEN) Equity Lens (Dans et al., 2007). This section directed me to focus on the specific content of each guideline and consisted of questions that assessed multiple elements of how CPGs addressed or did not address health equity considerations. It also included a question that I added about any recommendations that addressed or made problematic assumptions relative to health service organization (i.e., structure of health service, access to health service). The development of Dans and colleagues' (2007) Equity Lens (Figure 5-1) was undertaken through funding an initiative aimed at addressing the needs and challenges of health professionals and other vested interest groups to provide evidence-informed, cost-effective, and equitable health care. The Equity Lens is a proposed lens with the aim to improve the process of CPG development by formulating strategies to consider not just effectiveness and efficiency but also equity and local appropriateness. It is guided by the notion that guidelines can influence practice and can either reduce or exacerbate inequities. Its purpose is to assist the users of CPGs assess and evaluate how well CPGs address issues of equity.The Equity Lens outlines the rationale for the included elements and indicates what to look for in recommendations when attempting to assess and evaluate the equity implications of a guideline.

Figure 5-1

The Equity Lens (Dans et al., 2007)



The equity lens

Criteria	Why it is important	What to look for in recommendations
1. Do the public health recommendations in the guidelines address a priority problem for disadvantaged[a] populations?	Some guideline statements address public health issues, which will entail allocation of resources. Guideline developers must make sure these are priorities for disadvantaged populations.	Discussions on the burden of disease in disadvantaged populations.
2. Is there a reason to anticipate different effects of intervention in disadvantaged[a] and privileged populations?	Overestimates of effectiveness may lead to inappropriate use of resources for ineffective technology, whereas underestimates may lead to lost opportunities for better health. Both situations may aggravate disparities.	Discussions on differences between disadvantaged and privileged populations, in terms of biology of the disease, adherence, and baseline risks.
3. Are the effects of the intervention valued differently by disadvantaged[a] compared with privileged populations?	Disadvantaged populations may value an outcome differently, resulting in changes in the balance between benefits, harms, and costs.	Values may be assessed in guideline development panels through consultations with disadvantaged populations, involvement of their caregivers, reference to relevant research, or transparent reflection.
4. Is specific attention given to minimizing barriers to implementation in disadvantaged[a] populations?	Disadvantaged populations usually have limited access to health care.	Discussions of barriers to implementation in disadvantaged populations, and identification of strategies to overcome these barriers.
5. Do plans for assessing the impact of the recommendations include disadvantaged[a] populations?	Recommendations may have different effects in disadvantaged populations even after consideration of the first four questions. The only sure way to find out is by monitoring impact in disadvantaged populations.	Plans for monitoring disadvantaged groups according to place of residence, race, occupation, gender, religion, education, socioeconomic status, or social network and capital.

[a] refers to various groups vulnerable to inequity by virtue of place of residence, race, occupation, gender, religion, education, socioeconomic status, and social network and capital.

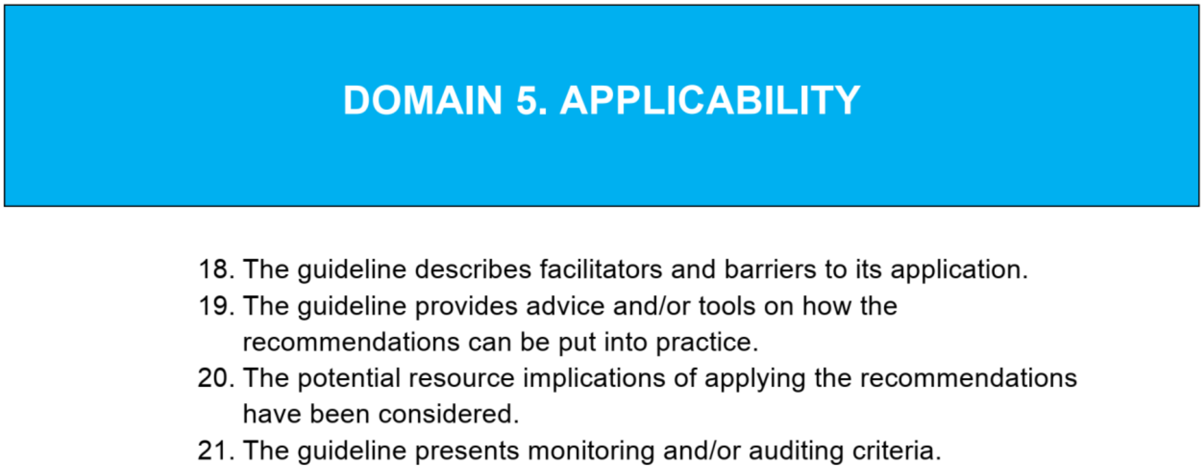
The Equity Lens has been employed by other researchers interested in assessing the inclusion or omission of an equity focus in CPGs (Eslava-Schmalbach et al., 2017; Mizen et al., 2012; Prescott et al., 2020; Shi et al., 2014). It draws upon the work of Evans and Brown (2003) to define disadvantaged populations as groups vulnerable to inequity by virtue of place of residence, race, occupation, gender, religion, education, socioeconomic status, and social network and capital. As such, for the purpose of this study, I adopted this definition of disadvantaged populations and have incorporated all five questions of The Equity Lens as elements of the analysis process to examine how CPGs may implicitly or explicitly discuss health equity and how they may inadvertently exacerbate health inequities in the Northeastern Ontario COPD context. In appreciation of the limitations associated with the term "disadvantaged populations," I will refer to "disadvantaged populations" as "systemically and structurally disadvantaged populations" (Bryant & Raphael, 2018; Raphael & Bryant, 2015; Raphael, 2015). The Equity Lens also refers to "privileged populations", which for the purpose of this work is understood to be those that do not experience systemic or structural inequity.

Section 3 of the framework examined the guideline development and application process of each included CPG. Like Sections 1 and 2, it also draws upon the work of Mizen and colleagues (2012). I included this as an aspect of my analysis framework because it builds off Sections 1 and 2. In addition to The Equity Lens, Mizen et al. (2012) "also looked in more detail at the information provided on the guideline development process to identify potential means to address health inequities experienced by individuals with intellectual disabilities and other disadvantaged groups" (p. 2). Section 3 of my analysis framework also draws upon Domain 5 of the Appraisal of Guidelines for Research & Evaluation II Instrument (AGREE II, 2017). The AGREE II Instrument was developed by an international collaborative panel of clinicians, researchers, and decision-makers with the purpose to measure the quality of guidelines based on the methods used to develop, construct, and represent recommendations. The 23-item tool includes six domains: 1) scope and purpose, 2) stakeholder involvement, 3) rigour of development, 4) clarity of presentation, 5) applicability, and 6) editorial independence. Makarski and Brouwers (2014) identified the AGREE II Instrument as a resource in both the development and evaluation of CPGs. It has been used by multiple health organizations such as Cancer Care

Ontario’s Program in Evidence-based Care, the National Institute for Health and Care Excellence in the United Kingdom, the World Health Organization, and the National Academy of Clinical Biochemistry Laboratory Medicine in the United States. For my analysis framework in this study, I included items 18–21 in Domain 5-Applicability of the AGREE II instrument (Figure 5-2) in Section 3 because applicability refers to the likely barriers and facilitators to implementation, strategies to improve uptake, and resource considerations associated with guideline uptake. Including applicability in the analysis process was relevant as it provided an opportunity to evaluate each CPG specifically related to this domain and it supports the purpose of the study in terms of understanding how CPGs do or do not address equity.

Figure 5-2

AGREE II Instrument Domain 5: Applicability (AGREE II, 2017)



DOMAIN 5. APPLICABILITY

18. The guideline describes facilitators and barriers to its application.
19. The guideline provides advice and/or tools on how the recommendations can be put into practice.
20. The potential resource implications of applying the recommendations have been considered.
21. The guideline presents monitoring and/or auditing criteria.

I included this domain given that if recommendations within CPGs are assessed to be challenging relative to applicability, this is also related to how CPGs may also contribute to inequity. Table 5-2 outlines the framework that guided the analysis.

Table 5-2

Analysis Framework

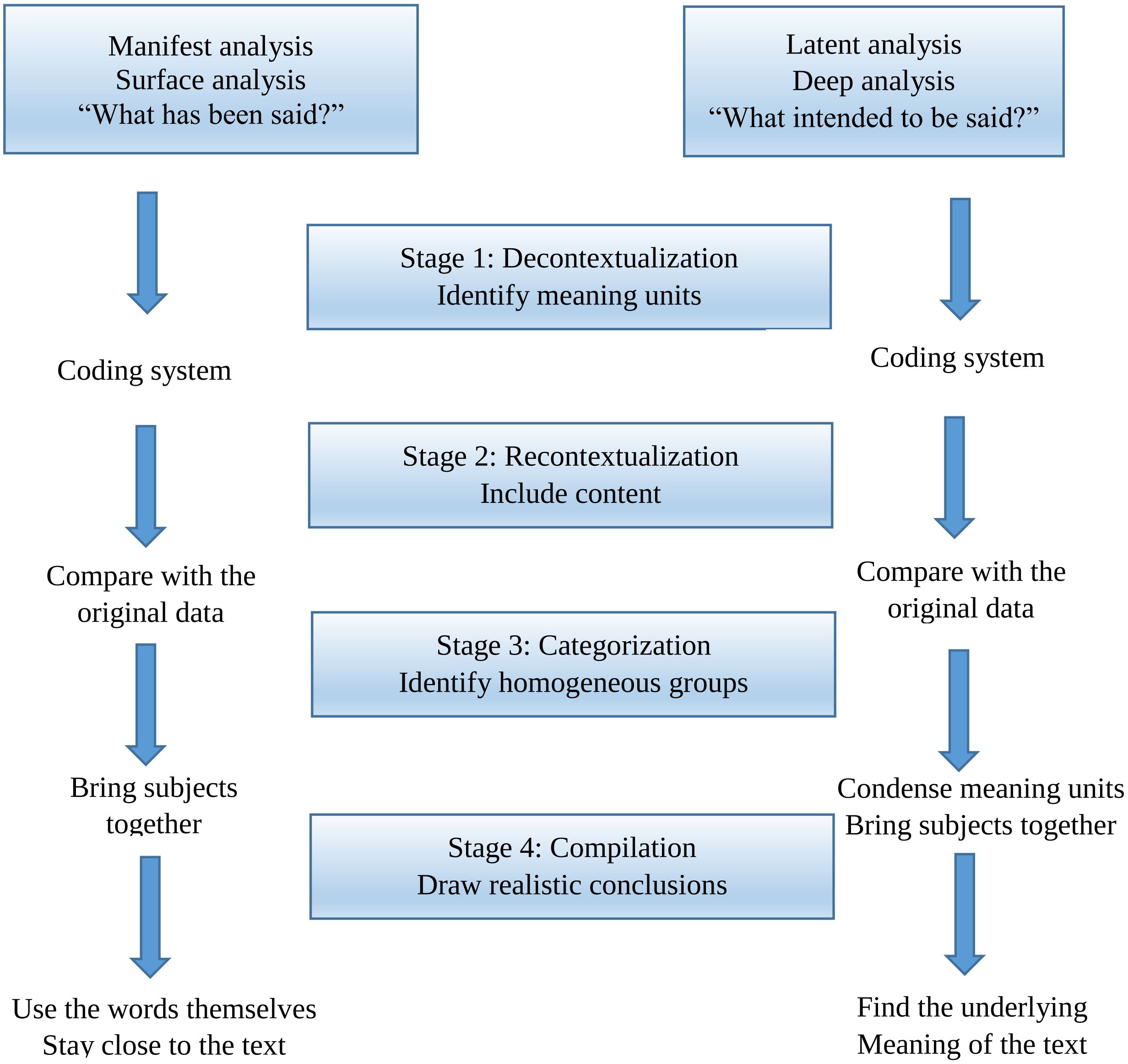
CPG __________________ Date of Publication_____________ Status____________
Section 1: Population Relevance
a. What COPD population does the guideline address?
b. Are any population groups excluded from the guideline?
c. Are groups at high risk of COPD identified?
Section 2: Guideline Content
a. Do the recommendations in the guideline address a priority problem for disadvantaged populations? (criterion one)
b. Are there recommendations within the CPG that address and/or make assumptions relative to health service organization (i.e., structure of health service, access to health service)? If so, what are they?
c. Is there a reason to anticipate different effects of interventions in disadvantaged and privileged populations? (criterion two)
d. Based on this, is there a reason for disadvantaged populations as compared with privileged populations to value the effects of the interventions differently? (criterion three)
e. Is specific attention given to minimizing barriers to implementation in disadvantaged populations? (criterion four)
f. Are there plans for assessing the impact of the recommendations on disadvantaged populations? (criterion five)
Section 3: Guideline Development and Application Process
a. Is an expert in COPD included in the guideline development group?
b. Is an expert in equity included in the guideline development group?
c. Is there evidence that the design of the literature search strategy could identify studies relevant to COPD and disadvantaged populations?
d. Is there evidence of consultation with people living with COPD and/or their carers representative of diverse contexts and regions in the development and implementation of the guideline? (adapted from criterion three)
e. Does the guideline describe facilitators and barriers to its application? If so, what are they? (Domain 5, Item 18)
f. Does the guideline provide advice and/or tools on how the recommendations can be put into practice? If so, what are they? (Domain 5, Item 19)
g. Does the guideline consider potential resource implications of applying the recommendations? If so, what are they? (Domain 5, Item 20)
h. Does the guideline present monitoring and/or auditing criteria? (Domain 5, Item 21)

Content Analysis. The analysis framework as described above guided my extraction of units of analysis from the sample of CPGs. The extracted data then underwent qualitative content analysis, a systematic approach to analyze written text regardless of format. Coding, classifying, and pattern identifying construct an interpretation of data from which to draw logical conclusions about the study phenomenon (Elo & Kyngas, 2008; Elo, Kaariainen et al., 2014; Hsieh & Shannon, 2005). The content analysis approach used in this study is described by Bengtsson (2016) and extends beyond an identification of similar and different texts to include 'what the text talks about' (Graneheim & Lundman, 2004). Analyzing the content of the text reveals its inherent assumptions and beliefs. This is accomplished in the following four iterative stages: decontextualization, recontextualization, categorization, and compilation.

The initial stage of decontextualization involved becoming familiar with data through critical reading and re-reading. Each CPG was read and re-read in its entirety prior to breaking it into smaller units of analysis. Using the elements for analysis as outlined in Table 3, I then identified specific sections of each CPG as the units of analysis. This decontextualizing work assisted with the labelling and listing of preliminary codes within each unit of analysis. The second stage, recontextualization, necessitated reviewing the match between the extracted data and assigned code label. As I explored the analysis process further, some of the extracted data and labels underwent revision for congruency and relevance to the study purpose and question. In the categorization stage, similar codes were organized, combined, and condensed for the purpose of creating categories. The categories were also assigned a label representative of its composite of code labels. Finally, the compilation stage required manifest analysis, whereby I described what the CPGs actually say by staying close to the text, using the words themselves, and describing the visible and obvious in the text. Then, I undertook latent content analysis, an extension to an interpretive level, in which I sought underlying meaning relative to the research purpose, to yield a representation of data that includes an interpretation of the meaning of the descriptive categories. Figure 5-3 represents an adaptation of Bengtsson's (2016) method of content analysis that aligns with the goals of the study design.

Figure 5-3

Overview of Process of Qualitative Content Analysis Adapted from Bengtsson (2016)



Data Management

Individual electronic files for each CPG and its associated units of analysis were kept. Extracted data from the sample of guidelines are accessible only by me on a password-protected laptop computer used specifically for this study. All electronic materials are housed in the secure Laurentian University (LU) Google Drive. I stored all hard copies of data and study-related materials in a locked and secured cabinet in my home office. Only I have access to the locked cabinet in the office.

Ethical Considerations

In accordance with Article 5 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2, 2018), privacy, confidentiality, security, and identifiable information are not directly applicable to my study. The type of information identified, collected, and analyzed are publicly available documents. No types of information fulfill the TCPS2 criteria with regards to person-specific identifying information. With this in mind, my study received ethical approval from the Laurentian University Research Ethics Board (LUREB) via a delegated ethical review (Appendix A).

A relevant ethical concern, however, is representation of the work of published authors. Practical strategies to respectfully showcase and integrate scrutinized, documented ideas include acknowledging the historical context of the original document and the critique and clarification of text rather than focusing on persons (Thorne, 2016). Within qualitative research, scholars discuss the concept of representation (Sandelowski, 2006; Thorne, 1998, 2016). Representation is a component of research validity and refers to how subjects are represented in the inquiry. As such, there is the potential for large differences to exist between reality and representation (Sandelowski, 2006; Thorne, 2016).

In my study, the subjects are the CPGs and consideration was given to how they are represented. As described in the data analysis section, I first read the entire CPG line-by-line as the unit of analysis. Once I had a sense of the entire document, the unit of analysis of the CPGs that would be subject to analysis included sections of guidelines that pertain to elements of the analysis process (Table 5-2). For my study, when I conducted the analysis and interpretation of the findings, it was my professional obligation as a researcher to ensure that I acknowledged and appreciated the historical context of each CPG and focused the discussion on the CPG text itself rather than on the authors responsible for their development.

Rigour

The rigour of an interpretive description study addresses the accuracy and representativeness of the data from a defined sample to guide practice decisions (Thorne et al., 1997; Thorne, 2016). To this end, I attended to four interactive rigour qualities: 1) epistemological integrity, 2) representative credibility, 3) analytic logic, and 4) interpretive authority. 1) Epistemological integrity involves a logical and defensible line of reasoning as demonstrated through the researcher's implementation of each step of the research process, beginning from conception of the inquiry to knowledge dissemination. My research demonstrated epistemological integrity by providing a theoretical or empirical rationale for each step of the research process. 2) Representative credibility refers to a connection between the phenomenon of inquiry and the study sample (Thorne, 2016; Thorne et al., 2004). My study addresses representative credibility as the phenomenon of interest (how health equity is addressed in COPD CPGs) is consistent with the sample of COPD CPGs. 3) Analytic logic refers to the enactment of thoughtful, purposeful, and planned procedures to reveal the processes involved in transforming data into findings (Sandelowski & Barrosso, 2002; Thorne et al., 2004).

In my study, I demonstrated analytic logic through the stages of content analysis undertaken. The planned, purposeful, and explicit analysis procedures permitted me to transform the data into the construction of interpretive findings. 4) Interpretive authority necessitated that I, as the researcher, acknowledged my orientation, bias, or experiences so that the perspective of the researcher is known to the knowledge user (Thorne, 2016). My study addressed interpretive authority through my explicit articulation of my orientation and any bias I may have in relation to the work. My interpretive authority continually evolved as I engaged in the study activities.

The product of this study is a systematically developed interpretive description of how health equity is addressed by COPD CPGs. I am accountable for producing a trustworthy interpretation based on relevant knowledge and evidence, research methods, and analytical procedures. Therefore, I recognize my professional responsibility to be knowledgeable and transparent about the application of procedures that extend beyond data collecting and reporting results.

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Chapter 6

Findings

I independently analyzed the ten guidelines in my sample using the analysis framework as outlined in Chapter 5 Table 5-2. Each of the guidelines addressed various problems related to COPD, including the diagnosis and management of COPD, pharmacotherapy, pulmonary rehabilitation, the management of dyspnea, and the prevention of acute exacerbation of COPD (AECOPD). Each of the guidelines and their subsequent recommendations involved various adult COPD populations in terms of the stages of the disease, including stable, moderate, severe, very severe, or advanced COPD. Through the analysis process, I systematically reviewed each guideline based on each of the three sections as outlined in the analysis framework that I developed for this study. The findings are organized and presented according to each of the three sections of the analysis framework. Each section includes illustrative excerpts of compelling evidence from the main text of the various CPGs that demonstrate how the sample of CPGs addresses or does not address equity.

Section 1: Population Relevance

COPD Population CPG Addresses

The analyzed CPGs indicated the COPD population that each guideline addressed. As mentioned, some guidelines addressed individuals with stable COPD while others addressed issues associated with more severe or advanced COPD. For example, “The aim of the GOLD Report is to provide a non-biased review of the current evidence for the assessment, diagnosis, and treatment of *patients with COPD*” (GOLD, 2021, p. 1), “This update applies to *all individuals with stable COPD*” (CTS, 2019, p. 3), and “The present clinical practice guideline applies to *adult patients diagnosed with COPD*" (CTS, 2010, p. 160). The following excerpt illustrates guidelines for patients with advanced COPD:

> The present clinical practice guideline provides direction on managing dyspnea in *patients with advanced COPD.* For the purposes of the present guideline, *patients with advanced COPD are defined as those with COPD associated with either a forced expiratory volume in 1 s of lower than 50% predicted, or a medical research council dyspnea score of 4 to 5 in the setting of progressive disease associated with a limited prognosis.* (CTS, 2011, p. 2)

Interestingly, the next excerpt does not identify people explicitly, only the condition: "This guideline…will address the nursing assessment and management of stable, unstable and acute dyspnea associated with COPD" (RNAO, 2005, p. 14). Such a statement refers solely to the disease condition and does not acknowledge the human aspect associated with the disease and that such a guideline is for the management of stable, unstable, and acute dyspnea in individuals living with COPD.

Excluded Populations

Many of the guidelines acknowledged that a substantive group of individuals who remain undiagnosed exist, yet experience symptoms associated with the disease. For example, "Recent robust population data have confirmed that many individuals with COPD remain undiagnosed, but symptomatic, with an increased risk of exacerbations, pneumonia and death. However, *undiagnosed COPD*, but asymptomatic, can also have exacerbations and pneumonia" (CTS, 2019, p. 2) and "The Canadian Lung Association (2008) suggests that COPD affects an estimated 1.5 million Canadians. They further suggest that 1.6 million Canadians 40 years or older may currently have *undiagnosed COPD*; thus, in excess of three million Canadians may be living with COPD" (RNAO, 2010, p. 1). However, it can be understood that those who remain undiagnosed may be due to lack of access to primary care or spirometry testing and thus are excluded from guidelines that guide care for individuals with COPD.

Three guidelines specifically identified groups that were excluded from these guidelines. The following example clearly identifies that individuals living with various illnesses are excluded from the guideline: "The present clinical practice guideline *does not address liver disease, necrotizing panniculitis, antineutrophil-cytoplasmic-positive vasculitis or mass screening/ targeted testing of neonates.*" (CTS, 2012, p. 110). It is noteworthy to state that all but one guideline excluded systemically and structurally disadvantaged populations in the sense that they were not explicitly designated.

Identification of High Risk Groups of COPD

Some CPGs explicitly identified groups at high risk of COPD. For example, some guidelines clearly stated that smoking is a major risk factor for COPD: "Chronic obstructive pulmonary disease (COPD) is a respiratory disorder largely caused by smoking…" (CTS, 2008, p. 2A). Although COPD is primarily caused by smoking, it is encouraging to see that some guidelines also indicated other causes of illness that are beyond individual attribution of blame like smoking. Naming other causes of illness, in addition to smoking, implicitly addresses equity through social determinants of health by focusing on factors beyond individual control: "Often, the prevalence of COPD is directly related to the prevalence of tobacco smoking, *although in many countries, outdoor, occupational, and indoor air pollution…are major COPD risk factors"* (GOLD, 2021, p. 6) and:

> In Canada, cigarette smoke is the main inflammatory trigger in COPD. COPD develops in some smokers but not others due to a complex interaction between the susceptible host

> and its changing environment. Some host factors have been well studied, including alpha1-antitrypsin (AAT) deficiency, a history of childhood viral infections and bronchial hyper-responsiveness. *Environmental risk factors other than exposure to tobacco smoke include occupational exposures and air pollution.* (CTS, 2007, p. 6B)

Other guidelines implicitly identified groups at risk for COPD through the articulation of the incidence, morbidity, and mortality of men and women within certain age ranges: “There appears to be a continuous rise in the incidence and morbidity of COPD in women between the ages of 55 and 74.…At present, nationally, COPD affects 3.9 per cent of men and 4.8 per cent of women…” (RNAO, 2010, p. 1), and:

> Since the 1960s there has been an increase in morbidity in women with COPD. There has been an increase in mortality especially in men…In 1999 in Canada, COPD was the fourth leading cause of death in men (5,544 deaths) and the fifth in women (3,974 deaths)….From 1988 to 1999, although the rates among men decreased by 7%, mortality rates in women increased by 53% and are still increasing. Mortality rates also increase rapidly for all individuals over 75 years of age. The change in age structure of the population with an increasing number of people aged over 65 years will result in continued increases in mortality rates for COPD (particularly in women) in the foreseeable future. Furthermore, the estimated mortality rate is a significant underestimation…. (RNAO, 2005, p. 20)

It is important to note that the GOLD (2021) international guideline extensively discusses those at high risk for COPD and discusses the concept of equity and social determinants of health, illustrated by the following excerpt:

> *Poverty* is consistently associated with airflow obstruction and lower socioeconomic status is associated with an increased risk of developing COPD. It is not clear, however,

> whether this pattern reflects exposure to indoor and outdoor air pollutants, crowding, poor nutrition, infections, or other factors related to low socioeconomic status. (GOLD, 2021, p. 12)

Based on the review of Section 1 of the analysis framework, Table 6-1 presents a visual compilation of the analysis of how well each guideline attended to equity considerations specific to population relevance. Blue indicates that the guideline clearly addresses a specific element pertaining to equity consideration, while green indicates it is somewhat addressed, yellow indicates it is poorly addressed, and red indicates a particular equity consideration is not addressed at all. The findings specific to Section 1 indicate that six of the ten analyzed guidelines clearly specify the COPD population that the guideline addresses; for example, individuals with stable COPD, individuals with alpha 1-antitrysin deficiency, and patients with advanced COPD. Four of the ten guidelines somewhat address the COPD population given that they are vague as they state, for example, that the population the guideline addresses is simply individuals with COPD. Six of the ten guidelines either clearly or somewhat identify explicitly the populations that the guidelines do not address or that are excluded. It is important to note that I found that all the guidelines did not comprehensively address systemically and structurally disadvantaged populations throughout the entirety of the guidelines. Finally, only four of the analyzed CPGs clearly identify those that are at high risk of developing COPD. The four guidelines that somewhat address or poorly address this group make implicit statements where I was then able to deduce that they were referring to those at risk. Two of the ten guidelines do not identify those at high risk.

Table 6-1

Compilation of Included CPGs in relation to Section 1 of Analysis Framework-Population Relevance

	CPGs and Status n=10									
	GOLD (2021)	**CTS (2019)**	**CHEST/ CTS (2015)**	**CTS (2012)**	**CTS (2011)**	**CTS (2010)**	**CTS (2008)**	**CTS (2007)**	**RNAO (2010)**	**RNAO (2005)**
	Current	**Current**	**Current**	**Under Review**	**Under Review**	**Under Review**	**Under Review**	**Under Review**	**Not Stated**	**Not Stated**
1. What COPD population does the guideline address?	🟩	🟦	🟩	🟦	🟦	🟦	🟩	🟩	🟦	🟦
2. Are any population groups excluded from the guideline?	🟥	🟩	🟥	🟦	🟥	🟥	🟩	🟩	🟩	🟩
3. Are groups at high risk for COPD identified?	🟦	🟦				🟨		🟦	🟨	🟨

How well the guideline attends to equity considerations as outlined in Section 1 of the Analysis Framework
Legend:
Blue: Clearly addresses Green: Somewhat addresses Yellow: Poorly addresses Red: Does not address at all

Section 2: Guideline Content

Equity Lens Criterion One: Do the CPG Recommendations Address a Priority Problem for Disadvantaged Populations?

Although each CPG addresses a priority problem for individuals living with COPD, only one of the CPGs addresses a priority problem for systemically and structurally disadvantaged populations. The international GOLD 2022 report (GOLD, 2021), as indicated in the excerpt above, foregrounds the problem for systemically and structurally disadvantaged populations (i.e., those living in poverty). Most guidelines do include a discussion of the burden of disease, however, not specifically in relation to systemically and structurally disadvantaged populations. In reality, many individuals living with COPD may be systemically and structurally disadvantaged. However, based on the definition of "disadvantaged populations" utilized in this work, having COPD does not render one disadvantaged. The included guidelines address specific facets of the management of COPD, such as prevention of acute exacerbations, pulmonary rehabilitation, and managing dyspnea, as indicated in the following excerpts provided below from included CPGs. While these are indeed priority problems for individuals living with COPD, generally speaking, these CPGs do not address priority problems specifically for systemically and structurally disadvantaged populations. For example, "There remain many questions, clinical care gaps and treatment barriers regarding the optimal management of dyspnea in patients with advanced COPD and, specifically, whether various therapeutic options are effective in this setting" (CTS, 2011, p. 2) and:

> Patients with advanced COPD almost universally experience significant dyspnea in the final year of life…. Moreover, COPD patients at the end of life experience more dyspnea than lung cancer patients…and, yet, are often prescribed less medication and have less access to

> comprehensive care than patients dying from lung cancer.…The optimal management of dyspnea in patients with advanced COPD is, however, an often neglected aspect in the continuum of care…(CTS, 2011, p. 1)

Recommendations that Make Problematic Assumptions

The analysis of included CPGs involved a careful examination of whether there were recommendations within a CPG that made problematic assumptions relative to health service organization (i.e., structure of health service, availability of and access to health service). All CPGs had statements and recommendations within them that made problematic assumptions. The assumptions identified through the analysis process were grouped according to topic area, including but not limited to health services and health care professionals (i.e., access to HCP, screening), pulmonary rehabilitation, pharmacotherapy, and vaccinations. One major premise associated with all recommendations is that they are intended for the care of individuals living with COPD. It is acknowledged that there are potentially a million people or more who are living with COPD yet remain undiagnosed. Further, it may be difficult to detect or determine, particularly amongst systemically and structurally disadvantaged populations, if there is no access or inconsistent access to HCPs or services. As such, there is a problematic assumption that individuals with suspected or confirmed COPD have access to primary care providers, screening, and a host of resources as illustrated in the following findings, and as a result, systemically and structurally disadvantaged populations may be slipping through the cracks.

Integrated, Optimal, and Comprehensive Care. Findings revealed that included CPGs discuss recommendations as part of an optimal and comprehensive approach to care of individuals with COPD. Language such as “optimal,” “comprehensive,” and “effective” is used throughout CPGs and within their recommendations. Again, without acknowledgement or discussion of equity considerations for systemically and structurally disadvantaged populations, this suggests that the inability to implement recommendations leaves those living with COPD with suboptimal, less effective, and perhaps incomplete care. Statements such as those outlined below imply that not following such recommendations results in suboptimal care without actually addressing equity issues when developing recommendations. Inherent then within this is that despite recommendations, if they cannot be implemented because of a lack of appreciation of complex factors affecting systemically and structurally disadvantaged populations, it is at this point when CPG recommendations can exacerbate and perpetuate inequity.

In the context of individuals living with COPD who are disadvantaged, they thus may continue to experience acute exacerbation of illness, poor symptom control, and require expensive health services. For example, "In clinical practice, *an integrated, comprehensive approach* to care should include: a diagnosis of COPD confirmed with spirometry; clinical evaluation of the patient; and comprehensive management, which includes nonpharmacological and pharmacological interventions" (CTS. 2019, p. 2), and "This section discusses the *optimal* use of inhaled and oral pharmacologic maintenance therapies shown to improve shortness of breath, exercise tolerance, physical activity and health status in stable COPD patients" (CTS, 2019, p. 6).

Health Services and Health Care Professionals. The following illustrative excerpts from the main text of CPGs demonstrate problematic assumptions underlying the recommendations of CPGs related to access to health services and health care professionals that can provide regular and serial level service. These excerpts make problematic assumptions about systemically and structurally disadvantaged populations, particularly systemically and structurally disadvantaged populations and individuals with COPD who live in rural and northern communities. These recommendations assume that individuals with COPD have access to diagnostic testing, including spirometry, primary care providers and allied health professionals with expertise to conduct comprehensive assessments and provide care, specialists and specialized services, palliative care services, and assistive devices such as walking devices, oxygen therapy, and non-invasive ventilation in the form of non-invasive positive pressure ventilation (NPPV) at home. For example, "It is important to remind physicians that spirometry is essential for the diagnosis of COPD.…However, more than a single postbronchodilator spirometric assessment may be necessary for diagnosing COPD for patients with mild airway obstruction at baseline…" (CTS, 2019, p. 2) and "Management of AECOPD requires careful history, physical examination and limited laboratory investigations (i.e., chest radiograph in those presenting to emergency department; arterial blood gases in patients with low oxygen levels on oximetry)" (CTS, 2008, p. 6A). Other illustrative examples are listed below:

> Spirometry is the most reproducible and objective measurement of airflow limitation. It is a noninvasive and readily available test.…Good quality spirometric measurement is possible in any healthcare setting and all healthcare workers who care for COPD patients should have access to spirometry. (GOLD, 2021, p. 26)
>
> Targeted testing [spirometry, more extensive pulmonary function tests, cardiopulmonary testing, blood tests, radiology, echocardiography, sputum cytology] of symptomatic individuals at risk for the development of COPD combined with intensive smoking cessation counselling can slow the progression of disease (Level of Evidence=1A). (CTS, 2007, p. 9B)

Some recommendations outline expectations of the HCP to both regularly and serially assess the patient experience of dyspnea. For example, "Furthermore, for these recommendations to be applied in the management of dyspnea in patients with COPD, clinicians and clinical documentation must *regularly* and *serially assess* the patient experience of dyspnea." (CTS, 2011, p. 6). This kind of recommendation requires individuals living with COPD to have the means and ability to regularly engage with HCPs in a variety of settings and contexts. Such a recommendation does not address or take into account the complex realities of systemically and structurally disadvantaged populations.

Moreover, recommendations about importance and need of access to a health care specialist are clearly evident within CPGs. Again, such recommendations do not take into account systemically and structurally disadvantaged populations, contexts, and communities whereby specialists are scarce such as in northern and rural contexts. This then requires the need to travel to other larger centers in order to access specialist services. This unfortunately may not even be in the realm of possibility for systemically and structurally disadvantaged populations who do not possess the means or resources to do so. Recommendations that make problematic assumptions in relation to this notion are listed below:

> In patients with COPD with a previous or recent history of exacerbations, we recommend education and case management that *includes direct access to a health care specialist* at least monthly, to prevent severe acute exacerbations of COPD, as assessed by decreases in hospitalizations (Grade 1C). (CHEST/CTS, 2015, p. 11)
>
> *Referral to a specialist* may be appropriate when there is uncertainty over the diagnosis; symptoms are severe or disproportionate to the level of obstruction; there is an accelerated decline of function (FEV1 decline of 80 mL or more per year over a two-year period); and the onset of symptoms occurs at a young age. Specialists can also assist in the assessment and management of patients who fail to respond to bronchodilator therapy, or those who

> require pulmonary rehabilitation or an assessment for oxygen therapy. Specialist assistance may also be needed for the management of patients with severe or recurrent exacerbations of COPD, for patients with complex comorbidities, and for those requiring assessment for surgical intervention (i.e., bullectomy, lung volume reduction surgery [LVRS], lung transplantation). (CTS, 2007, 11B)
>
> NMES [neuromuscular electrical stimulation] and chest wall vibration are helpful in reducing dyspnea in patients with COPD. We recommend that NMES and chest wall vibration, undertaken by knowledgeable providers, be used in the management of dyspnea in patients with advanced COPD. (Grade of recommendation 2B). (CTS, 2011, p. 5)

As mentioned, some recommendations speak to the importance of palliative care services for individuals living with COPD and their carers without acknowledging or recognizing the implications of such recommendations on systemically and structurally disadvantaged populations. For example, “Palliative care services must be available for individuals and their carers living with COPD. (Level of Evidence=III)” (RNAO, 2010, p. 14), and “Palliative care, end-of-life care, and hospice care are important components of the care of patients with advanced COPD.” (GOLD, 2021, p. 66), and;

> **Physicians have a responsibility** to help patients with COPD and their caregivers to plan for the end of life and to make sure the necessary support is in place to assist them through this critical terminal phase.…These patients in particular will benefit from timely discussions about end-of-life issues. Discussions that underscore the value of palliative services and the effective alleviation of terminal dyspnea help to reduce anticipatory anxiety. (CTS, 2008, p. 7A)

The above-mentioned excerpts may be problematic because of a lack of palliative care specialists and/or specialist centres.

The proceeding recommendation assumes that individuals with advanced COPD actually have a choice of assistive devices such as walking aids, rollators, and NPPV to assist them in the management of their dyspnea. Such a recommendation does not take into consideration individuals who may not have private health insurance or qualify for funding to cover the cost of assistive devices at all and for whom therefore choice is not an option. For example, “NPPV may improve hospitalization-free survival in selected patients after recent hospitalization, particularly in those with pronounced daytime persistent hypercapnia ($PaCO_2 \geq 52$ mmHg) (Evidence B)” (GOLD, 2021, p. 68), and;

> COPD patients with dyspnea benefit from the use of walking aids. It is recommended that patients with advanced COPD be informed of the potential benefits of walking aids and undergo professional assessment for *choosing* a suitable device (Grade of recommendation 2B). (CTS, 2011, p. 5)

The next two recommendations may be problematic for individuals and/or groups who are disadvantaged because of geography and/or socioeconomic status, as such a recommendation requires the need and ability to travel to seek a service such as non-invasive positive pressure ventilation or all that is required relative to lung transplantation: “NPPV should be administered in a setting that allows close cardiopulmonary monitoring and access to personnel skilled at endotracheal intubation and invasive mechanical ventilation (Level of Evidence=1A).” (CTS, 2007, p. 21B-22B) and:

> Patients with COPD are considered to be potentially in the transplant window if they meet at least one of the following criteria: FEV1 less than 25% predicted (without

> reversibility), partial pressure of arterial carbon dioxide greater than 55 mmHg or elevated pulmonary artery pressures with progressive deterioration (e.g., cor pulmonale) (Level of Evidence=3B). (CTS, 2007, p. 22B)

The following recommendation makes many problematic assumptions. It suggests that nurses provide COPD education on a variety of topics such as nutrition, relaxation, smoking cessation, and disease self-management. Since the guideline and its recommendations do not address equity considerations for systemically and structurally disadvantaged populations, such a recommendation may assume the existence, availability, and accessibility of health services, community resources, and appropriate health care professionals, and access to nutritious food. It clearly ignores the complex challenges experienced by systemically and structurally disadvantaged populations:

> Nurses working with individuals with dyspnea related to COPD will have the appropriate knowledge and skills to:
>
> Recognize the importance of individual's self report of dyspnea
>
> Provide COPD patient education including:
>
> - Smoking cessation strategies
> - Pulmonary rehabilitation/exercise training
> - Secretion clearance strategies
> - Breathing retraining strategies
> - Energy conserving strategies
> - Relaxation techniques
> - Nutritional strategies
> - Role/rationale for oxygen therapy

> - Role/rationale for medications
> - Inhaler device techniques
> - Disease self-management and action plans
> - End-of-life issues
>
> Conduct appropriate referrals to physician and community resources
>
> (Level of Evidence=IV). (RNAO, 2010, p. 12)

Interestingly, some guidelines use fairly directive language aimed at a physician's responsibility to their patients. The following statement is quite problematic, as it does not consider the complex realities and experiences of systemically and structurally disadvantaged populations, of whom may include individuals experiencing COPD. Moreover, realistically, how are physicians going to ensure these considerations when many of them are beyond their control:

> …*Physicians must ensure patients have* the proper support to live in a smoke free environment, receive appropriate vaccinations, adhere to prescribed medication (including using proper inhaler technique), receive self-management education and coaching, remain physically active and be referred to and complete pulmonary rehabilitation…(CTS, 2019, p. 3).

Pulmonary Rehabilitation. Many of the analyzed guidelines discuss the substantial benefits of pulmonary rehabilitation (PR) and go on to recommend that all individuals living with COPD have access to PR. For example, "*Pulmonary rehabilitation reduces hospitalization* among patients who have had a recent exacerbation ($\leq$ 4 weeks from prior hospitalization) (Evidence B)." (GOLD, 2021, p. 61), "In patients with moderate, severe or very severe COPD who have had a recent exacerbation (i.e., < 4 weeks), *we recommend pulmonary rehabilitation to prevent acute exacerbations of COPD* (Grade 1C)." (CHEST/CTS, 2015, p. 10), "It is strongly recommended that patients with moderate, severe and very severe COPD participate in PR (Grade: 1C)" (CTS, 2010, p. 164), and "Clinically stable patients who remain dyspneic and limited in their exercise capacity despite optimal pharmacotherapy should be referred for *supervised pulmonary rehabilitation* (Level of Evidence: 1A)." (CTS, 2007, p. 20B). The following excerpt is a clear recommendation to HCPs who are caring for individuals living with COPD who have experienced acute exacerbation of their COPD (AECOPD). This recommendation, through demonstrated evidence, states that:

> It is strongly recommended that COPD patients undergo *PR within one month following an AECOPD* due to evidence supporting improved dyspnea, exercise tolerance and HRQL compared with usual care. (GRADE: 1B) PR within one month following AECOPD is also recommended due to evidence supporting *reduced hospital admissions and mortality* compared with usual care (Grade: 2C). (CTS, 2010, p. 165)

Some guidelines acknowledge that access to PR programs is limited yet continue to make such recommendations without considering how to meaningfully address this reality for individuals living with COPD, let alone systemically and structurally disadvantaged populations. Some even go as far as to suggest that it is the standard of care for patients with COPD. This type of statement suggests that those individuals who do not participate in PR are receiving substandard or suboptimal care. There is an assumption that individuals living with COPD readily have access to PR. HCPs in the area of respiratory disease clearly know that this is not the case given that only a small fraction have access to PR. As such, recommendations in CPGs related to PR are indeed based on the clear evidence that it is beneficial but do not fully address or discuss how to mitigate the complex issues related to access, thus not addressing the realities of systemically and structurally disadvantaged populations. Access to PR is also problematic for individuals who live in rural and northern contexts. Some CPGs implicitly address access issues through statements such as, “*Pulmonary rehabilitation programs must be available* for individuals with COPD to enhance quality of life and reduce healthcare costs. (Level of Evidence=1a)” (RNAO, 2010, p. 14). Some recommendations go on to state that PR is the standard of care in the management of dyspnea. This is evident in the following illustrative excerpts:

> Pulmonary rehabilitation (PR) participation is the *standard of care* for patients with chronic obstructive pulmonary disease (COPD) who remain symptomatic despite bronchodilator therapies. However, there are questions about specific aspects of PR programming including *optimal* site of rehabilitation delivery, components of rehabilitation programming, duration of rehabilitation, target populations and timing of rehabilitation. (CTS, 2010, p. 159)
>
> In addition, appropriate pharmacological therapies including short- and long-acting bronchodilator therapies, inhaled corticosteroids in combination with long-acting beta-2 agonists, theophylline preparations, as well as nonpharmacological therapies including pulmonary rehabilitation should be appropriately used in the management of dyspnea for patients with advanced COPD… (CTS, 2011, p. 6)

Such recommendations can perpetuate inequity among those individuals living with COPD who do not have access to PR and most certainly they do not address the complex experiences of systemically and structurally disadvantaged populations. Given that CPGs state that PR is part of the standard of care, this then implies that those who are not able to access or participate in PR are receiving substandard care.

Additionally, analysis revealed recommendations in relation to location and duration of pulmonary rehabilitation. For example, “It is recommended that longer PR programs, beyond six to eight weeks duration, be provided for COPD patients (GRADE: 2B)” (CTS, 2010, p. 163). Such recommendations have the potential to exacerbate inequity amongst systemically and structurally disadvantaged populations who are not able to access PR programs and/or HCPs to perform required assessments and develop individualized plans. There also are recommendations that state that there are no major differences between community or home site and hospital-based sites for PR. For example, “There are no differences in major patient-related outcomes of PR between nonhospital- (community or home sites) or hospital-based sites. It is strongly recommended that all COPD patients have access to PR programs regardless of program site. (GRADE: 1A)” (CTS, 2010, p. 162). Such a recommendation may be viewed as helpful to systemically and structurally disadvantaged populations because of geography; however, it may also perpetuate inequity as this may require support from HCPs and resources, such as equipment, that may not be easily available. Additionally, recommendations are made that suggest PR programs longer than six or eight weeks be provided to COPD patients, requiring substantive commitment. The illustrative examples presented within this section, although well intended, do not address implications for systemically and structurally disadvantaged populations. As such, analysis revealed that despite CPG recommendations about PR, systemically and structurally disadvantaged populations continue to be at risk of acute exacerbations, lower health related quality of life, hospital admissions, and death.

Pharmacotherapy. Pharmacotherapy is vital for those living with COPD in order to manage dyspnea, prevent acute exacerbation of illness, and reduce health service utilization and mortality:

> A *fundamental and achievable goal* of therapy in managing stable COPD is to reduce the occurrence and severity of AECOPDs. Furthermore, providing appropriate preventive therapy for patients at increased risk of exacerbation increases the likelihood of reducing and preventing ED visits and hospital admissions. In patients with severe COPD, reducing AECOPD may also reduce mortality… (CTS, 2019, p. 8)

The following excerpts indicate problematic assumptions made in CPG recommendations about pharmacotherapy. The pharmacotherapy recommendations in the analyzed CPGs do not address equity considerations for systemically and structurally disadvantaged populations. Further, such recommendations make assumptions about access to appropriate HCPs who can prescribe such medication and closely monitor responses to pharmacotherapy and/or the ability of an individual to obtain prescribed medication. For example, "Patients should be *routinely monitored and evaluated* for their response after any change in their therapy, as many have persisting symptoms with an impact on their well-being" (CTS, 2019, p. 6). This finding is also substantiated by the following illustrative examples:

> For patients with moderate to severe COPD, who have a history of one or more moderate or severe COPD exacerbations in the previous year despite optimal maintenance inhaler therapy, we suggest the use of a long term macrolide to prevent acute exacerbations of COPD (Grade 2A).…This recommendation places high value on the prevention of COPD exacerbations. However, clinicians prescribing macrolides need to consider in their individual patients the potential for prolongation of the QT interval and hearing loss as well as bacterial resistance. The duration and exact dosage of macrolide therapy is unknown. (CHEST/CTS, 2015, p. 19)

> For stable patients with chronic obstructive pulmonary disease, we suggest treatment with oral slow-release theophylline twice daily to prevent acute exacerbations of COPD (Grade 2B).… Patient decisions may also be informed by the relatively narrow therapeutic window with respect to adverse effects of treatment with theophylline… Theophylline use requires vigilance on the part of the physician in order to avoid serious drug interactions, which lead to changes in serum theophylline levels. (CHEST/CTS, 2015, p. 20–21)

Given that inhalation devices are used to optimize inhaled medication, some recommendations assume that individuals have these costly devices. For example, ‘‘Nurses will assess patients' inhaler device technique to ensure accurate use. Nurses will coach patients with sub-optimal technique in proper inhaler/device technique" (RNAO, 2010, p. 9).

Additionally, some recommendations require that individuals living with COPD have access to outpatient clinics or home care in order to receive IV therapy post hospitalization for acute exacerbation.

> The decision of changing a therapy should always occur after a complete evaluation of the patient and the potential benefit to a change in therapy; as well as an assessment of any adverse effects of the therapy, and with a review of patient adherence, inhaler technique and patient preferences. (CTS, 2019, p. 1)
>
> For patients with an acute exacerbation of COPD in the outpatient or inpatient setting, we suggest that systemic corticosteroids be given orally or intravenously to prevent hospitalization for subsequent acute exacerbations of COPD in the first 30 days following the initial exacerbation. (CHEST/CTS, 2015, p. 19)

Vaccinations. Many of the recommendations within the analyzed CPGs outline the importance of various vaccinations in reducing serious illness and the prevention of AECOPD. Analysis revealed problematic assumptions with such recommendations given that they assume that individuals have access to vaccination. For example, “Vaccinations prevent acute exacerbations of COPD (AECOPD).” (CTS, 2008, p. 4A), “*Influenza vaccination* reduces serious illness and death in COPD patients (Evidence B).” (GOLD, 2021, p. 46), “In patients with COPD, we recommend administering the influenza vaccine annually to prevent acute exacerbations of COPD (Grade 1B).” (CHEST/CTS, 2015, p. 9). “The WHO and CDC recommend *SARS-Cov-2 (COVID-19) vaccination* for people with COPD (Evidence B).” (GOLD, 2021, p. 46), and “The *23-valent pneumococcal polysaccharide vaccine*…has been shown to reduce the incidence of community-acquired pneumonia in COPD patients aged <65 years with an FEV_1 <40% predicted and in those with comorbidities (Evidence B).” (GOLD, 2021, p. 46). For populations who are disadvantaged by virtue of place of residence, socioeconomic status, and/or social network, accessing vaccine and/or services where they are provided may be quite challenging.

Smoking cessation. Recommendations related to smoking cessation assumed individuals with COPD have access to smoking cessation treatment and counselling. For example, “In patients with COPD, we suggest including smoking cessation counselling and treatment using best practices as a component of a comprehensive clinical strategy to prevent acute exacerbations of COPD (Grade 2C)” (CHEST/CTS, 2015, p. 9), and “Smoking cessation strategies should be instituted for patients who smoke… (RNAO, 2010, p. 7). Similarly, the proceeding illustrative example more specifically discusses smoking cessation in a way that again may be quite problematic for systemically and structurally disadvantaged populations:

> …in general, effective smoking cessation programs include behavioral, physiological, and psychological components composed of acknowledging current smoking followed by advice to quit, pharmacological therapies (nicotine replacement therapy, antidepressants, nicotine receptor modifier therapy), and counseling (in- person counseling or by telephone) with cessation rates that range from 8.8 – 34.5%. Smoking cessation that includes counseling and pharmacological interventions are cost-effective. (CHEST/CTS, 2015, p. 9–10)

Oxygen Therapy. Many guidelines make recommendations related to oxygen therapy. Such recommendations make assumptions about access to Respiratory Therapists and oxygen therapy companies in the community who can provide consultations, assessments, service, potential cost considerations, and assistance navigating programs aimed to assist with costs. Further, such recommendations do not take into consideration individuals who may not have private health insurance or qualify for funding to cover the cost of oxygen therapy at all and for whom therefore choice is not an option. For example, "Oxygen therapy. The long-term administration of oxygen (>15 hours per day) to patients with chronic respiratory failure has been shown to increase survival in patients with severe resting hypoxemia." (GOLD, 2021, p. 67), and:

> Continuous oxygen therapy for hypoxemic COPD patients reduces mortality, and may reduce dyspnea in some patients. The CTS has previously recommended that patients with advanced COPD who are hypoxemic at rest receive long-term continuous oxygen therapy because of a mortality benefit. Oxygen therapy may also provide symptomatic benefit by reducing dyspnea when administered at rest to hypoxemic patients with advanced COPD (Grade of recommendation 2B). (CTS, 2011, p. 6).

Recommendations that Address Health Services

Analysis of the CPGs revealed that some of the guidelines included explicit statements acknowledging and/or addressing health service organization (i.e., structure of health service, and availability of and access to health service). More specifically, the RNAO CPG parses out their recommendations into practice, education, organizational and policy, and program/services recommendations. Equity considerations are articulated within the organizational and program/services recommendations. These are particularly relevant to rural and northern communities where access to health services and the recruitment and retention of health human resources are particularly challenging. For example, some guidelines addressed considerations about access to medication and oxygen therapy. "Furthermore, *poor access* to inhaled medications can be a problem in some countries." (CHEST/CTS, 2015, p. 18), "Organizations should have available *sample medication delivery devices*, *spacer devices*, sample templates of action plans, visual analogue scales, numeric rating scales, MRC scales and patient education materials (Level of Evidence=IV)." (RNAO, 2010, p. 13), and "Funding regulations for oxygen therapy must be revisited to include those individuals with severe dyspnea, reduced ventilatory capacity and reduced exercise tolerance who do not qualify under the current criteria (Level of Evidence=IV)," (RNAO, 2010, p. 14).

The following illustrative examples discuss health human resources: "Organizations *need to have in place COPD educators* to teach both nurses and patients." (RNAO, 2010, p. 12; RNAO, 2005, p. 11), "Organizations will ensure sufficient nursing staff to provide essential care, safety and support for individuals with all levels of dyspnea (Level of Evidence=IV)" (RNAO, 2010, p. 12), and:

> Organizations need to ensure that a critical mass of health professionals are educated and supported to implement this guideline in order to *ensure sustainability*. Organizations will ensure sufficient nursing staff to provide essential care, safety and support for individuals with all levels of dyspnea. (RNAO, 2005, p. 11).

The following example illuminated the need for access to PR: “An urgent need exists *to increase access* to pulmonary rehabilitation programs across Canada (Level of Evidence=2A).” (CTS, 2007, p. 20B). Whereas the following examples highlight the need for HCPs to consider their respective organizations or practice settings and the needs and wishes of the individuals. Such a statement presents an opportunity for equity considerations for systemically and structurally disadvantaged populations:

> Similar to the original guideline publication, this document needs to be reviewed and applied, based on *the specific needs of the organization or practice setting/environment, as well as the needs and wishes of the client.* This supplement should be used in conjunction with the guideline as a tool to assist in decision making for individualized client care, as well as ensuring that appropriate structures and supports are in place. (RNAO, 2010, p. 1)
>
> It is acknowledged that effective care depends on a coordinated interdisciplinary approach incorporating ongoing communication between health professionals and patients. Personal preferences and *unique needs as well as the personal and environmental resources of each individual patient* must always be kept in mind. (RNAO, 2005, p. 14)

Guidelines that address health services are noteworthy; the analysis of all included guidelines reveals this is not the case across all CPGs. Although those CPGs that do include equity type statements such as those listed above are to be commended, there is still much work to be done as these statements are not consistent throughout the CPG process and tend to be supplementary. Equity considerations ought to be inherent throughout the entire CPG process and subsequent documentation and consistent across all CPGs.

Equity Lens Criterion Two and Three: Reason to Anticipate Different Effects and Values of Interventions between Disadvantaged and Privileged Populations

Based on the recommendations within CPGs that make assumptions about health service organization (i.e., structure of health service, availability of and access to appropriate services), criterion two of The Equity Lens provided an opportunity to assess if there was a reason to anticipate different effects of interventions in disadvantaged and privileged populations. In terms of analysis, according to The Equity Lens criterion, this involved assessing if CPG recommendations included discussion on the differences between disadvantaged and privileged populations in terms of biology of the disease, adherence, and base line risks. Similarly, criterion three of The Equity Lens provided an opportunity to assess if the effects of the interventions are valued differently by disadvantaged compared with privileged populations. In terms of analysis, this involved determining if the guideline developer sought an assessment of values through consultation with disadvantaged populations, involvement of their caregivers, reference to relevant research, or transparent reflection.

I found that the analyzed CPGs are likely to further widen health inequities experienced by individuals living with COPD and other disadvantaged groups by making recommendations that are advantageous to privileged groups (i.e., those that do not have any difficulties in having the availability of and access to appropriate health services). None of the guidelines included discussion of the differences between disadvantaged and privileged populations in terms of biology of the disease, adherence, and base line risks or an assessment of values through consultation with systemically and structurally disadvantaged populations, involvement of their caregivers, reference to relevant research, or transparent reflection.

Equity Lens Criterion Four: Is Specific Attention Given to Minimizing Barriers to Implementation in Disadvantaged Populations?

Given that systemically and structurally disadvantaged populations usually have limited access to health care, criterion four of The Equity Lens provided an opportunity to assess if CPG developers paid specific attention to minimizing barriers to the implementation of CPG recommendations in systemically and structurally disadvantaged populations. This would be evident if a guideline discussed barriers to implementation in systemically and structurally disadvantaged populations and identified strategies to overcome these barriers. Although brief, one guideline did acknowledge regional disparity in access to pulmonary rehabilitation and offered strategies to address this barrier:

> Despite the proven benefits of pulmonary rehabilitation, a recent national survey revealed that only 98 programs exist in Canada. These programs combined have a capacity to serve only approximately 1.2% of the COPD population in Canada. *Regional disparity in access* to pulmonary rehabilitation was also highlighted in the survey: most programs were located in Ontario and Quebec, whereas some provinces (e.g., Newfoundland, Prince Edward Island) had none. Strategies should be developed to improve availability of pulmonary rehabilitation at a lower cost. In this regard, self-monitored home-based rehabilitation is a promising approach… (CTS, 2007, 20B)

Equity Lens Criterion Five: Plans for Assessing Impact of Recommendations on Disadvantaged Populations

Given that CPG recommendations may have different effects in disadvantaged groups, according to Dans and colleagues (2007), the only reliable way to find out is by monitoring the impact in systemically and structurally disadvantaged populations. Criterion five of The Equity Lens requires the determination of whether or not a CPG articulated plans for monitoring disadvantaged groups according to place of residence, race, occupation, gender, religion, education, socioeconomic status, or social network and capital. None of the included CPGs subject to analysis outlined plans for assessing the impact of the recommendations on systemically and structurally disadvantaged populations as required in criterion five of The Equity Lens. This is particularly important to note given that recommendations within CPGs may have different effects in systemically and structurally disadvantaged populations and the only sure way to find out is by monitoring their impact in systemically and structurally disadvantaged populations. Impact was discussed primarily in relation to the purpose of a development panel to evaluate the impact of its work on recommendations in the CPG related to management and prevention of COPD. It is not clear however, what the evaluation of the impact entailed. Further, one guideline made an organization recommendation that outlined what organizations may choose to do in order to monitor the impact of CPG implementation. Despite this, however, consideration of impact in relation to systemically and structurally disadvantaged populations was not discussed. The following examples illustrate this finding:

> The GOLD Science Committee was established in 2002 to review published research on COPD management and prevention, to evaluate the impact of this research on

> recommendations in the GOLD document related to management and prevention, and to post yearly updates on the GOLD website. (GOLD, 2021, p. v)
>
> Organizations need to develop specific pre-implementation and outcome markers to monitor the impact of the implementation of this BPG on the care of individuals with dyspnea related to COPD. Organizations may wish to evaluate:
>
> Nursing knowledge base pre- and post-implementation, Length of time between acute exacerbations of COPD (AECOPD) for specific individuals (perhaps globally represented by the number of acute care admissions and/or use of acute care resources over time pre- and post-implementation).
>
> Development of documentation strategies to monitor and enhance care of individuals living with dyspnea related to COPD (integration of usual and present dyspnea on vital sign records within the institution).
>
> Development of policies institutionalizing an education program for nurses caring for individuals living with dyspnea related to COPD (Level of Evidence=IV). (RNAO, 2010, p. 13; RNAO, 2005, p. 151)

Findings revealed that all of the guidelines make assumptions that either address and/or make problematic assumptions about health service organization (i.e., structure of health service, access to health service, resources). Many of the problematic assumptions are such that the various CPGs make recommendations that are not feasible or are simply unattainable for systemically and structurally disadvantaged populations. It is important to note that such recommendations do not take into account their implications for systemically and structurally disadvantaged populations. Table 6-2 depicts a visual representation of the analysis of how well each of the 10 guidelines attended to equity considerations as outlined by the INCLEN Equity

Lens criteria (Dans et al., 2007) in Section 2 of the analysis framework. Blue indicates that the guideline clearly addresses a specific element pertaining to equity consideration, while green indicates it is somewhat addressed, yellow indicates it poorly addressed, and red indicates a particular equity consideration was not addressed at all. The findings of Section 2 of the analysis clearly indicate that none of the ten guidelines clearly addressed any elements of equity considerations as outlined by the INCLEN Equity Lens.

Table 6-2

Compilation of Included CPGs in relation to Section 2 of the Analysis Framework-Guideline Content including The Equity Lens

	CPGs and Status n=10									
	GOLD (2021)	**CTS (2019)**	**CHEST/ CTS (2015)**	**CTS (2012)**	**CTS (2011)**	**CTS (2010)**	**CTS (2008)**	**CTS (2007)**	**RNAO (2010)**	**RNAO (2005)**
	Current	**Current**	**Current**	**Under Review**	**Under Review**	**Under Review**	**Under Review**	**Under Review**	**Not Stated**	**Not Stated**
1. Do the recommendations in the guideline address a priority problem for disadvantaged populations? (Criterion 1)	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
2. Is there reason to anticipate different effects of interventions in disadvantaged and privileged populations? (Criterion 2)	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
3. Are the effects of the intervention valued differently by disadvantaged compared with privileged populations? (Criterion 3)	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
4. Is specific attention given to minimizing barriers to implementation in disadvantaged populations? (Criterion 4)	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟨	🟥	🟥
5. Are there plans for assessing the impact of the recommendations on disadvantaged populations? (Criterion 5)	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟨	🟨

How well the guideline attends to equity considerations as outlined in The Equity Lens
Blue: Clearly addresses Green: Somewhat addresses Yellow: Poorly addresses Red: Does not address at all

Section 3: Guideline Development and Application Process

COPD Experts

Analysis revealed that in all of the included CPGs, multiple health care professionals with expertise in COPD were involved as authors in the development guideline group. All of the development panel members of included guidelines except for one consisted of interprofessional membership, including but not limited to respirologists, physiotherapist, pharmacists, respiratory therapists, and registered nurses. Given the focus of the nursing guideline, the members of that development panel were all nurses, yet the recommendations were subject to review by professionals from other disciplines. For example, "Its members are recognized leaders in COPD research and clinical practice with the scientific credentials to contribute to the task of the Committee and are invited to serve in a voluntary capacity." (GOLD, 2021, p. v), "The COPD guideline panel comprised 12 experts: six respirologists with experience in COPD management, research and research methodology including three clinicians/epidemiologists; two primary care physicians appointed by the College of Family Physicians of Canada; and one pharmacist." (CTS, 2019, p. 4), "This guideline is unique because a group of interdisciplinary clinicians who have special expertise in COPD clinical research and care led the development of the guideline process with the assistance of methodologists." (CHEST/CTS, 2015. p. 6–7). "The Canadian Thoracic Society (CTS) Optimizing Pulmonary Rehabilitation in COPD Clinical Practice Guideline document was developed by an Expert Working Group panel of representative professionals involved in the coordination, design, delivery and evaluation of PR." (CTS, 2010, p. 160).

The CTS A1AT deficiency targeted testing and augmentation therapy clinical practice guideline was developed by a panel of representative professionals involved in the care of

> patients with COPD and A1AT deficiency. The overall process was coordinated by the CTS Respiratory Guideline Committee and staff, with the assistance of consultant librarian and methodology experts. (CTS, 2012, p. 110)

> The Canadian Thoracic Society (CTS) clinical practice guideline document on managing dyspnea in patients with advanced COPD was developed by an expert working group panel of representative professionals involved in the care of patients with advanced COPD. Membership included respirologists, family physicians, internists, nurses and health care administrators. (CTS, 2011, p. 2)

> In January of 2004, a panel of nurses with expertise in practice, education and research related to chronic obstructive pulmonary disease was established by the RNAO. At the onset, the panel discussed and came to consensus on the scope of the best practice guideline. (RNAO, 2005, p. 15)

Equity Experts

Despite clear and explicit articulation within the analyzed guidelines regarding the expertise of CPG development members, there was no articulation of expertise of development members relative to health equity.

Literature Search and Disadvantaged Populations

Analysis revealed that none of the reviewed CPGs demonstrated that the design of the literature search strategy could identify studies relevant to COPD and systemically and structurally disadvantaged populations. The following excerpts demonstrate that there was no indication of attention to equity or systemically and structurally disadvantaged populations within the various literature searches:

> A database search for existing chronic obstructive pulmonary disease guidelines was conducted by a university health sciences library. An initial search of the Medline, Embase and CINAHL databases for guidelines and articles published from January 1, 1995 to December 2003 was conducted using the following search terms: “chronic obstructive pulmonary disease”, “COPD”, “chronic obstructive lung disease”, “COLD”, “chronic bronchitis”, “emphysema”, “family caregivers”, “coping with chronic illness”, “oxygen devices”, “rehabilitation”, “assessing control”, “medications”, “randomized controlled trials”, “systematic reviews”, “practice guideline(s)”, “clinical practice guideline(s)”, “standards”, “consensus statement(s)”, “consensus”, “evidence based guidelines” and “best practice guidelines. (RNAO, 2005, p. 87)

> The literature search identified 165 citations, of which 156 were excluded after review. Of the nine citations meeting the inclusion criteria, one was a systematic review (34), which included four of the remaining citations and referred to 14 additional studies not identified in the search. Of the remaining four citations, one study was a four-day crossover RCT (35), one was a meta-analysis of the effects of nebulized opioids (36), one concerned epidural use of methadone (37) and one was an abstract of a substudy that focused on opioid responsiveness, which was subsequently published as a full-length article. (CTS, 2011, p. 4)

Involvement of People Living with COPD and/or Carers

The excerpts below indicate that a variety of “external experts” were consulted and the “benefit to the patient” was considered, but none of them describe consultation with patients or their families and/or caregivers. None of the CPGs described consultation with those with intimate experiential lived experience of what it is like to live with COPD. This is clearly evident in the following excerpts:

> The CTS independently invited formal review of the update by an external (non-CTS) content expert. The lead author responded to the comments and made corresponding changes. Two members of the CRGC [Canadian Respiratory Guidelines Committee] then completed their own review and provided further feedback for consideration. Upon acceptance, the Committee recommended approval of the guideline to the CTS Executive Committee. (CTS, 2019, p. 5)
>
> For each clinical question, we considered the strength and directness of the evidence supporting an intervention or treatment approach. For each therapeutic approach, w also considered: the potential health benefit to the patient; the morbidity and mortality impact on the overall COPD population; risks/harms; the burden placed on the patient; and the cost-effectiveness (these are the factors categorized under the "Contextualization and Deliberations" domain of the guidelines)." (CTS, 2019, p. 5)
>
> We also included informed clinical remarks with PICO clinical questions and recommendations, in an effort to compliment recommendations with practical clinical advice. Some of these remarks are not based on strong evidence, but represent the consensus opinions of panel members based on expertise. (CTS, 2019, p. 5)
>
> Expert reviewers identified by the working group and the Canadian Respiratory Guidelines Committee, on the basis of their clinical and methodological expertise, were invited to review the document. A draft of the clinical practice guidelines was circulated to the reviewers, feedback was gathered and relevant changes were incorporated into the document. (CTS, 2011, p. 2; CTS, 2010, p. 160)

> This process [critical appraisal of recommendations] was further strengthened by the circulation of the draft guideline to external experts who were given an opportunity to comment and help formulate the final recommendations before formal organizational approval and peer-review publication. (CTS, 2010, p. 160)
>
> The revised draft (ii) was then widely circulated for feedback from external experts from affiliated societies (family physicians, nursing, physical therapy, respiratory therapy, pharmacists). The final draft incorporated revisions from these numerous experts and was submitted for publication. (CTS, 2007, p. 6B)

This was further evident via the acknowledgements that were made within some guidelines. Gratitude is expressed to HCPs who served as reviewers of CPGs and provided their input and guidance. Within the CPGs, no such acknowledgments are made to the contributions of individuals living with COPD or their carers whereby one can deduce that is because their input and contributions to the CPGs were not sought:

> The authors would like to thank Anne Van Dam from CTS and Samir Gupta and Christopher Licskai, Executive members of the CTS CRGC for their input and guidance. We would like to acknowledge with sincere appreciation our expert reviewer, Marc Miravitlles from the Pneumonology Department, University Hospital Vall d'Hebron, Ciber de Enfermedales Respiratorias (CIBERES), Barcelona, Spain. (CTS, 2019, p. 12)
>
> This draft was submitted to a set of external stakeholders for review and feedback of the content. It was also critiqued using the AGREE instrument. An acknowledgement of these reviewers is provided at the front of this document. Stakeholders represented healthcare consumers, various healthcare disciplines as well as a professional association. External stakeholders were provided with specific questions for comment, as well as the opportunity

> to give overall feedback and general impressions. The results were compiled and reviewed by the development panel. Discussion and consensus resulted in revision to the draft document prior to publication. (RNAO, 2005, p. 16)

> Expert reviewers identified by the Working Group and the Canadian Respiratory Guidelines Committee on the basis of their clinical and methodological expertise, were invited to review the document. A draft of the clinical practice guideline was circulated to the reviewers, feedback was gathered and relevant changes were incorporated into the document. (CTS, 2012, p. 110–111)

The analysis revealed that one of the included guidelines demonstrated evidence of minimal consultation with people living with COPD and/or their carers representing diverse contexts and regions in the development and implementation of the guideline. The RNAO (2005) guideline, through an acknowledgement statement, identified 24 health care professionals and two “healthcare consumers” who were invited to provide feedback. The lack of clarity about who the “health care consumers” are and how they were invited and chosen to participate presents as an opportunity for improvement for CPG developers. This is evident in the following example, “Acknowledgement: Stakeholders representing diverse perspectives were solicited for their feedback and the Registered Nurses’ Association of Ontario wishes to acknowledge the following for their contribution in reviewing this Nursing Best Practice Guideline. (RNAO, 2005, 4–5)

Barriers and Facilitators to Application

Domain 5-Applicability, item 18 of the AGREE II Instrument provided an opportunity to assess if the CPGs described barriers and facilitators to their application. In terms of analysis, this involved determining if the CPGs discussed barriers to implementation in systemically and structurally disadvantaged populations and identified strategies to overcome these barriers. Although some guidelines articulated that HCPs, for example, should reassess patients relative to attainment of treatment goals and identify barriers to successful treatment, very few actually addressed barriers specifically in relation to CPG application. For example, "Following implementation of therapy, patients should be reassessed for attainment of treatment goals and identification of any barriers for successful treatment." (GOLD, 2021, p. 92). Those that identified barriers did not identify strategies to overcome them. Some do not address either barriers or facilitators. The following are examples of excerpts from CPGs that discuss barriers to implementation:

> It is estimated that only 1.2% of the more than 750,000 Canadians suffering from COPD have access to PR programs (9). The capacity for increasing access to these programs may be hampered by various factors including cost, accessibility and patients' mobility limitations (10). Nonhospital-based programs presently account for only 7% of the total number of programs accessible by patients in Canada, but could be an alternative to hospital-based programs if effectiveness was assured (9,10). (CTS, 2010, p. 161)
>
> Access to PR and adherence to participation remain two of the most significant challenges in this field. Only a very small proportion of patients with COPD have access to PR programs (9). Acknowledging the important benefits of the intervention (3-5,61) and appreciating that PR is now the standard of care for patients who remain symptomatic despite appropriate bronchodilator therapies (1), there is an immediate urgency for these obstacles to be addressed and to be removed. It is not acceptable for health care providers, patients or health care systems to accept the current status quo—the benefits cannot be ignored. (CTS, 2010, p. 165)

> In spite of dyspnea being often poorly controlled and incapacitating in advanced stage COPD …. access to supportive services such as palliative care services in hospital or at home is much more limited for these individuals than for persons with cancer…(RNAO, 2010, p. 11; RNAO, 2005, p. 149)

> The Working Group recognized and acknowledged potential barriers to the more widespread use of opioids in this setting, the lack of specific protocols and familiarity with the use of NMES, and the potential limitation of sufficiently trained individuals to deliver these effective techniques. (CTS, 2011, p. 7)

One particularly interesting example of a barrier to uptake of recommendations is represented below. It describes an instance when there are variations in recommendations among CPGs developed by various groups and organizations that potentially lead to confusion among HCPs.

> Opioids are infrequently prescribed in this setting, despite the evidence supporting their benefit. Several issues contribute to this reality including unfamiliarity with dosing, concerns regarding respiratory depression and/or addiction, the fear of other significant side-effects, as well as concerns and attitudes about addiction and dependence. An additional obstacle to the optimal management of dyspnea in advanced COPD has been a lack of attention in some clinical guideline statements. Standards from the European Respiratory Society and the American Thoracic Society make no recommendation (111) regarding opioid use. An earlier consensus document from the American Thoracic Society (112) specifically recommended against the use of opioids in patients with COPD except in the terminal stages. The Global Initiative for Chronic Obstructive Lung Disease stated that ‘‘…some clinical studies suggest morphine used to control dyspnea may have serious adverse effects and its benefits may be limited to a few sensitive individuals’’ (113),

> although that concern has recently been challenged (1). Conversely, the Canadian (109) and Australian (114) COPD guidelines included recommendations for considering opioids in the management of severe dyspnea. The Canadian COPD guidelines published in 2007 (109) specifically stated that "opioids remain the most effective dyspnea-relieving medication in end-of-life care", and included a table listing various opioid medications, mode of administration and commonly used dosages. The recent policy statement from the American College of Chest Physicians (6) and the American Thoracic Society statement (5) on palliative and end-of-life care also appropriately addressed the use of opioids in this setting. (CTS, 2011, p. 6–7)

The analysis revealed that more barriers to the implementation of recommendations than facilitators were described in the included CPGs. However, one guideline did explicitly outline strategies for organizations to consider facilitating implementation of the guideline.

> Organizations need to have in place best practice guideline specific strategies to facilitate implementation. Organizations may wish to develop a plan for implementation that includes: A process for the assessment of the patient population (e.g., numbers, clinical diagnostic practices, co-morbidities, average length of stay) of individuals usually cared for in their institution that are living with dyspnea related to COPD. A process for the assessment of documentation practices related to the monitoring of dyspnea (usual and present dyspnea and dyspnea related therapies (e.g., SPO2). A process for the evaluation of the changes in the patient population and documentation strategies pre- and post-implementation. A process for the assessment of policies supporting the care of individuals living with dyspnea related to COPD (Level of Evidence=IV). (RNAO, 2010, p. 13; RNAO, 2005, p. 151)

> Nursing best practice guidelines can be successfully implemented only where there are adequate planning, resources, organizational and administrative support. Organizations may wish to develop a plan for implementation that includes: An assessment of organizational readiness and barriers to education. Involvement of all members (whether in a direct or indirect supportive function) who will contribute to the implementation process. Dedication of a qualified individual to provide the support needed for the education and implementation process. Ongoing opportunities for discussion and education to reinforce the importance of best practices. Opportunities for reflection on personal and organizational experience in implementing guidelines. In this regard, RNAO (through a panel of nurses, researchers and administrators) has developed the Toolkit: Implementation of Clinical Practice Guidelines, based on available evidence, theoretical perspectives and consensus. The RNAO strongly recommends the use of this Toolkit for guiding the implementation of the best practice guideline on Nursing Care of Dyspnea: The 6th Vital Sign in Individuals with Chronic Obstructive Pulmonary Disease (COPD) (Level of Evidence=IV). (RNAO, 2010, p. 14; RNAO, 2005, p. 152)

Advice/Tools for Practice

Domain 5-Applicability, item 19 of the AGREE II Instrument provided an opportunity to assess if CPG developers provided advice and/or tools on how the recommendations can be put into practice. Some guidelines did not discuss any advice or tools to assist users to implement the recommendations with their practice. It is noteworthy that if developers did provide tools, these tools were more informational in nature than tools that address how to implement recommendations with systemically and structurally disadvantaged populations. Often any included tools associated with a CPG offer a more concise presentation of recommendations in the form of pocket cards. Although possibly useful in that these teaching guides and dissemination kits offer a concise outline of recommendations, these tools do not guide HCPs in terms of contextual considerations that may affect how well they are able to implement recommendations in their practice, thus affecting their uptake. For example, "It is also anticipated that we will produce a separate implementation document that will include key indicators of appropriate care and practical guidance for healthcare system change." (CTS, 2019, p. 12), "The Registered Nurses' Association of Ontario and the guideline development panel have compiled a list of implementation strategies to assist healthcare organizations or healthcare disciplines who are interested in implementing this guideline. A summary of these strategies follows…." (RNAO, 2005, p. 53) and:

> A teaching and dissemination slide kit, complementing existing CTS teaching aids for the diagnosis and management of COPD, is being developed and will be similarly posted for viewing and download. Patient/family/care giver and health care professional information sheets (two in total) will be posted for viewing and download, and also further disseminated by the Canadian and provincial lung associations. Finally, a trifold pocket 'Slim Jim' summarizing key recommendations and information from this clinical practice guideline will be forwarded to all family physicians in Canada, provincial Ministries of Health, and selected provincial and regional health authorities. (CTS, 2011, p. 7)
>
> In this regard, RNAO (through a panel of nurses, researchers and administrators) has developed the Toolkit: Implementation of Clinical Practice Guidelines, based on available evidence, theoretical perspectives and consensus. The RNAO strongly recommends the use of this Toolkit for guiding the implementation of the best practice guideline on Nursing

> Care of Dyspnea: The 6th Vital Sign in Individuals with Chronic Obstructive Pulmonary Disease (COPD). (RNAO, 2010, p. 14; RNAO, 2005, p. 12, 48, 152)

Potential Resource Implications

Domain 5-Applicability, item 20 of the AGREE II Instrument provided an opportunity to assess if CPG developers considered potential resource implications of applying the recommendations. Only one of the CPGs subject to analysis made a general statement that addressed the potential resource implications of applying the recommendations:

> Recommendation 8.7 - Nursing best practice guidelines can be successfully implemented only where there are adequate planning, resources, organizational and administrative support. Organizations may wish to develop a plan for implementation that includes:
>
> An assessment of organizational readiness and barriers to education.
>
> Involvement of all members (whether in a direct or indirect supportive function) who will contribute to the implementation process.
>
> Dedication of a qualified individual to provide the support needed for the education and implementation process.
>
> Ongoing opportunities for discussion and education to reinforce the importance of best practices.
>
> Opportunities for reflection on personal and organizational experience in implementing guidelines.
>
> In this regard, RNAO (through a panel of nurses, researchers and administrators) has developed the Toolkit: Implementation of Clinical Practice Guidelines, based on available evidence, theoretical perspectives and consensus. The RNAO strongly recommends the use of this Toolkit ……(RNAO, 2010, p. 14; RNAO, 2005, p. 152)

Monitoring and/or Auditing Criteria

Domain 5-Applicability, item 21 of the AGREE II Instrument provided an opportunity to assess if the CPG developers described processes and procedures for monitoring and/or auditing it. Some guidelines address their processes relative to the frequency of how often their CPG is updated. I found that although this is stated in theory, the stated timelines for review and update of said guidelines are not necessarily what happens in practice. For example, the CTS guideline on managing dyspnea in patients with advanced COPD was published in 2011 and is only now currently under review in 2022, well beyond the stated review process of every three years. The following are excerpts from CPGs about updates:

> The guideline will be formally reviewed every three years or sooner to determine the need for and nature of any updates, in accordance with the CTS Living Guideline Model (details available at https://cts-sct.ca/guideline-library/methodology/). Authors and/or the CTS COPD Assembly Steering Committee members will also use the continuously updated McMaster Plus database, whereby they will receive alerts when new articles pertaining to these PICO questions are published (starting from the last date of the literature search conducted for this guideline). This will serve to prompt members to consider timely guideline updates with evolving evidence and will facilitate formal literature reviews. (CTS, 2019, p. 5)
>
> The present document, including the questions and content, will be regularly reviewed and updated to reflect the changing and growing body of evidence in this area. At minimum, after a two-year period, the literature will be reviewed for new evidence to further inform, revise or update the guideline recommendations. (CTS, 2011, p. 2)

> The Registered Nurses' Association of Ontario (RNAO) has made a commitment to ensure that this practice guideline is based on the best available evidence. In order to meet this commitment, a monitoring and revision process has been established for each guideline every three years. (RNAO, 2010, p. 1)

The 2005 RNAO CPG proposed explicit actions to guide the update of their guideline as listed below:

> The Registered Nurses' Association of Ontario proposes to update this best practice guideline as follows:
>
> 1. Each nursing best practice guideline will be reviewed by a team of specialists (Review Team) in the topic area every three years following the last set of revisions.
>
> 2. During the three-year period between development and revision, RNAO Nursing Best Practice Guidelines program staff will regularly monitor for relevant new literature in the subject area.
>
> 3. Based on the results of the monitor, program staff will recommend an earlier revision period. Appropriate consultation with a team of members comprised of original panel members and other specialists in the field will help inform the decision to review and revise the guideline earlier than the three-year milestone.
>
> 4. Three months prior to the three year-review milestone, the program staff will commence the planning of the review process by:
>
> a. Inviting specialists in the field to participate in the Review team. The Review Team will be comprised of members from the original panel as well as other recommended specialists.
>
> b. Compiling feedback received, questions encountered during the dissemination phase as

> well as other comments and experiences of implementation sites.
>
> c. Compiling new clinical practice guidelines in the field, systematic reviews, meta-analysis papers, technical reviews, randomized controlled trial research, and other relevant literature.
>
> d. Developing a detailed work plan with target dates and deliverables." (RNAO, 2005, p. 54)

It is noteworthy that despite almost all of the included CPGs not adhering to their stated update timelines, the GOLD 2022 report was the only analyzed CPG that indeed met its stated update criteria. The GOLD group consistently posts to its website annual updates of its guideline:

> Immediately following the release of the first GOLD report in 2001, the GOLD Board of Directors appointed a Science Committee, charged with keeping the GOLD documents up-to-date by reviewing published research, evaluating the impact of this research on the management recommendations in the GOLD documents, and posting yearly updates of these documents on the GOLD website. (GOLD, 2021, p. 2)

In terms of monitoring the impact of recommendations, some guidelines addressed that this was their goal yet did not articulate specific measurable objectives related to how they would do this:

> Our goal is to monitor the impact of these actionable recommendations through their ability to correct knowledge gaps and improve actual behaviors within the target user groups. On a population level, we also believe that monitoring the frequency of COPD ED visits, hospital admissions and re-admissions would be relevant metrics to assess the success of this guideline. (CTS, 2019, p. 12)

Although it did not follow its stated proposed plan for updating its CGP, the RNAO 2005 CPG encouraged organizations to consider how the implementation of their CPG would be monitored and evaluated within their organizations and outlined some indicators for organizations to consider:

> Organizations implementing the recommendations in this nursing best practice guideline are encouraged to consider how the implementation and its impact will be monitored and evaluated. The following table, based on a framework outlined in the RNAO Toolkit: Implementation of Clinical Practice Guidelines (2002b) illustrates some indicators for monitoring and evaluation….(RNAO, 2005, p. 52)

What is not clear and is difficult to ascertain from these guidelines are the resources (financial and human) that may or may not be associated with each CPG development process. In light of this, it is incumbent upon organizations that engage HCPs to develop CPGs to be realistic about their monitoring and auditing timelines and how their CPGs are evaluated.

Based on the analysis of Section 3 of the analysis framework, Table 6-3 presents a visual compilation of how well each guideline attended to equity considerations specific to guideline development and application processes. Blue indicates that the guideline clearly addresses a specific element pertaining to equity consideration, while green indicates it is somewhat addressed, yellow indicates it is poorly addressed, and red indicates a particular equity consideration was not addressed at all. The findings of Section 3 of the analysis framework indicate that all of the analyzed CGPs included individuals who are recognized as experts in COPD in the development groups. Conversely, none of the CPGs addressed or indicated if any of the development group members had expertise in equity. None of the CGPs demonstrated evidence that the design of the literature search strategy could identify studies relevant to COPD and systemically and structurally disadvantaged populations nor evidence of consultation with people living with COPD and/or their carers representing diverse contexts and regions in the development and implementation of the guideline. Analysis of the guidelines specifically related to items as outlined in Domain 5 of the AGREE II Instrument revealed that none of the ten guidelines clearly addressed barriers and facilitators to their application. Two of the ten guidelines somewhat addressed barriers and facilitators to its application in the form of organizational recommendations that would facilitate application of recommendations within the CPG.

Findings also revealed that although many of the CPGs provide a variety of tools that may assist users to utilize the guideline in practice (i.e., in the form of a summary Slim Jim, tables, condensed information), none of the guidelines explicitly provide advice or tools about "how" the recommendations can be put into practice. Further, none of them outline how recommendations could be put into practice in relation to systemically and structurally disadvantaged populations. In addition, none of the ten guidelines clearly considers potential resource implications of applying the recommendations. Finally, the international CPG is the only guideline that not only clearly presents their monitoring and/or auditing criteria, it also upholds its stated commitment to providing an annual update. This cannot be said of the other nine guidelines. Although five of these nine guidelines outline monitoring criteria, they poorly address this element and how it is enacted. Four of these nine guidelines do not address monitoring and/or auditing criteria within their CPG at all.

Table 6-3

Compilation of Included CPGs for the Section 3 of Analysis Framework-Guideline Development and Application Process Including AGREE II Instrument Domain 5-Applicability

	CPGs and Status n=10									
	GOLD (2021)	**CTS (2019)**	**CHEST / CTS (2015)**	**CTS (2012)**	**CTS (2011)**	**CTS (2010)**	**CTS (2008)**	**CTS (2007)**	**RNAO (2010)**	**RNAO (2005)**
	Current	**Current**	**Current**	**Under Review**	**Under Review**	**Under Review**	**Under Review**	**Under Review**	**Not Stated**	**Not Stated**
1. Is an expert in COPD included in the guideline development group?	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
2. Is an expert in health equity included in the guideline development group?	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
3. Is there evidence that the design of the literature search strategy could identify studies relevant to COPD and disadvantaged populations?	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
4.Is there evidence of consultation with people living with COPD and/or their carers representative of diverse contexts and regions in the development and implementation of the guideline? (adapted from criterion three)	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
5. Does the guideline describe facilitators and barriers to its application? (Domain 5, Item 18)	🟨	🟥	🟥	🟥	🟨	🟨	🟥	🟨	🟩	🟩
6. Does the guideline provide advice and/or tools on how the recommendations can be put into practice? (Domain 5, Item 19)	🟩	🟨	🟥	🟨	🟨	🟥	🟥	🟥	🟨	🟨
7. Does the guideline consider potential resource implications of applying the recommendations? (Domain 5, Item 20)	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟨	🟨
8. Does the guideline present monitoring and/or auditing criteria? (Domain 5, Item 21)	🟦	🟨	🟥	🟨	🟨	🟥	🟥	🟥	🟨	🟨

How well the guideline attends to equity considerations as outlined in Section 3 of the Analysis Framework including Domain 5 of AGREE II Instrument

Legend:

Blue: Clearly addresses Green: Somewhat addresses Yellow: Poorly addresses Red: Does not address at all

Opportunities for CPGs to Acknowledge and Address Equity Considerations

While analyzing the CPGs, I noticed statements throughout that presented as opportunities for CPGs developers to acknowledge and address equity considerations. Opportunities exist for developers to discuss recommendations from an equity perspective beyond potential limiting CPG clinical questions guiding the review and subsequent recommendations. Areas where developers may inject equity considerations include but are not limited to the types of clinical questions posed and subsequent literature search (e.g., exploring questions and research/literature from a naturalistic paradigm has the potential to uncover equity issues) and opportunities to engage patients and carers beyond rudimentary consultation to active participants in the CPG development process. Similar to the high value placed on the inclusion of quality evidence that contributes to the formulation of recommendations, equity considerations and patient and/or caregiver involvement must be guiding principles of the entire CPG process. The following illustrative examples represent potential opportunities: *"Endorsements:* This guideline is endorsed by the U.S. COPD Coalition, the International Primary Care Respiratory Group, and the Canadian Respiratory Health Professionals." (CHEST/CTS, 2015, p. 2). A potential goal/hope for the future would be that health organizations and associations that focus on health equity would endorse CPGs. The following illustrative example suggests that the collaborative effort amongst CHEST and CTS was a novel and unique partnership. There may be opportunities for professional associations and organizations that develop CPGs to work collaboratively with health organizations and groups that focus on health equity to develop CPGs. This would be a novel approach and evolution of historic processes: "The AECOPD Guideline is unique not only for the topic of the guideline, prevention of acute COPD exacerbations, but also for the first-in-kind partnership between two of the largest thoracic societies of North America.” (CHEST/CTS, 2015, p. 6). Perhaps there is an opportunity for additional partnerships among CPG development groups and their associated institutions to gather to discuss how to more systematically include equity considerations among all CGPs.

CPGs are formed based on relevant and meaningful clinical questions on a particular topic area relevant to COPD as evident in the following statement:

> The present clinical practice guideline has addressed several clinically meaningful questions regarding the management of dyspnea in patients with advanced COPD, using an evidence based, systematic review process led by a representative interprofessional panel of experts in the field. The evidence from the literature reviews, and the experience and guidance afforded by the expert working group members, enabled the formulation of relevant recommendations, fully recognizing that there are significant and large gaps in the scientific literature in this area. (CTS, 2011, p. 6)

What about meaningful questions about COPD and systemically and structurally disadvantaged populations? There is an opportunity to pose meaningful research questions that shape CPGs relative to the care of disadvantaged individuals living with COPD. Doing so presents an opportunity to acknowledge gaps and consider equity. Toward the conclusion of most CPGs, the authors typically identify gaps in the literature and suggest research questions to be addressed in future research. When doing so, this is yet another opportunity to make statements geared toward equity considerations for systemically and structurally disadvantaged populations. For example, “Nursing research related to interventions for individuals with COPD must be supported (Level of Evidence=IV).” (RNAO, 2010, p. 14), and “It has become very apparent from this process that there is a paucity of high-quality evidence and scientific literature on this topic." (CNO, 2012, p. 115). The following excerpts from CPGs further illustrate this notion:

> It has become apparent from this process that there is a paucity of high quality evidence, scientific literature and information regarding this topic. Further study is required to address many important clinical questions, and to provide further understanding of dyspnea in this setting. (CTS, 2011, p. 7)
>
> However, the process also clearly identified many gaps in our understanding that are deserving of further study and attention. These include gaps relating to optimal maintenance programming and maintaining the benefits of rehabilitation, the intensity of exercise training, incremental benefits of various program components, the value of exercise and activity outside the PR setting, the contributions and effects of anxiety and depression or other patient-specific factors in this setting, various adjunct techniques to maximize the training afforded by PR, and barriers to participation and adherence to PR. (CTS, 2010, p. 165)
>
> The contributions and effects of managing depression and anxiety on dyspnea also require further study. Research of the use of supplemental oxygen in this setting is necessary. Regarding opioids, several important clinical questions remain unanswered. Although opioids have proven to be beneficial, the optimal initiation dose, dosing interval, titration schedule and delivery route are not well understood.
>
> To what degree are beneficial effects or adverse effects of opioids sustained over time? Can the available data supporting oral opioids for dyspnea translate to intravenous therapy as it does in general palliative care management for those patients unable to use the oral route? Does adherence to opioid therapy change over time, and what are the

> factors (i.e., side-effects, patient/caregiver fears or misconceptions about addiction and dependence, or fears about opioids hastening death) that influence adherence? Are some opioids more efficacious or tolerated better than others? Are patients with advanced COPD at a higher risk of opioid-induced complications than other patients with severe dyspnea, and are conventional concerns with appropriately dosed and monitored opioids in patients with hypercapnia justified? Other important areas also require further study including whether the benefits from NMES realized in the research laboratory are fully transferable to the clinical setting. These important research questions require attention to advance our understanding in this area. (CTS, 2011, p. 7)

Although rare, statements such as the example listed below, shed a glimmer of light relative to equity considerations within CPGs.

> PICO question 1 addresses the following categories: a) pneumococcal vaccinations; b) influenza vaccinations; c) smoking cessation programs; d) pulmonary rehabilitation; e) education/action plans/case management; and f) telemonitoring. These topics may be considered “complex interventions”30 in that they contain multiple interacting components and possess non-linear causal pathways subject to a host of variables. Rigorous evaluation of complex interventions can be complicated by numerous factors, including the need to adapt interventions to local contexts and issues of feasibility and acceptability”.
>
> (CHEST/CTS, 2015, p. 8)

> In 2018 GOLD held a one-day summit to consider information about the epidemiology, clinical features, approaches to prevention and control, and the availability of resources of COPD in LMICs. Major conclusions of the summit included that: there are limited

> data about the epidemiology and clinical features of COPD in LMICs but the data available indicate there are important differences in these features around the world; there is widespread availability of affordable tobacco products as well as other exposures (e.g., household air pollution) thought to increase the risk of developing COPD, diagnostic spirometry services are not widely available and there are major problems with access to affordable quality-assured pharmacological and non-pharmacological therapies. (GOLD, 2021, p. 2)

There is an opportunity for all CPGs to go much further in terms of integrating equity considerations throughout the CPG process from start to finish. Although it is commendable that these CPG developers acknowledge such circumstances, they do not go far enough in terms of integrating the spirit of such statements throughout the CPG itself or its development process. Another opportunity to consider equity presents itself within the following statement.

> Similarly, we must better understand issues concerning adherence to participation in PR programs. Patients and health care systems cannot realize the benefits of PR with infrequent or short-lived participation. *Patients must advance their attitudes and behaviours, and accept PR as an integral component of their management.* However, changes in more than patient adherence are necessary for this to be successful. Barriers to participation in PR and the burdens of therapy must also be acknowledged and minimized…(CTS, 2010, p. 166)

The authors of this statement are to be somewhat commended for stating that we must better understand issues concerning adherence to participating in pulmonary rehabilitation programs and the barriers to participation in pulmonary rehabilitation must be acknowledged and minimized. However, such a statement falls short, as it is patronizing and problematic. It does not at all make suggestions on how to do so nor does it take into consideration the circumstances and experiences of systemically and structurally disadvantaged populations. It suggests that patient lack of adherence is related to their personal attitudes, behaviours, and lack of acceptance when clearly there are other complex system and access issues also at play. Additionally, the following statement also presents an opportunity to articulate how to support and enable patients to participate in pulmonary rehabilitation as well as an opportunity to make recommendations grounded in evidence from an equity perspective.

> Health care professionals and health care systems involved in the care of patients must support and enable patients to participate in PR. A collective effort by health care professionals is required for patients, families and health care systems to fully realize the many substantive benefits of PR in COPD. (CTS, 2010, p. 166)

Summary

In summary, the findings revealed through the analysis process uncover the notion that there is much variation in the way that international, national, and provincial CPGs address equity considerations as identified in the literature. In relation to Section 1 of the analysis framework that deals with population relevance, six of the ten CPGs clearly identified the COPD population that each guideline addressed while four of the ten somewhat addressed this. Only one CPG clearly articulated if any groups were excluded from the guideline while five somewhat addressed this item and four did not address this at all. Four of the CPGs clearly identified groups at high risk for COPD while one somewhat addressed this item, three poorly addressed this, and two did not address this item at all. Perhaps the most enlightening findings of all the results are from Section 2 of the analysis framework using The Equity Lens criteria. None of the ten CPGs addressed the first three criterion of The Equity Lens (*Do the recommendations in the* *guideline address a priority problem for disadvantaged populations? Is there reason to anticipate different effects of interventions in disadvantaged and privileged populations?).* Only one guideline was assessed to poorly address criterion 4 (*Is specific attention given to minimizing barriers to implementation in disadvantaged populations?)*, whereas the remaining nine did not address this criterion at all. Only two CPGs poorly addressed criterion five (*Do plans for assessing the impact of the recommendations include disadvantaged populations?),* whereas the remaining eight did not address this criterion at all.

Finally, findings of Section 3 of the analysis framework concerning guideline development and application processes, including Domain 5-Applicability of the AGREE II Instrument, revealed that all ten CPGs included experts in COPD in the guideline development group. None of the ten CPGs included an expert in health equity in the development guideline group, had any evidence that the design of the literature review search strategy could identify studies relevant to COPD and systemically and structurally disadvantaged populations, nor was there any evidence of consultation with people living with COPD and/or their carers representative of diverse contexts and regions in the development or implementation of the guideline. Only two of the ten CPGs somewhat addressed facilitators and barriers to their application where four poorly addressed this item and four did not address this item at all. Only one guideline somewhat addressed the item pertaining to whether the CPG provided advice and/or tools on how recommendations could be put into practice, five poorly addressed this, and four did not address this item at all. Eight of the CPGs did not address potential resource implications of applying recommendations at all and two poorly addressed this item. One CPG was assessed to have clearly addressed monitoring and/or auditing criteria while five poorly addressed this item, and four did not address this item at all. My study uncovered the variation across COPD CPGs in how they address or do not address equity and the assumptions made by those who develop CPGs that unintentionally exacerbate health inequity for systemically and structurally disadvantaged populations.

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Chapter 7

Discussion

This chapter is situated within a political context based on the work of Dawes (2020). It begins with a discussion of the political determinants of health followed by a discussion of the tension between neoliberalism (as a political determinant of health) and social justice and the implications for health equity. I argue that CPG development within a neoliberalist ideology is in part responsible for the fundamental gaps between CPG recommendations and realistic practice in low-resourced settings, including rural and northern communities in Ontario. My study demonstrates that although health equity is often a guiding principle in the context of health policy, the findings reveal that intentional discussion of health equity in CPGs is lacking. There are unintended consequences associated with CPGs that contribute to health inequity for systemically and structurally disadvantaged populations. More often than not, the CPG development processes and developers themselves opted not to provide resources for health equity. Borrowing from the work of Montori (2020), I further argue that as a way to counter neoliberalism within the context of CPGs, three critical and iterative junctures must be discussed and considered when assessing how well CPGs address or do not address equity: 1) before the development process begins, 2) during the CPG development process, and 3) developer and user responsibilities for implementation. This includes a discussion that invites further dialogue with all vested interest groups in terms of how long-standing CPG processes related to their development and implementation may potentially evolve to consider equity and social justice as guiding principles into the future.

It is my intention in this discussion to raise awareness and strongly encourage those who develop CPGs and other health policies to discuss health equity in their work. My study aligns with the work of Dawes (2020) and Montori (2020), more specifically in that we must confront the reality that the status quo of CPG processes is not working. Health inequities continue to persist. We must engage in meaningful conversations about how we can advance efforts aimed at formally incorporating equity discussions and considerations in the development of CPGs and health policy in general.

The Political Determinants of Health

In the words of Dawes (2020), “it is not a fluke” (p. 41) that some groups experience poverty or health disparities. My study serves as an opportunity to pause and think about how CPGs, developed within a neoliberal context, contribute to health inequity. Based on the work of Dawes, I pose the following question: Why do individuals living with COPD in rural and northern environments in Ontario continue to experience poor health as compared to their southern Ontario counterparts? I, along with Dawes, would argue that the answer to this question is because of the political determinants of health. The “political determinants of health inequitable distribute social, medical, and other determinants and create structural barriers to equity for population groups that lack power and privilege (p. 42)”.

Dawes (2020) argued that the political determinants of health are influential in shaping the health of a nation. His work suggests that once we clearly understand the political determinants of health and how they interface with health policy, will we be in a better position to use the political processes to implement change. This discussion, based on the findings of my study, provides a glimpse into how CPGs development processes are situated within neoliberalism, without regard for equity for systemically and structurally disadvantaged populations. My study concurs with Dawes’ idea about how structures and processes contribute to variations in health conditions within different groups. Findings of my study illustrate the detrimental assumptions that developers of CPGs, particularly in relation to health and human resources and infrastructure, that conflict with the reality of underserved contexts. My findings indicate a failure of CPGs to serve as a conduit to bridging the gap between theory and practice. Health care professionals cannot make evidence-informed choices when attempting to implement recommendations that are not feasible or unrealistic for implementation in underserved contexts and with systemically and structurally disadvantaged populations. Appreciating that the political determinants of health are complex, I next focus specifically on the antagonist relationship between neoliberalism and social justice.

Neoliberalism versus Social Justice: Implications for Health Equity

Neoliberalism is a theory of political economic practices that proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong private property rights, free markets, and free trade (Harvey, 2005). Neoliberalism is a prominent political ideology for many governments and institutions around the world that emphasizes the principles of individualism, privatization, and the reduction of state interventions in economic and social activities over the principles of social rights and collective welfare (Braedley & Luxton, 2010; Mykhalovskiy, Choiniere, Armstrong, & Armstrong, 2020; Navarro, 2007; Polzer & Power, 2016). Scholars have suggested that neoliberalism consists of three central and related aspects, including 1) an ideology that champions markets free of state intervention, 2) a set of policy measures centered on freeing markets from state regulation, and 3) a mode of governance that understands and reinforces the notion that power is and can be exercised outside the state sector (Connell, 2010; Mykhalovskiy et al., 2020; Armstrong, 2013).

In Canada, neoliberal relations of health care also manifest as the growing treatment of health as an individual responsibility (Mykhalovskiy et al., 2020; Polzer & Power, 2016). A neoliberalist approach defers the responsibility of health to individuals and does not place responsibility on the systems and structures that greatly affect health. Polzer and Power (2016) further suggested that neoliberal approaches to social policy favour a model of citizenship where individuals are expected to demonstrate their duties to maintain their health through their own "free choices" and "informed decisions" (p. 4). The focus on individual behaviours and biological processes rather than social determinants as explanations of health reflects a neoliberal approach to health(care) (Polzer & Power, 2016). Braedley and Luxton (2010) suggested that neoliberalism is not advancing social justice and equality but rather reinscribes, intensifies, and creates injustices and inequality and neoliberalism developed as a defence of capitalism and in fierce opposition to socialism. Bryant and Raphael (2018) contended that the acceptance of neoliberalism as a governing ideology has seen Canada further reducing the State role in managing the economy and providing economic and social security to its citizens that has implications for systemically and structurally disadvantaged populations. Scholars have suggested that neoliberalism contributes to health inequity (Braedley & Luxton, 2010; Brassolotto, Raphael, & Baldeo, 2014; Bryant & Raphael, 2018; Hofrichter, 2003; Mykhalovskiy et al., 2020; Navarro, 2007; Raphael, 2010, 2011; Raphael & Bryant, 2023; Raphael & Sayani, 2019). Raphael (2010) suggested that the political and economic forces of neoliberalism in Canada could surpass the best intentions of health researchers attempting to promote health equity. This notion provides health researchers an important motivation to continue to challenge neoliberalist perspectives that exacerbate health inequities.

My analysis of COPD CPGs has revealed that other than the annually updated international GOLD guideline, none of the guidelines addressed equity considerations of their recommendations for systemically and structurally disadvantaged populations. This analysis therefore indicates that CPGs inhabit a neoliberal perspective as they do not address or discuss the social determinants of health (SDoH) nor diverse contexts (i.e., social problems, health and political issues, economic conditions) in which they may, or may not be, implemented. In fact, some guidelines, whether intentionally or unintentionally, clearly perpetuate inequity by not attending to equity considerations at all throughout the CPG process. This work illuminates a glaring question: Where within all aspects of the CPG process are the considerations and discussions pertaining to equity, SDoH, and systemically and structurally disadvantaged populations?

Graham (2004) stated that SDoH refer to societal factors, usually the unequal distribution of their factors that contribute to both the overall health of Canadians and existing inequalities in health. Raphael (2011) identified various SDoH discourses and their contributions and limitations toward advancing the SDoH agenda in Canada and elsewhere. He asserted that the SDoH concept is common to Canadian policy documents produced by the federal government, yet little effort is undertaken to strengthen their quality and promote their more equitable distribution through public policy action and systemic-structural reform. He further argued that this is because "the SDoH concept and its public policy implications conflict with government approaches to welfare state retrenchment and deference to the dominant societal institution in Canada, the marketplace" (p. 221).

Within this neoliberal context, many SDoH researchers are reluctant to identify policy implications of SDoH. Raphael (2011) illustrated this by pointing to research about, for example, cardiovascular and respiratory disease and type II diabetes, where researchers include robust discussion about the importance of SDoH on these chronic diseases, yet recommendations are limited to promoting healthy lifestyles (i.e., eating fruits and vegetables, increasing physical activity, and avoiding alcohol and tobacco). Such an example represents missed opportunities by researchers and those in government to recognize the role they can play in "addressing the underlying structural drivers of health inequalities and the treatment of basic needs" (p. 222).

It is well known that SDoH strongly influence the health of individuals and communities and represent the quantity and quality of a variety of resources a society makes available to its citizens. Yet, because of the conflict between SDoH and government approaches to health and welfare, governments have weakened their commitments to provide citizens with various benefits and supports (Raphael, 2008; Bryant, 2009; Bryant & Raphael, 2018; Raphael, 2010; Raphael & Bryant, 2023). Brassoloto et al. (2014) argued that a substantial barrier to meaningful action on SDoH is the internalization of discourses and traditions that treat health as individualized and depoliticized. Other critical health scholars also asserted that Canada's efforts to strengthen the quality of SDoH that are experienced through public policy lags well behind those seen in other developed nations (Raphael, 2010, 2011; Raphael & Sayani, 2019). According to Raphael (2011), "various discourses that consider SDoH but ignore their public policy antecedents allow governmental authorities to neglect the quality of SDoH that are experienced and their inequitable distribution" (p. 230). Since Raphael's work in 2011, where he discusses seven discourses on the SDoH, more recently, Raphael and Bryant (2023) have updated this earlier work and identified an eighth discourse that includes the notion that the SDoH and their distribution results from the processes inherent to capitalism.

Given the findings of my study and the benefits and limitations associated with CPGs themselves within the literature and as outlined in Chapter 4, there is opportunity to improve the evolution of CPG processes to include considerations of health equity and SDoH more fully and explicitly. I challenge those within the CPG realm to engage in dialogue and discussion about the formal inclusion of an equity and SDoH lens within the CPG processes. This could assist developers of CPGs to explicitly include these concepts as guiding principles threaded throughout the entire CPG process. Doing so has the potential to formally acknowledge and address the health realities of diverse populations including systemically and structurally disadvantaged populations within CPGs. In turn, this may facilitate CPG uptake and the opportunity for recommendations at the practice, educational, organizational, and policy level to better address the complexities of the lived experience of systemically and structurally disadvantaged populations. Raphael and Sayani (2019) suggested that the public is given little exposure by governmental authorities to the importance of promoting health equity through public policy action on the social determinants of health. They further stated that efforts by public health units to promote health equity through action on SDoH have implications for those in jurisdictions where government attention to these issues is lacking. For example, over the past decade, the Sudbury and District Health Unit (SDHU), now Public Health Sudbury and Districts (PHSD), has evolved its work to move beyond modifying service delivery toward taking a leadership role in placing the SDH and equity on the public policy agenda (Sudbury and District Health Unit, 2012ab). This included the 2011 production of a video entitled, *"Let's Start a Conversation about Health and Not Talk About Health Care at All"* that changes the focus from health care to the social and economic factors that impact health (Sudbury and District Health Unit, 2011). I would suggest that the ideas proposed by Raphael and Sayani's work be applied to

CPG processes to benefit individuals living with COPD in under-resourced rural and northern areas including Northern Ontario. This begs the question, is there a will and thus potential for institutions and developers of COPD CPGs to consider health disparities associated with COPD and subsequent recommendations about the screening, diagnosis, and management of COPD from an equity approach as a means to move toward social justice?

My study findings also revealed that there is an undertone of a neoliberal individualistic view of health care within these guidelines. Such a tone views individuals as personally responsible for their health and that the problem is the individual and not the systems that perpetuate inequity among systemically and structurally disadvantaged populations. For example, statements such as, “Patients must advance their attitudes and behaviours, and accept PR as an integral component of their management” (CTS, 2010, p. 166). Some guidelines went as far as making patronizing and inappropriate statements aimed at individuals living with COPD without acknowledgement, care, or consideration of the complex experiences and circumstances of systemically and structurally disadvantaged populations. Such a tone and approach present a missed opportunity for developers of CPGs to make evidence-informed recommendations from a health equity and socially just approach. This involves initiating and advocating for health policies and social systems that aim to address health disparities and inequities experienced by systemically and structurally disadvantaged populations living with COPD. It also requires shifting from a neoliberalist view to one that views health not primarily as an individual responsibility but rather the responsibility of government. Doing so provides the opportunity to view health from an equity and SDoH perspective that causes us to pause and critically examine and reflect on the systems and structures that promote health inequities. I suspect that researchers are starting to do this, but then the issue becomes trying to convince the government to implement recommended changes that come from their work that advance health equity.

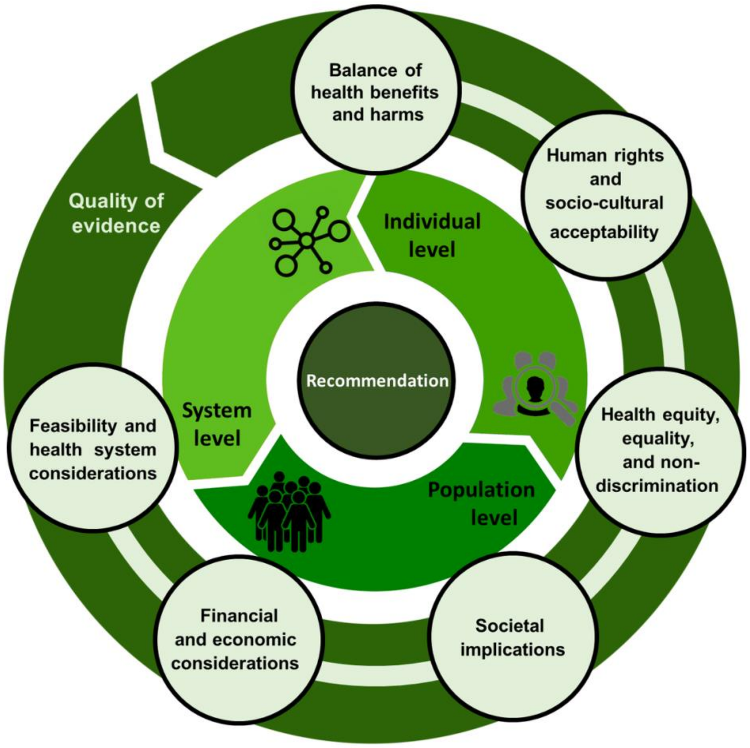
Fundamental Gaps between CPG Recommendations and Realistic Practice

The World Health Organization (2014) contended that health agencies and individuals who develop CPGs seem to take for granted that their CPGs will be adequately adapted to local contexts. However, Maaloe and colleagues (2021) demonstrated the injustice of unfit clinical practice guidelines in low-resource realities. They suggested that fundamental discrepancies exist between recommendations and realistic best practice in low-resource settings. These authors stated that these discrepancies cause “alarming risk” of preventing actual use of CPGs, disenfranchise and demoralize HCPs, drain resources, and paradoxically cause unintentional harm in clinical practice (p. e875). They posed questions about whose perspectives count in current CPG development processes. Many scholars have asserted that front-line health providers with knowledge and experience in low-resource clinical practice with insight into sustainable development are rarely invited to participate in or influence the CPG development or adaptation processes, yet they are asked to use CPGs that are dangerously incomplete, irrelevant, impractical, or outdated (Andrews, Pritchett, & Woolcock, 2012; Maaloe et al., 2021; Nielsen & Randall, 2012). Further, Norris and Ford (2017) suggested that pilot testing among end-users of CPGs and post implementation evaluation are often neglected.

By way of attempting to address the challenges of unfit CPGs in low-resource contexts, Maaloe and colleagues (2021) discussed the WHO-INTEGRATE framework by Rehfuess, Stratil, Scheel, Portela, Norris, and Baltussen (2019) (Figure 7-1). This work outlined how CPG developers around the world can more effectively stratify recommendations for low-resource settings and account for predictable contextual barriers of implementation (e.g., human resources) and gains and losses (cost-efficiency). The framework encourages a structured process of reflections during CPG development within its six criteria: balancing of health benefits and harms, human rights and sociocultural acceptability, health equity, equality and non-discrimination, societal implications, financial and economic considerations, and feasibility and health systems considerations. A seventh criterion, quality of evidence, applies to all six of the above-mentioned criteria.

Figure 7-1

The WHO-INTEGRATE (INTEGRATe Evidence) Framework version 1.0 (Rehfuess et al., 2018)

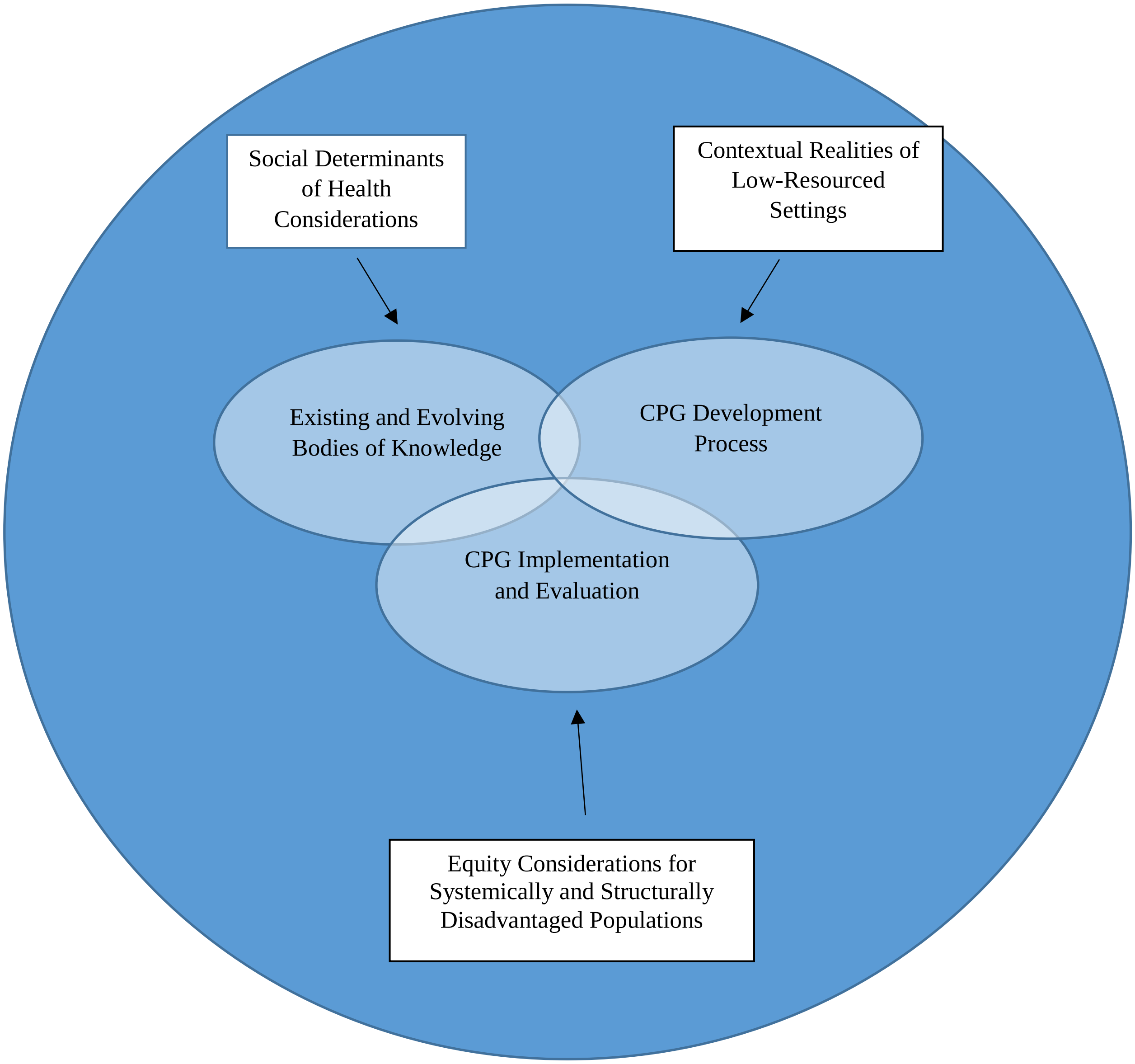


Maaloe and colleagues (2021) argued that the way forward involves the development of contextualized and realistic clinical practice guidelines for health care providers practicing in unique, diverse, and challenging contexts, where guidance is most acutely needed. They asserted that the development of more realistic CPGs at the global level would pave the way for simpler and achievable adaptation at local levels. This aligns with the views of McCaul, Ernstzen, Temmingh, Draper, Galloway, and Kredo (2019) who suggested that high quality contextualization and adaptation of CPGs might have greater potential to make the best use of scarce resources. Maaloe et al. (2021) acknowledged the ethical dilemma that exists between producing acceptable CPGs for unacceptable realities and the moral duty to deal with realities that must not be accepted in the long run. The development and adaptation of high quality, contextualized, and realistic CPGs will assist health care providers in saving lives rather than causing immobility by a desire for perfection (Maaloe et al., 2021).

From a critical perspective, my study has revealed unintended negative consequences of COPD CPGs, particularly within low-resource, rural, and northern settings. A discussion of my findings aligns with the work of Montori (2020) since I argue there is a need for revolutionary change in the arena of CPGs that would provide hope for careful and kind care within the health care system. This is an opportunity to counteract neoliberalism within what I understand to be three iterative and critical junctures within the context of CPGs so that health equity is explicit within all aspects of CPG processes (i.e., before CPG development process-existing and evolving bodies of knowledge, during CPG development, and developer and user responsibilities for CPG implementation), by means of advancing social justice. This includes a deliberate consideration and discussion of SDoH, contextual realities, and equity considerations for systemically and structurally disadvantaged populations. These three iterative and critical junctures are discussed in the proceeding section and are represented by the aspirational model I created, which is presented below in Figure 7-2.

Figure 7-2

Introducing Social Justice in CPGs



First Critical Juncture: Before CPG Development Process Begins—Existing and Evolving Bodies of Knowledge

The first critical juncture occurs before the CPG development process begins. One could argue that the assessment of quality of any CPG recommendations, especially within the context of health equity, is heavily contingent upon the availability of quality evidence that specifically addresses equity and systemically and structurally disadvantaged populations. The creation of new knowledge that thus contributes to the published body of evidence in any given area serves as the base from which CPG developers search, apprise, and eventually draw upon for their recommendations. In terms of the body of evidence that exists in a particular area that a particular guideline is to address, it is not the fault of CPG developers that in some respect, the recommendations they make are only as good as the body of knowledge that they are to adjudicate, that is, if the body of knowledge even exists.

Any given body of knowledge has substantial variety in how it does or does not consider equity and aspects related to systemically and structurally disadvantaged populations that experience health inequity. The context of the body of knowledge must also be considered relative to the maturity of the evidence. For example, a body of evidence in any given area may be robust and mature, whereas others may be emerging. It is also important to consider the evolution of a body of evidence as it relates to equity considerations as these may be more apparent in newer evidence. I would argue that the GOLD 2022 CPG that was analyzed in my study (GOLD, 2021) began to discuss SDoH and equity considerations more so than any other CPG in this study. When formulating CPG recommendations, developers must also make judgements relative to the generalizability or transferability of findings that form the basis of said recommendations. What is within their purview, however, is selecting search methods, assessing quality of published evidence, and determining which evidence to include on which to base and/or formulate CPG recommendations. Sometimes, there is no evidence and the developers include their own expertise and experiences when formulating CPG recommendations. Given this, I would argue that authors that represent and work within the context of systemically and structurally disadvantaged populations must be directly included throughout the CPG development process.

In 2009, the World Health Assembly made a resolution to reduce health inequities through action on the social determinants of health (WHA, 2009) by calling for researchers and those organizations who fund research to prioritize these areas (Ostlin et al., 2011). Similarly, many scholars and organizations have discussed shifts in both public health practice and health research to advance health equity and quality improvement (Bowleg, 2017; Canadian Institutes of Health Research [CIHR], 2022ab; CIHR, 2021ab; Eslava-Schmalbach, Garzon-Orjuela, Elias, Reveiz, Tran, & Langlois, 2019; Liburd, Hall, Mpofu, Williams, Bouye, & Penman-Aguilar, 2020; McNulty et al., 2019; Ostlin et al., 2011; Scott & Rawal, 2018; World Health Assembly, 2009; World Health Organization [WHO], 2005; 2008).

There is a need to strengthen research on health equity with a focus on SDoH and doing so requires a paradigm shift that explicitly addresses social, structural, political, and economic processes that influence population health (Bowleg, 2017; Ostlin et al., 2011; Reutter & Kushner, 2010; Trinh-Shevrin et al., 2015). In Canada, the CIHR (2022a) is committed to achieving a more equitable, diverse, and inclusive Canadian research enterprise and has suggested that it is essential to creating innovative and impactful research required to advance knowledge and understanding, and to respond to local, national, and global challenges. McNulty and colleagues suggested that the scientific enterprise has invested disproportionately in research that failed to eliminate health disparities and instead the focus ought to be on designing new research that includes a focus on populations experiencing disparities in health. Collectively, there is a will to explicitly consider equity and SDoH in the development of innovative health research. In turn, this presents as an opportunity to see an increase in health research that focuses on equity, that in turn may potentially make its way to be seriously considered by authors of CPGs in the development processes and subsequently included in CPG recommendations.

CPG Development Process

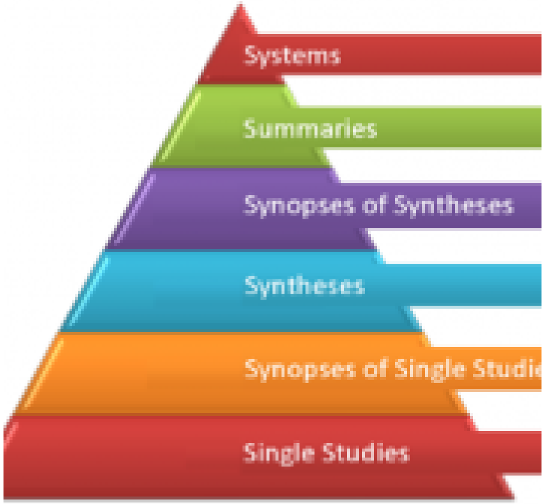
The second critical juncture occurs during the CPG development process itself. Given the diverse approaches that CPG developers may employ with the process, it is not surprising that so too are the ways in which equity may or may not be considered. Developers of CPGs may well or not be aware of the variety of tools and checklists that can be used to assist them (Akl et al., 2017; Dans et al., 2007; Pottie et al., 2017; Schunemann et al., 2014; Welch et al., 2017ab) to articulate equity considerations in the CPG development process and the recommendations that they ultimately make. There is a high degree of variation with respect to how CPG developers consider equity and integrate it throughout a CPG.

When deciding on their approach to CPG development, particularly in relation to formulating the clinical questions that guide the CPG and subsequent literature review, it is critical that developers pose clinical questions that include systemically and structurally disadvantaged populations. Doing so will also encourage developers to go beyond the traditional search methods and inclusion criteria. I would suggest that developers must invest in critical considerations of what constitutes a particular body of evidence, such as where is the evidence coming from?, is it predominantly from a particular region(s), context?, who is contributing to the body of evidence and how?, what and who are the dominant voices?, are there critical voices that are not being represented within the evidence?, and does the body of evidence address systemically and structurally disadvantaged populations? If the answer to any of these questions suggests that the body of evidence is missing key aspects of equity, developers should consider going beyond the published evidence when formulating recommendations. Developers can consider the inclusion of grey literature (i.e., reports, epidemiological data) that may add value to recommendations via the inclusion of statements that consider context, diversity, and implications for systemically and structurally disadvantaged populations that exists in relation to health inequity. In doing so, CPG developers can then clearly express equity considerations along with each recommendation.

Initially, as an undergraduate and graduate student, and then as a registered nurse involved in the development of a best practice guideline for COPD, I became ever more aware of the hierarchy of evidence and levels of evidence. This hierarchy of evidence is often referred to at the 6S pyramid (Figure 7-3), whereby a part of the evidence’s ability to guide clinical action increases as one moves up the pyramid, whereas the base of the pyramid represents the breadth of knowledge (DiCenso, Bayley & Haynes, 2009; Windish, 2013).

Figure 7-3

6S Pyramid-Hierarch of Evidence (DiCenso, Bayley, & Haynes, 2009).



In the context of CPG development, developers refer to quality and strengths of evidence when grading recommendations. This system values well-designed randomized controlled trials (RCTs) with consistent and directly applicable results. Other types of evidence are ranked below RCT and are less desirable or viewed less favourably and may affect developer assessment of the quality of recommendations based on such evidence. Evidence from individuals' lived experience of illness or anecdotal evidence based on clinical experience or opinion are not highly ranked.

CPG developers employ hierarchy, quality, and strength of evidence as the basis of CPG recommendations. Critical questions arise as to what types of evidence to include in CPGs?, what types of evidence are awarded greater value than others?, and why is this? It is common practice for CPG developers to utilize the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) framework, a widely accepted method that provides a systematic approach for making clinical practice recommendations by grading the quality of the evidence. The GRADE approach, however, depends upon the types of clinical questions posed, including the population that the question(s) applies to, and it thus determines the quality of the evidence that the literature search related to the question(s) yields. As such, if the clinical questions posed do not consider equity nor systemically and structurally disadvantaged populations, then the literature that results (and assessed for quality) will not be representative. As mentioned above, this further illustrates the need for a paradigm shift that explicitly addresses social, political, and economic processes that influence population health to strengthen research on health equity (Ostlin et al., 2011). In turn, it may be past due to reconsider how we understand the hierarchy and levels of evidence.

Within the hierarchy and levels of evidence that recommendations are based on, evidence obtained from meta-analysis or systematic reviews of randomized controlled trials are superior. Next comes well-designed cohort or case-control studies. Below that, are well-designed quasi-experimental studies without randomization. Evidence from observational studies, non-experimental descriptive studies (i.e., comparative studies, correlation studies, case studies), or qualitative studies are assigned lesser value and evidence obtained from expert committee reports or opinions and/or clinical experiences of respected authorities even less (if any at all). In their GRADE Handbook, Schünemann, Brożek, Guyatt, and Oxman (2013) ask developers to define health care questions including all outcomes of interest Those developing recommendations about management of a particular chronic disease and whether or not to use a particular therapeutic or diagnostic intervention are encouraged to pose questions, such as Should [intervention] vs. [comparison] be used for [health problem]? , Should [intervention] vs. [comparison] be used in [population]?, and Should [intervention] vs. [comparison] be used to diagnose [target condition] in [health problem and/or population]? These questions are important, however, equally important is how to incorporate clinical questions and evidence from theoretical and qualitative research (Debolt, Brizendine, Tomann, & Harris, 2021; Goodridge et al., 2019; Lundell, Modig, Holmner, & Wadell, 2020; Pleasants, Riley & Mannino, 2016; Siegel, Krishnan, Lamson-Sullivan, Cerreta, & Mannino, 2016; Willard-Grace et al., 2021) that is interpretive in nature and can perhaps illuminate and address equity considerations from systemically and structurally disadvantaged populations. Similar to other GRADE tools, the GRADE CERQual (2018) approach is a transparent method for assessing the confidence of evidence from reviews and qualitative research that I argue CPG developers must use to confidently include such evidence in their development processes and subsequent recommendations.

CPG Implementation and Evaluation: Developer and User Responsibilities

The third critical juncture occurs during the implementation and evaluation of CPG recommendations by developers and users. Findings of my study revealed that some of the institutions that CPG developers are associated with state that they update recommendations either on an annual basis or every three years based on any new evidence within newly published literature. However, the processes employed by developers of CPGs to evaluate the impact of their work are generally unclear and non-existent, especially for how their recommendations impact systemically and structurally disadvantaged populations. What if CPG developers included The Equity Lens in their evaluation of their guidelines and did not just leave it to the user to evaluate how well the guideline addresses equity? Some developers of CPGs use the Appraisal of Guidelines for Research & Evaluation II (AGREE II) Instrument (2017). As seen in my work, Domain 5-Items 19–21 speaks to applicability. What if a Domain that relates to equity was added to the AGREE II instrument?

Users of CPGs are often left to evaluate the recommendations made within guidelines on their own and determine how they utilize them (or not) in their practice. As discussed in Chapter 3, understanding how equity is addressed in CPGs has implications for their uptake by health care professionals (HCPs) who may struggle with the feasibility, relevance, attainability, and applicability of recommendations, especially within contexts that experience structural and service variations in health systems. This may offer insight as to why guidelines are often underutilized by HCPs. Finally, guideline recommendations also may be challenging to implement in contexts where inequities and/or structural vulnerabilities impede the delivery of and access to quality services (i.e., lack of infrastructure, diagnostic services, and specialist HCPs).

Incorporating Knowledge and Lived Experiences of HCP and Individuals within Systemically and Structurally Disadvantaged Populations

My analysis also revealed that there was limited to no consultation with individuals living with COPD and/or their carers. I suggest that this is highly problematic. Individuals with COPD and/or their carers must be active participants in the CPG development process. Review of supporting documents revealed that the Canadian Thoracic Society (CTS) (2022a) outlines its processes relative to new guideline topics or updates. A section of this document refers to panel composition whereby developers are directed to apply the CTS Patient/Public Involvement (PPI) process (CTS, 2022b). The PPI process is articulated in another supporting document of the CTS that outlines opportunities for consultation and/or participation. Despite this, analysis of CPGs revealed no detailed information of such participation and/or consultation. Scholars have argued of the importance of incorporating the knowledge and lived experiences of health care professionals, patients, and carers in underserved communities who are systemically and structurally disadvantaged in health care planning and policy (Bantham, Ross, Sebastião, & Hall, 2021; Bigdeli, Rouffy, Lane, Schmets, & Soucat, 2020; Crawford et al., 2002; Hawley, 2015; Macaulay, Reinap, Wilson, & Kuchenmüller, 2022; Maguire & Murphy, 2022; Mulvale et al., 2019; Park, 2020; Standerfer, Loker, & Lochmann, 2022).

Knowing this, from a social justice perspective, organizations involved in CPG development must mandate and insist that patients and/or members of the public representing diverse perspectives, including systemically and structurally disadvantaged populations, be immersed in the CPG development processes. Incorporating these critically important perspectives will assist CPG developers in making recommendations that are relevant and more appropriate for addressing vulnerable and systemically and structurally disadvantaged populations and support greater uptake and sustainability. This idea is supported by Montori (2020) as an opportunity for CPG developers to co-create recommendations as one way to contribute to kind and humane health care.

Opportunity to Evolve and Enhance CPGs Processes—What Could Be?

The development and methodological processes of CPGs have a history dating back to the 1970s (Woolf, 1992). Since then, CPGs have evolved from those that were based mainly on expert opinions derived from clinical practice to those based on systematic searches of peer-reviewed research and evidence (Murad, 2017). The efforts of those institutions and individuals who develop CPGs and attempt to provide health care professionals with clear evidence-based guidelines to draw upon when providing care to individuals are to be applauded. CPGs provide recommendations that aim to standardize care (Gupta et al., 2009; Kredo et al., 2016; Schunemann, Zhang & Oxman, 2019; Weisz, Cambrosio, Keating, Knaapen, Schlich, & Tournay, 2007; Woolf, Grol, Hutchinson, Eccles & Grimshaw, 1999), with an implicit goal of achieving equity of care among diverse populations. However, the findings of my study suggest that this aim is not necessarily achievable in the current form of CPG processes and there is more work to be done, particularly about how we understand and incorporate the experiences of systemically and structurally disadvantaged populations and equity within CPGs.

As mentioned in Chapter 4, CPGs provide a way to bridge the gap between policy, best practice, local context, and patient choice. CPGs attempt to improve outcomes at both an individual and a system level (Kredo et al., 2016). They are designed to improve quality of care, reduce variation in practice, and ensure effective and efficient evidence-based care is delivered (Boivin et al., 2010; Grol et al., 2003; Woolf et al., 1999). In doing so, they have the potential to reduce morbidity and mortality, improve efficiency, contain costs, and ensure consistency in practice and points of reference for HCPs (Giugliano, Lloyd-Jones, Camargo Jr, Makary & O’Donnell, 2000; Woolf et al., 1999). However, my study suggests that the way CPG recommendations are presented is problematic and challenging to implement in rural and northern contexts, especially for systemically and structurally disadvantaged populations. Although recommendations aim to standardize care in relation to a variety of aspects (i.e., improve COPD diagnosis, management of AECOPD and dyspnea, and pharmacological and non-pharmacological disease management and reduce hospitalization, readmission, and mortality), my analysis reveals a lack of consideration of equity and contextual realities in low-resourced environments. CPGs present the ideal, the optimal, tenets of comprehensive care for individuals living with COPD. They do not represent a “one-size-fits-all” or even a “one-size-fits-most” approach, nor should they. CPGs possess a powerful platform. Given this, it is more than appropriate for developers of CPGs to, not only present recommendations based on the best available quality evidence for multiple sources and paradigms, but also include discussions of recommendations from an equity perspective. They must consider the implications of what they are recommending on those who are disadvantaged by virtue of place of residence, race, occupation, gender, religion, education, socioeconomic status, and social network and capital. I also think that CPG developers have an ethical obligation to go beyond current practices and somehow come together to collectively discuss how to evolve CPG processes to include an Equity Lens. Anything less perpetuates the status quo and perpetuates or even exacerbates health inequities experienced by systemically and structurally disadvantaged populations.

Furthermore, CPGs can influence public policy as they often bring attention to under-recognized health problems, clinical services, and preventative interventions and to neglected patient populations and high-risk groups (Woolf et al., 1999). As such, they can promote distributive justice by advocating for better delivery of service for those in need. Interestingly and perhaps rather concerning and perplexing is that in carrying out this research, I found that despite this very important opportunity among the CPGs analyzed, there was a paucity of the integration, consideration, and discussion of equity—and by extension—the social determinants of health within them (Woolf et al., 1999). Now more than ever, there is an opportunity for the processes associated with CPGs to continue to evolve to keep pace with contemporary approaches and understandings that meaningfully and appropriately address and promote health equity and reduce health inequities. These are priority issues for health researchers (Browne et al., 2012; Greenwood et al., 2018; Pinto et al., 2012; Raphael, 2010; Reutter & Kushner, 2010), systemically and structurally disadvantaged populations, communities, and the HCPs.

A review of the literature as outlined in Chapter 4 discusses the criticisms of CPGs. Perhaps most scathing is the criticism that describes the creation and development of the Registered Nurses Association of Ontario (RNAO) CPGs as “part of an ideological agenda that is scientifically, socially, politically, and ethically unsound" (Holmes et al., 2008, p. 394). These authors argued that guidelines symbolize ready-made tools and rules that impede critical thinking and reflection within practice and that they produce an illusion of scientific and ethical truth that cannot be translated into the real world of practice. Building off this criticism, my analysis of CPGs revealed problematic ways in which CPG developers perhaps unintentionally exacerbate health inequity, particularly for systemically and structurally disadvantaged groups.

CPGs can contribute to patient transformation and support HCP practice to improve the lives of patients living with chronic illness and contribute to fostering healthy communities. They also have great potential and accountability to foster innovative policy, whereby in conjunction with HCPs and patients, they can leverage their position to champion health equity considerations and mobilize resources for positive change toward more compassionate care.

My study revealed CPGs as what Montori (2020) would refer to as unkind and uncaring. CPGs present as a protocol for disease yet do not address depleting health human resources or contextual realities of systemically and structurally disadvantaged populations. In some respects, CPGs view the patient as the problem. In this respect they are, using Montori's word, cruel. They present the ideal and the unattainable for systemically and structurally disadvantaged populations and rural and northern communities that do not have the luxury of health human resources and/or health infrastructure. Individuals living with chronic illness(es) are just that. They are not their illness but rather individuals who live with a chronic illness that requires regular and ongoing care with the right service of care at the right time throughout their lifespan. This care ought to be informed by evidence but it must also be considerate of the context of a life, where one lives, and an appreciation of its uniqueness.

Conclusion

The preceding discussion highlighted the political determinants of health, the tension that exists between neoliberalism and social justice, the implications for health equity, and the gap that exists between CPG recommendations and realistic practice in low-resource settings. It also included a discussion of a strategy to counteract neoliberalism through deliberate and thoughtful inclusion of SDoH, contextual realities, and equity considerations within three iterative and critical junctures where equity must be considered, including before CPG development, during CPG development processes, and responsibilities of developers and users of CPG. The limited or lack of inclusion of equity considerations in CPGs has detrimental implications for the populations that CPGs aim to address but also for health care professionals who may feel inadequate if they are not able to implement recommendations given unique and challenging circumstances they face in their practice environments.

Evidence-based recommendations in COPD CPGs aim to reduce hospital readmission for individuals following an acute exacerbation, slow the illness trajectory, prevent the acquisition of infectious respiratory disease, and improve management of symptoms and quality of life (Brignardello-Petersen et al., 2021; Guerra-Farfan et al., 2022; Shekelle, 2022). In an ideal world, guidelines, as currently developed and written, would be implemented by health care professionals and decision- and policymakers, leading to, among many things, a reduction of health service utilization and health care costs, and see individuals living with COPD appropriately diagnosed and managed. The incidence and prevalence of COPD in Northeastern Ontario is higher than that of our southern counterparts and the health costs associated with health service utilization continue to increase. Appreciating that this is not an ideal world and there are many complex circumstances contributing to this problem, I would argue that given that CPGs and their associated processes do not explicitly and comprehensively discuss health equity, they play a role in this complex puzzle.

It is critical that CPGs are embedded within an equity perspective and consider not only the implications of recommendations on systemically and structurally disadvantaged populations, but throughout the CPG development process as well. Further work is required to be more inclusive of systemically and structurally disadvantaged populations and health equity. My study reinforces the work of scholars who highlight the importance of participation from structurally and systematically disadvantaged populations in research and policy and the importance of making this participation feasible and beneficial for the participants. Doing so may result in recommendations that are more meaningful and appreciate context and the social determinants of health. This may have greater positive effect at the practice, educational, and organizational and policy level. It may also increase their uptake, which could in turn see a reduction in health service utilization and increased quality of life for systemically and structurally disadvantaged individuals living with COPD.

Further, given that CPG developers rely on the availability of evidence on which to base their recommendations, how can the scientific community collectively work together to strengthen or even include an equity perspective in all aspects of the scientific process associated with knowledge creation, CPG development, implementation, and evaluation? The discussion regarding levels and quality of evidence and the results of my study beg the question, is there an opportunity to revisit the hierarchy of evidence so that it somehow includes an equity perspective? A final thought for all to reflect upon. Given the patchwork approach to equity considerations within CPGs, how can the numerous organizations from around the globe who have a stake in the clinical practice guideline realm come together to evolve the processes associated with CPG development, implementation, and evaluation to better harmonize clear approaches that include consideration of equity, social justice, and context? I contend that my study findings and discussion are translatable across all CPGs and other health policy documents. My study serves as a spark to initiate awareness, discussion, and reflection on how we may evolve CPG development processes and associated evidence in an effort to strive for a more equitable and healthy society. Future work must be done to gain additional insight into how to address the political, social, and economic factors that contribute to health inequity and adversely affect the health of systemically and structurally disadvantaged populations.

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Chapter 8

Conclusion

My study is novel as there is limited research that critically examines COPD CPG documents through the lens of health equity and access to health service in the context of Northeastern Ontario. The analysis and findings of my study provide insight about the inclusion (or omission) of an explicit or implicit health equity focus in CPGs for COPD. In turn, I hope my study contributes to the discussion of and illuminates considerations of health equity and access to health services for all systemically and structurally disadvantaged populations including those living in Northeastern Ontario. In addition, my study also provides insight into how CPGs, that intend to offer a more systematic approach to care, may actually exacerbate health inequities. My study also contributes to the discourse surrounding CPG development processes to ensure health equity is considered more fully within recommendations made. As such, health equity would be considered earlier on in the development process as opposed to current practice where it may be considered only in the implementation and uptake phases. Findings also reveal the need to revise the AGREE II Instrument so that a domain directly addressing health equity is added as an element of the quality of guidelines. My study also illustrates the value of performing this kind of analysis for CPGs of other chronic diseases including screening, diagnosis, and management.

To ensure my work is meaningful to diverse disciplines, I recruited supervision from various disciplines. My study speaks across disciplinary languages and invites further inter-disciplinary engagement on the issue of equity and CPG development and uptake in Ontario, Canada, and across the globe. An important outcome of my study is that it provides recommendations aimed at more purposeful and appropriate health policy and service planning and provision to support health equity for systemically and structurally disadvantaged populations, and more specifically for individuals living with COPD and their carers in Northern and rural Ontario.

Suggestions for Future Study

As a health researcher working from a critical social approach, my study illuminates the challenges associated with achieving health equity for all and the need to work toward collaborating with vested interest groups to attempt to address these challenges through research and collaborative strategic planning. Knowing this, my doctoral work represents the initial stage of a program of research I am committed to continuing. I plan to engage in a future study that explores the perceptions of health equity relative to COPD for HCPs, decision- and policymakers, and individuals living with COPD and their carers in Northeastern Ontario. I invite collaboration with other scholars, clinicians, individuals living with chronic illness and their carers, and health care professionals across various sectors and diverse practice settings on research endeavours aimed toward the achievement of health equity.

Knowledge Translation and Exchange (KTE)

My research aims to enact a Knowledge-to-Action (KTA) Framework (CIHR, 2015; Graham et al., 2006). This framework articulates the complex and dynamic processes associated with knowledge creation and the actions related to its uptake and utilization in practice. It supports knowledge exchange, which the Canadian Foundation for Health Care Improvement (CFHI, 2020) defines as collaborative problem solving between researchers and decision-makers that happens through linkage and exchange. This aligns with both the KTA framework and the goal of interpretive description where I will seek ways to share the findings of my study with relevant vested interest groups including decision- and policymakers, HCPs, members of the community, as well as health researchers. I hope to engage in collaborative dialogue with vested interest groups so that my research may contribute to the larger conversation about how to move toward health equity for residents of Northeastern Ontario.

In addition to the publication of two articles included in this work, some potential ways in which I will foster this knowledge exchange may be through a policy brief intended for policy and decision-makers and an infographic of the findings that may be useful to those in applied practice and within the community. I intend to share a one-page summary of the findings with those who have a vested interest in CPG development and chronic disease management. I will prepare manuscripts for publication from this work that has not already been published. I will submit my work for consideration for presentation at relevant conferences, including the Lung Health Foundation Better Breathing Conference and the Canadian Respiratory Conference (CRC), followed by interactive communication. I will also prepare a report for the Lung Health Foundation whereby the former Ontario Respiratory Care Society (ORCS) Research and Fellowship Committee has supported this work through doctoral fellowship awards. I intend to discuss my findings with members of the Lung Health Foundation (LHF) Health Care Provider Network (HCPN), leaders of the Registered Nurses Association of Ontario (RNAO) responsible for guideline development, and members of the Canadian Thoracic Society (CTS) and the Canadian Respiratory Health Professionals (CRHP).

Concluding Thoughts

Health equity for systemically and structurally disadvantaged populations is a long-standing issue. As discussed in my doctoral thesis, it is well known that individuals living in rural and Northern Ontario experience more health disparities as compared to our southern Ontario counterparts. Given the state of health care and the ongoing health and social realities of systemically and structurally disadvantaged populations, particularly within the ongoing global

COVID-19 pandemic, now more than ever there is a need to engage in dialogue and discussion about how health equity is considered, particularly within the context of CPGs and chronic disease management.

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Appendices

Appendix A: LUREB Ethical Approval Certificate

LaurentianUniversity
UniversitéLaurentienne

APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS

Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New X / Modifications to project / Time extension

Name of Principal Investigator and school/department	Christina McMillan Boyles, Interdisciplinary PHD in Rural & Northern Health, supervisors, Philippa Spoel, Phyllis Montgomery
Title of Project	An Interpretive Description of Health Equity in COPD Clinical Practice Guidelines
REB file number	6020975
Date of original approval of project	March 10, 2021
Date of approval of project modifications or extension *(if applicable)*	
Final/Interim report due on: *(You may request an extension)*	March 10, 2022
Conditions placed on project	

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.
All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.

Rosanna Langer

Rosanna Langer, PHD, Chair, *Laurentian University Research Ethics Board*