Education Needs in Oxygen Therapy for Individuals with Interstitial Lung Disease in Alberta

by

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A thesis submitted in partial fulfillment of the requirements for the degree of

Master of Science

in

Rehabilitation Science

Faculty of Rehabilitation Medicine

University of Alberta

Abstract

Background and Rationale

Interstitial lung disease (ILD) is a rare, chronic, and progressive lung disease. Individuals with ILD experience chronic cough, breathlessness, fatigue, and consequently, a reduced health-related quality of life (HRQL). The American Thoracic Society guidelines recommend long-term supplemental oxygen therapy (O_2) in ILD for its potential to improve symptoms in individuals with hypoxemia at rest or upon exertion. However, numerous studies suggest that individuals who use O_2 face several obstacles, including the physical burden of O_2 devices and the associated social stigma, leading to reduced participation in daily activities. Several studies highlight the importance of education in facilitating the integration of O_2 into the lives of individuals with ILD. However, preliminary data from Alberta shows inadequate patient education and support for individuals living with ILD who require O_2. Thus, the aim of our study is to understand the educational needs for individuals with ILD who are utilizing O_2. As many educational tools are based on work in chronic obstructive pulmonary disease (COPD), a secondary aim was to examine how O_2 education needs may differ between ILD and COPD.

Methods

A qualitative research approach using the methodology of Interpretative Description was used to explore the perspectives of individuals living with ILD or COPD and health care professionals (HCP) (respiratory therapists, respirologists, registered nurses, physiotherapists). Interpretative Description is rooted in the naturalistic paradigm and aims to answer real-world questions by exploring common themes across a range of experiences. Separate focus groups were completed for each participant group: 1) HCPs, 2) individuals with a lived experience with ILD (ILE-ILD) and 3) individuals with a lived experience of COPD (ILE-COPD). Using convenience and purposeful sampling were selected from a previous study, pulmonary rehabilitation programs, and local support groups. Transcripts were then cleaned and uploaded to the data organization software NVivo 10 (QSR International Pty Ltd, Melbourne, Australia). Data analysis followed the constant comparative method, with data collection and data analysis occurring concurrently. One primary researcher (SR) used inductive thematic analysis to identify themes, which were reviewed by the research team and stakeholder group.

Results

20 HCPs (registered nurses (n=3), respiratory therapists (n=11), physiotherapists (n=1), respirologists (n=5)) with a mean of 20.9 (SD ± 0.7) years in health care and a mean of 12.8 (SD ±8.4) years of experience working with individuals with ILD participated. Fourteen individuals (one caregiver) with ILD and ten individuals with COPD participated. The educational needs identified were: 1) Integration of O_2 into day-to-day life 2) Focusing on the positives 3) Self-management 4) Reliable and accurate resources 5) transition from hospital to home 6) ongoing support 7) empathy and empowerment 8) experiential learning 9) peer support. Education needs specific to ILD compared to COPD included the importance of more frequent assessments of O_2 needs and an emphasis on maintaining higher flow rates when using O_2.

Conclusion

Our study offers new insights into the educational needs of ILD patients for integrating O_2 into their daily lives. For professionals offering education, it is crucial to deliver empathetic instruction to help individuals maintain independence both inside and outside the home. These findings will inform the development of educational support for patients with ILD.

Preface

This thesis is an original work by Samira Rowland. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name " Boehringer Ingelheim Interstitial Lung Diseases Oxygen Access (ABILD O2) Project: Understanding the Needs and Impact of Oxygen Therapy for Individuals with Interstitial Lung Disease" ID No. Pro00119667, July 10, 2023.

Acknowledgements

Throughout the project, many individuals have offered invaluable support.

First and foremost, I would like to thank my supervisor, Dr. Michael Stickland, for his mentorship and for introducing me to the intricacies of the research world, while also supporting my goals outside of it. Your dedication to science and mentoring the next generation of researchers is truly inspirational, and I hope to integrate this into my future endeavors as a clinician and researcher.

I would also like to thank Dr. Stephanie Thompson and Dr. Heather Sharpe for providing guidance and sharing valuable advice throughout this project.

To the staff at the Edmonton Breath Easy Program, thank you for assisting me with recruitment and allowing me to observe and learn from your clinical perspectives. I am fortunate to have had the opportunity to gain a comprehensive view of the clinical field.

I would also like to thank my many colleagues for their support and guidance over my seven years of being involved in the laboratory. Additionally, I am grateful to my colleague, Andrew Brotto for being my first research mentor and for introducing me to the world of research.

Thank you to my family who encouraged my curiosity from a young age. Your support allowed me to discover and explore my passions, leading me to become the person I am today. And to my partner, Brent, for always being there for me and continually supporting me in my future endeavors.

Lastly, I cannot thank the participants of this study enough. Without your willingness to being open and share some sometimes-difficult experiences, this research would not be possible. For that I will be forever grateful.

Table of Content

Chapter I: Introduction

Background and Study Objectives

Interstitial lung disease (ILD) is a rare, progressive, chronic lung disease involving burdensome respiratory symptoms that lead to reduced quality of life (Ryu et al., 2007). ILD encompasses over one hundred different types of chronic restrictive lung diseases (Gupta et al., 2023). The diagnosis of ILD is complex due to its diverse pathology, often leading to incorrect or delayed diagnoses and, consequently, delayed treatment (Cosgrove et al., 2018; Gupta et al., 2023). ILD carries a poor prognosis, with survival rates ranging from three to five years after diagnosis (Ley et al., 2011). Furthermore, compared to age- and sex-matched healthy individuals, those with ILD face a 23% higher unemployment rate and often require permanent disability leave (Algamdi et al., 2019).

Individuals with ILD experience a range of symptoms, including breathlessness (dyspnea), fatigue, and chronic cough. The International Classification of Functioning, Disability and Health (ICF) explores the role of disease and symptoms, highlighting their interconnectedness with contextual factors that shape an individual's activity and participation in society (WHO, 2013). In ILD, symptoms are described as being particularly limiting, leading to reduced participation in life and diminished independence (Overgaard et al., 2016; Sampson et al., 2015). Beyond physical limitations, individuals often face psychological challenges, such as anxiety and depression, due to the chronic nature of the disease and its impact on daily life (Ryerson et al., 2011). Therefore, interventions which work to ameliorate symptoms and the psychosocial impacts may help to improve the function and participation of individuals with ILD.

One commonly recommended intervention is long-term supplemental oxygen therapy (O_2). Supplemental O_2 is frequently recommended to individuals with ILD exhibiting hypoxemia. The American Thoracic Society recommends O_2 to individuals experiencing either resting or exertional hypoxemia;

however, these recommendations are based on expert opinion and research in other respiratory diseases such as chronic obstructive pulmonary disease (COPD) (Jacobs et al., 2020).

Previous research on the impact of O_2 for ILD patients is minimal, with no research available to inform on how O_2 impacts important outcomes such as survival rate. While O_2 has been demonstrated to alleviate dyspnea, there is inconsistency in the findings regarding its impact on quality of life (Bell et al., 2017; Khor et al., 2020; Visca et al., 2018). The lack of conclusive findings may result from the many challenges identified by individuals with ILD when using O_2, and O_2 therapy is frequently described as a trade-off between the good and the bad (Yet H. Khor et al., 2017a).

In the International Classification of Functioning, Disability and Health (ICF), interventions should facilitate the interaction between individuals and their environment. However, the use of oxygen devices can introduce additional challenges to this interaction (Yet H. Khor et al., 2017). O_2 can be a source of stigma and physical burden as the devices are often bulky (Dakkak et al., 2021; Graney et al., 2017). Thus, the integration of O_2 into an individual's life is a personalized process, influenced by a variety of personal and contextual factors.

Appropriate education is an essential aspect in supporting individuals as they navigate the barriers associated with utilizing O_2 (Jacobs et al., 2020). Education has previously been described as "Any combination of planned learning experiences in which theory and evidence-based/evidence-informed practices are used to provide equitable opportunities for the acquisition of knowledge, attitudes, and skills that are needed to adapt, adopt, and maintain healthy behaviours" (Videto & Dennis, 2021). Additionally, patient education is essential in empowering patients throughout their O_2 and disease process (Kalluri et al., 2020; Khor, Dudley, et al., 2021). However, current literature has identified education surrounding O_2 as not meeting the needs of individuals with ILD (Holland et al., 2015; Yet H. Khor et al., 2017a; Morisset et al., 2016; Tikellis et al., 2023).

In Alberta, O_2 is primarily supplied and managed by private O_2 vendors who are regulated by a government-associated organization called Alberta Aids to Daily Living (AADL) (*Alberta Aids to Daily Living Program Manual Section R – Respiratory Benefits*). AADL requires vendors to provide education on the safety of O_2 and the contractual obligations between the client and AADL, such as equipment maintenance. However, there is no requirement for vendors to provide education outside of these conditions, such as how to use O_2 in your daily life.

Therefore, given the challenges associated with O_2 usage in ILD and the unmet patient education needs, the educational requirements of individuals with ILD may not be adequately understood and consequently unfulfilled. Therefore, the aim of our study was to understand the perspectives of individuals with ILD and health care providers (HCP) regarding the content and approaches they consider essential for integrating O_2 into their daily lives.

Study Objectives

1. To understand the educational needs of individuals with ILD who are utilizing O_2 from the perspectives of people with ILD and healthcare providers.
2. To understand how the educational needs identified by individuals with ILD and healthcare providers differ from those with COPD.

The corresponding research question was: What patient education content and approaches in oxygen therapy do patients with ILD and their healthcare providers identify as helping integrate oxygen therapy into their lives and how do these differ from COPD?

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Chapter 2: Literature Review

Experience of Health in ILD

Interstitial lung disease (ILD) is a progressive lung disease affecting lung tissue, resulting in diminished daily function, reduced quality of life, and decreased life expectancy (Ryu et al., 2007). Over one hundred lung conditions are categorized as ILD, with idiopathic pulmonary fibrosis and sarcoidosis being the most prevalent (Demedts, 2001). Although ILD can be caused by medication or exposure to harmful inhalants, most cases of ILD have unknown causes (Demedts et al., 2001). In Canada, the prevalence of ILD is estimated to be around 41 per 100,000 with an average age of ⩾50 years, although an ILD diagnosis can occur at any age (Hopkins et al., 2016). Unfortunately, ILD has a poor prognosis (median survival only 3-5 years); thus, receiving a diagnosis can be life-altering. As ILD is relativity uncommon and diverse, research in ILD is scarce. Thus, little is understood about the challenges experienced by individuals living with this condition.

ILD can remain relatively stable for some time; however, exacerbations, which are often unpredictable, can intensify existing symptoms of dry cough, fatigue, and breathlessness (Ryu et al., 2007). While symptoms can vary, breathlessness is the most common symptom reported in ILD. One suggested mechanism behind the experience of breathlessness is the development of reduced arterial oxygenation (hypoxemia) due to impaired lung function (Ryu et al., 2007). In ILD, hypoxemia can occur either at rest, during exercise (exertional hypoxemia), or in some cases, both. In cases of ILD, approximately 40% of individuals experience exertional hypoxemia, while approximately 17% experience resting hypoxemia. (Khor, Gutman, et al., 2021b).

Another common symptom of ILD is severe fatigue. Individuals with ILD have significantly greater fatigue scores on the World Health Organization Quality of Life Assessment instrument than healthy controls and have described fatigue as an "overwhelming" symptom (Jeffrey J Swigris et al., 2005; Vries et al., 2001). Furthermore, both breathlessness and fatigue have been shown to be strongly associated with reduced health-related quality of life (HRQL), functional status, and increased depression in ILD (Ryerson et al., 2011). Lastly, coughing, which is present in around eighty percent of patients with ILD, has been directly linked to increased anxiety and depression (van Manen et al., 2016). Unfortunately, the cause of coughing in ILD remains unknown, and there are currently no established guidelines for its treatment (van Manen et al., 2016). With diverse and persistent symptoms, coupled with the emotional burden of a poor prognosis, individuals experience reduced independence, mental well-being, and overall quality of life (Ryerson et al., 2011; Jeffrey J Swigris et al., 2005).

ILD and Other Respiratory Conditions

ILD is frequently grouped with chronic obstructive pulmonary disease (COPD), a more prevalent chronic lung condition. While both conditions present similar symptoms, their underlying pathophysiology is different. ILD is described as a disease of the lung tissue, whereas COPD is often referred to as a disease of the airways (Celli & Wedzicha, 2019; Ryu et al., 2007). COPD is often associated with a smoking history, reflecting a pattern of harmful habitual behaviours in this population. Conversely, in ILD, the cause is often linked to environmental toxins, genetics, or an unknown origin, rather than being attributed to behaviour (Demedts et al., 2001). While both ILD and COPD often develop impaired gas exchange, individuals with ILD generally experience a more pronounced impairment, and exertional hypoxemia tends to manifest more severely and earlier during the initiation of exercise than in individuals with COPD (Du Plessis et al., 2018).

Additionally, COPD progresses slower than ILD. COPD patients often live with their condition for more than twenty years, and death often arises from other co-existing medical conditions (e.g. cardiovascular disease)(Berry & Wise, 2010; Hopkins et al., 2016). Whereas in ILD, the condition itself is frequently the primary cause of death (Berry & Wise, 2010; Kärkkäinen et al., 2018). Nevertheless, despite these distinctions, clinical recommendations derived from COPD data are frequently extrapolated to individuals with ILD and as a result, guidelines for clinical practice are often inadequate in addressing the specific needs of ILD patients (Holland et al., 2020).

Long-Term Supplemental Oxygen Therapy in ILD

The current standard of care for those with ILD includes pharmaceutical therapies such as anti-fibrotic and steroid medications. New research has indicated promising results from these medications in slowing disease progression; however, they can have significant side effects (Raghu et al., 2018). Another pharmaceutical therapy often prescribed to patients with ILD is long-term supplemental oxygen therapy (O_2). Current American Thoracic Society guidelines recommend O_2 to individuals with ILD who exhibit either resting or exertional hypoxemia to improve levels of blood oxygen and reduce symptoms, therefore improving survival and quality of life (Khor, Dudley, et al., 2021). However, because of the limited and inconclusive literature in ILD, these recommendations are based on data in COPD. For example, the potential for O_2 to improve survival is based on findings in COPD, and at present, there are no data to support a survival benefit in ILD.

The impact of O_2 on symptoms and HRQL in ILD has been examined in several studies. Khor et al. (2017a) conducted a qualitative study exploring the experiences of individuals with ILD using O_2. They found a range of experiences, with some participants reporting O_2 to improve symptoms while others described experiencing little or no improvements. When looking at the scientific literature investigating O_2's impact on HRQL in ILD. Visca et al. (2018) evaluated the effect of O_2 on HRQL, using the King's Brief ILD questionnaire and the University of California San Diego Shortness of Breath Questionnaire, in a 2-week, open-label, cross-over, randomized control trial. HRQL, improved when using O_2 ; however, participants in this study were not blinded, and there was a large standard deviation in the University of California San Diego Shortness of Breath Questionnaire (Score (SD); oxygen; 41·0 (30·5), no oxygen; 49·1

(34·1))(Visca et al., 2018). Moreover, the differences in the King's Brief ILD questionnaire may have been due to the sensation of airflow from the nasal cannula, which by itself, has been shown to reduce breathlessness (Liss & Grant, 1988). Further, a randomized control pilot study that blinded participants using a sham-control (gas cylinder filled with room air) for twelve weeks found no significant difference in symptoms or HRQL (Khor et al., 2020). However, this trial was primarily focused on feasibility and may have been underpowered to determine the effectiveness of O_2. Finally, the two available systematic reviews looking at O_2 trials in ILD only included two studies which looked at HRQL and stated evidence was insufficient to draw a definitive conclusion (Bell et al., 2017; Sharp et al., 2016). Therefore, the impact of O_2 on symptoms and HRQL remains unclear.

In summary, studies looking at ILD and O_2 are extremely limited and of low quality and as a result, many of the potential benefits and recommendations are inferred from data related to COPD and expert opinions. Therefore, to provide a conclusive statement on the benefits of O_2 in symptoms, quality of life, and survival of ILD, more research is necessary.

Patient Education in Oxygen Therapy

One possible explanation for the diverse response to O_2 in ILD is the challenges associated with O_2 outweighing the potential benefits. O_2 equipment can be conspicuous and burdensome due to its bulkiness, weight, and visual appearance. Previous qualitative work identifies individuals with ILD viewing O_2 as a trade-off between the benefits and the associated challenges(Yet H. Khor et al., 2017a). Patients described O_2 as being physically limiting, a source of stigma by making their disease visible, and a catalyst for their fears and concerns surrounding disease progression (Graney et al., 2017; Yet H. Khor et al., 2017a). By tackling these challenges, the potential advantages of O_2, such as symptom reduction and enhanced quality of life, may be more evidently experienced.

One potential way to address the challenges associated with O_2 is through adequate patient education. The American Thoracic Society and other work have recognized the role of patient education in integrating O_2 into a patient's life through both information and hands-on-training to promote self-management and confidence (Caneiras et al., 2019; Jacobs et al., 2020; Jacobs, 2019; Jacobs et al., 2018). In the previously mentioned randomized controlled trials assessing O_2 in ILD (Khor et al., 2020; Visca et al., 2018), neither study explicitly outlined their approach to patient education, which may have contributed to the observed variability in results. Furthermore, while education may promote effective integration of O_2 into an individual's life, various studies in ILD have also identified patient education in O_2 as inadequate and needing improvement. These studies have indicated that patient education targeted to COPD is often generalized to individuals with ILD, leaving the needs of ILD patients unaddressed (Burnett et al., 2019; Graney et al., 2017; Khor et al., 2017a, 2017b). However, there is a lack of research examining the differences between ILD and COPD and their educational needs on O_2. Hence, the existing educational methods concerning O_2 may not sufficiently address the needs of individuals with ILD, thereby contributing to their experiences of challenges.

For example, as previously described, hypoxemia is more prevalent and severe in those with ILD when compared with COPD, with ILD patients often requiring higher flow rates and different oxygen equipment (Du Plessis et al., 2018; Graney et al., 2017; Khor et al., 2017b; Swigris, 2017). Consequently, O_2 may be required during more activities of daily living in individuals with ILD, and these patients may need more detailed instructions on utilizing O_2 during routine tasks, such as showering and cooking. The existing recommendations require individuals to obtain a new prescription from their healthcare provider before increasing oxygen flow rates. However, compared to COPD, ILD progresses much faster, resulting in a steady and rapid increase in oxygen needs. Thus, education which promotes self-management, such as understanding how to adjust O_2 to meet the increasing oxygen demands, may improve independence and HRQL in ILD. Moreover, prior studies have indicated that individuals with ILD see O_2 as a notable detrimental stage in the advancement of ILD, and frequently, the delivery of education lacks sensitivity and empathy (Overgaard et al., 2016). Thus, delivering emotionally sensitive education surrounding O_2 may be important for ILD in helping alleviate the fear and distress associated with O_2 use.

In summary, the challenges faced by those with ILD when using O_2 differ from those with COPD, and developing a deeper understanding of the specific O_2 education needs for patients with ILD could aid in minimizing obstacles and maximizing the potential benefits.

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Chapter 3: Education Needs in Oxygen Therapy for Individuals with Interstitial Lung Disease in Alberta

Introduction:

Interstitial lung disease (ILD) encompasses a range of chronic lung conditions characterized by diverse subtypes stemming from factors such as environmental inhalants, pharmaceutical exposure, or unidentified causes (Travis et al., 2013). Individuals with ILD experience symptoms such as breathlessness, chronic cough, fatigue, and a reduced health-related quality of life (J. J. Swigris et al., 2005). Long-term supplemental oxygen therapy (O_2) is frequently recommended to individuals living with interstitial lung disease (ILD) with the potential to reduce symptoms, improve health-related quality of life and survival (Jacobs et al., 2020). However, because ILD is a relatively rare disease with an estimated prevalence of 16.7 per 100,000 in North America, there is little research investigating effectiveness of O_2 in ILD, and recommendations on O_2 are based on research in chronic obstructive pulmonary disease (COPD) and expert opinion (Jacobs et al., 2020; Kaul et al., 2021). While the impact of O_2 on survival in ILD has yet to be investigated, studies investigating O_2 on six-minute walk distance, quality of life and symptoms are of low quality and show mixed results (Y. H. Khor et al., 2017; Nishiyama et al., 2013; Visca et al., 2011; Visca et al., 2018).

In the qualitative literature, individuals with ILD describe O_2 as having a physical and social burden, frequently indicating it limits their participation in life (Graney et al., 2017; Yet H. Khor et al., 2017a). Moreover, O_2 initiation is recognized by individuals living with ILD as a negative milestone in their disease trajectory, a representation of the “end stage” (Yet H. Khor et al., 2017a). Education has been identified as an important component when supporting individuals in using O_2 (Jacobs, 2019). However, several studies indicate that the education needs of patients with ILD surrounding O_2 use are unmet (Graney et al., 2017; Morisset et al., 2016).

Study Objectives

Therefore, given the various barriers surrounding O_2 and the unmet education needs, the objectives of our study were to:

1. Create an understanding of the educational content and approaches patients with ILD and their healthcare providers identify as helping to integrate O_2 into the lives of patients.
2. Create an understanding of how these findings may differ from individuals with COPD.

The corresponding research question was: What patient-education content and approaches in oxygen therapy do with ILD and their healthcare providers identify as helping integrate oxygen therapy into their lives and how do they differ from COPD?

Methods

Study Design

This qualitative study was approved by the University of Alberta Ethics Board (Pro00119667) and utilized Interpretative Description to guide the research process. Interpretative Description grew from the need of extending descriptive qualitative research and extend it through interpretation, resulting in practical findings that could be applied to the clinical field (Thorne, 2016). Interpretive Description supports the borrowing of methods to appropriately answer the question at hand and align the research with the epistemological underpinnings of the field of which the findings are intended for. Therefore, given the need that Interpretive Description grew from answering real-world clinical questions, employing this methodology provides an adaptable yet systematic framework to answer the objectives of this study(Thorne, 2016).

Participants Selection and Recruitment

HCP and ILE living with either ILD or COPD were recruited for this study. Criterion-based purposeful sampling was employed to select individuals with COPD or ILD from provincial support groups and pulmonary rehabilitation programs. The inclusion criteria were: 1) English-speaking and able to communicate their lived experiences and provide verbal consent to participate; 2) current or past use of O_2 therapy; 3) a self-reported diagnosis of ILD or COPD. Facilitators of the support groups were contacted, followed by interested potential participants being contacted through email by a research member. Alternatively, a research team member attended the beginning of a support group session to explain the research, and interested individuals would provide their contact information. ILE recruited through pulmonary rehabilitation were contacted after providing their consent to contact to a clinical staff member.

Purposeful sampling was initially employed for the sampling of HCPs, followed by purposeful sampling to maximize variation of the type of health care professional, setting of practice (e.g., inpatient, community), and region of practice in the province. Eligible HCPs included 1) having a lived experience providing care to either ILE or COPD 2) having ≥ 2 years of clinical experience. HCPs from a previous unpublished study were contacted by a researcher involved in that study to confirm their consent to be approached. (Sharpe et al., 2024). Following this, the primary investigator (SR) directly contacted them.

Data Collection

Focus Groups & Semi-Structured Interviews

A combination of semi-structured interviews and focus groups were used to gain an understanding of perspectives from various sources (Thorne, 2016). Using focus groups enabled for the comparison of experiences between individuals, while semi-structured interviews enabled for an in-depth exploration of distinct individual experiences (Thorne, 2016). To maximize accessible participation, focus groups and interviews were completed via telephone call, video calling platform or in-person. Separate focus groups were completed for each type of participant, HCP, ILE with ILD (ILE-ILD) and ILE with COPD (ILD-COPD), to ensure an inclusive sharing environment. All focus groups and interviews were no longer than one hour and were conducted by SR. At the beginning of each focus group, SR reviewed the informed consent and informed participants about her background. SR has an undergraduate degree in kinesiology and has experience in the pulmonary rehabilitation setting.

Focus groups and semi-structured interviews were guided by the outlines in Appendices A and B. Interview guides were based on a literature review for ILE, the inquiry focused on their general and learning experiences with O_2. For HCPs, we inquired about their experiences working with patients with O_2 and their perceived gaps in education surrounding O_2. Additional follow-up and probing questions were used for further exploration of unanticipated topics.

Audio from conversations was recorded and transcribed using the Otter.AI transcription software (Otter.ai, Los Angeles, CA, USA). Transcripts were cleaned and edited by SR by cross-referencing with the audio to ensure the transcript reflected conversation word-for-word. Quotations provided in the results were edited to ensure clarity and flow without changing the meaning.

Data Organization, Management, and Analysis

Interpretive Description involves moving from the descriptive aspect of analysis to the interpretive, ensuring the findings are rooted within the data (Thompson Burdine et al., 2021). Thematic analysis was used to identify patterns and connections within the data (Braun & Clarke, 2006). Therefore, thematic analysis guided by Morse and Field (1996) four cognitive processes was used to analyze the data. The four cognitive processes include 1) comprehending 2) synthesizing 3) theorizing and 4) recontextualizing.

Comprehension.

Comprehension was achieved by facilitating data collection, reviewing transcripts, and initial coding. Initial coding was completed using the NVivo 10 software (QSR International Pty Ltd, Melbourne, Australia). During the initial coding process, inductive coding was used to ensure that the codes accurately reflected the semantic meaning of the data. Reflexivity was maintained by SR through the use of a field notebook (Morse & Field, 1995; Thorne, 2016).

Synthesizing.

The synthesis process involved merging the codes produced during the comprehension phase with their respective transcripts, forming themes and sub-themes based on their shared characteristics. During this phase, the SR discussed the themes and supporting quotes with the larger research team. Discussion takeaways were recorded and considered in further analysis.

Theorizing.

Theorizing was completed by providing explanations to the data by revising and testing various relationships between the codes and themes. SR completed visual mind maps and engaged in discussion with the research team. To ensure credible findings, the initial themes were presented to the stakeholder group for their reflections. The stakeholder group was provided with a visual infographic of the findings supported by direct quotes, and stakeholders were asked to reflect on the following questions:1) Do these themes resonate with you? 2)Are there any gaps you feel are missing? 3) Do you have any other feedback or comments which were then incorporated into the final thematic scheme? The stakeholder group consisted of both ILE-ILD and HCP, some of which were participants in the study. Responses were provided individually to SR and incorporated into the final thematic scheme.

Recontextualizing,

Lastly, recontextualizing was completed by comparing the resulting theoretical scheme to other well-established theories and similarities and differences were examined. To ensure findings were rooted within the data, existing theoretical models were not introduced until this aspect of analysis (Thompson Burdine et al., 2021). To identify the findings' contribution to existing knowledge, findings were compared to existing literature, such as literature on other respiratory conditions, and other existing theoretical models, such as learning theories. This comparison enabled for the findings to be practically applied to practice, research, and policy.

Other Data

Field notes were completed after every conversation and included the level of the researcher's perceived rapport with participants, distribution of conversation in focus groups, and factors that may influence the data generation process (i.e. Loss of internet connection). Memos that tested the possible connections and tracked the logic of analysis were completed throughout the research process in one notebook for retrospective reference (Thorne, 2016). Memos were both written and visual representations of the current understanding of data and areas for future exploration. Lastly, participants completed a short demographic survey (Appendix C and D), and the results were entered into a password-protected spreadsheet. The survey data assisted in contextualizing the findings.

Results

Participants

Individuals with a Lived Experience of Interstitial lung Disease

Thirteen ILE-ILD and one caregiver participated. Most of the participants had been living with ILD for over two years (n=11) and had been using O_2 for more than one year (n=8). Eight oxygen therapy companies supplied oxygen to the participants. All participants resided in urban areas.

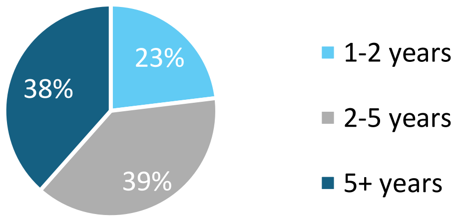

Figure 1. Proportional breakdown of time spent living with interstitial lung disease for study participants.

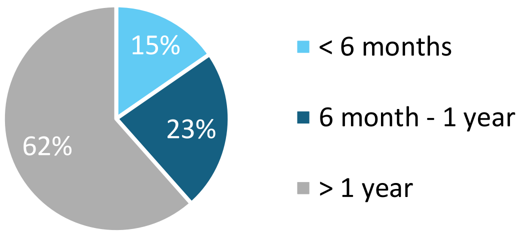

Figure 2. Proportional breakdown of duration of long-term supplemental oxygen therapy use in participants living with interstitial lung disease.

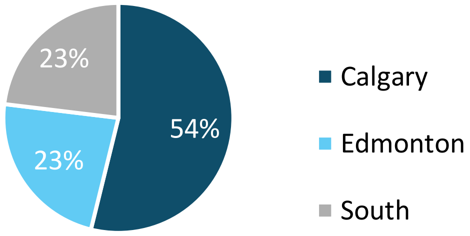

Figure 3. Proportional breakdown of geographical zones of residence for participants with a lived experience of interstitial lung disease.

Individuals with Lived Experience of Chronic Obstructive Pulmonary Disease ʻ

Ten ILE-COPD participated. Most participants had been living with COPD for more than five years (n= 8) and had been using O_2 for more than one year (n=8). In total, 5 different companies provided O_2 to the participants. Individuals were all identified as residing in an urban region.

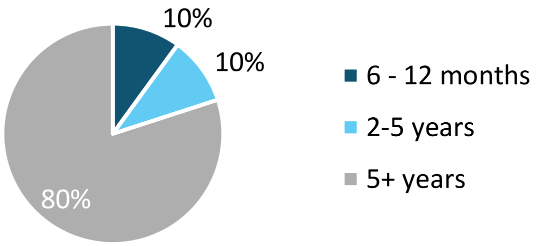

Figure 4. Proportional breakdown of time since being diagnosed with chronic obstructive pulmonary disease.

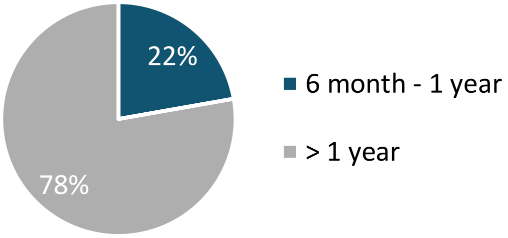

Figure 5. Proportional breakdown of duration of supplemental oxygen therapy use in participants with chronic obstructive pulmonary disease

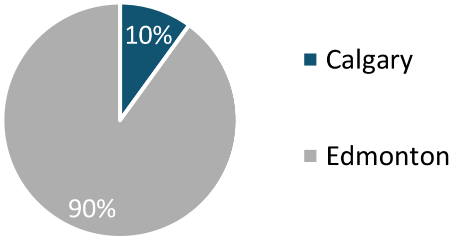

Figure 6. Proportional breakdown of geographic zones of residence for participants with chronic obstructive pulmonary disease.

Healthcare Professionals

A total of twenty HCPs participated. The average years of experience working in the field were 20.9 ± 9.7 years, and an average of 12.8 ± 8.4 years working with individuals with ILD. Three participants worked in a rural region. Participants consisted primarily of respiratory therapists (n=11).

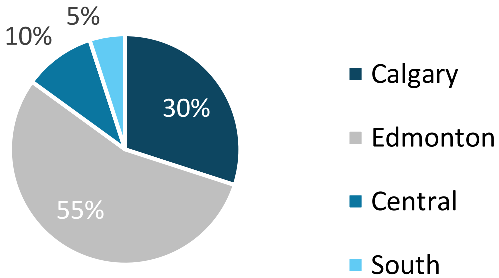

Figure 7. Proportional breakdown of geographic zones of practice locations of healthcare professionals within Alberta

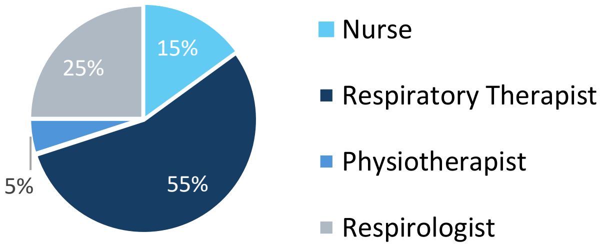

Figure 8. Proportional breakdown of occupations of the health care professional participants.

Themes and Subthemes

Three main themes were common throughout this included education content, education approaches, and a combination of both approaches and content. Sub-themes were consistent across participants except for three sub-themes specific to ILD. These included education related to ILD-specific O_2 needs, ILD-specific information, and the need for more frequent assessments.

Education Content

Participants highlighted more educational content was as an essential part of using O_2. The identified content included, focusing on the positives, self-management of O_2, and information on how to integrate O_2 into day-to-day life.

Focus on the Positives of O_2

This theme explores how both ILEs and HCPs recognized the importance of highlighting the positive aspects of O_2 to aid in its acceptance and use. HCPs frequently mentioned the importance of emphasizing the positives of O_2 with patients when initiating O_2. One HCP mentioned how initiating O_2 can be a time for the patient to regain control of their disease process: *“They have a little bit of ownership of their disease because they've got this tool that can help them"* (HCP).

HCPs frequently discussed the benefits of O_2 and highlighted that understanding the patient's values is crucial in the process of strengthening the rationale for O_2. ILE-ILD also recognized the role of knowing the benefits in initiating O_2"*I decided … I had had to do it (start oxygen), I know that there's benefits to it*" (ILE).

One HCP emphasized the importance of discussing the benefits of O_2 as to "*make the benefit side a little heavier*" than the burden side (HCP). Among the potential benefits discussed by both HCPs and ILE-ILD were decreased breathlessness, enhanced physical activity, diminished distress, and improved mental clarity. Nonetheless, many HCPs acknowledged the difficulty of discussing the benefits as they rely on their own clinical observation, given that the scientific evidence of O_2 in ILD is limited.

Self-management with Oxygen

Participants identified the importance of receiving information on how to manage their flow rate and O_2 devices, such as how to clean the filter. ILE described how it was important for them to be provided with flow rates that they knew were appropriate for them:

> *We were just given … a lot of times just poor information … [They would say] 'go by how you feel?' Well, that doesn't work for me, because my oxygen [saturation] could go down below eighty into the high seventies (percent oxygen saturation) and … I wouldn't feel it* (ILE).

ILE described wanting more information about specific flow rates that they should be using and how long their devices could provide that flow rate for: *"I think it's important for people to really understand how much oxygen they need. And to use it properly. I think that is key … a lot of us are just winging it"* (ILE).

HCP also identified the importance of patients understanding their oxygen needs and meeting them by either increasing the flow rate, or by pacing themselves during exertion. Many HCPs recommend that patients use pulse oximeters to help them monitor their oxygen needs throughout various exertion levels. In addition, ILE-ILD mentioned how they frequently used pulse oximeters to monitor their O_2 needs; in fact, they often kept their pulse oximeter within reach at all times.

One major frustration highlighted by HCPs was the common occurrence of patients using a portable oxygen concentrator when it did not meet their O_2 needs *"A lot of people really don't understand the downfalls [of the] portable oxygen concentrator, what it … can't do. And that's really lacking.*" (HCP). One HCP explained how patients frequently desired the "*moon in the size of a pea*" (HCP), meaning that while many individuals prefer the portability of a small oxygen concentrator, it frequently lacks the capacity to deliver the necessary flow rates for appropriate oxygen delivery. However, one ILE-ILD mentioned that when using their portable oxygen concentrator, they prefer not to check their blood saturation levels, as they knew it was likely below their target saturation. *"I actually don't want to know [my oxygen saturation] …I just rather not know. Because what am I going to do? Stay at home?"* (ILE).

How to integrate O_2 into Day-to-Day Life

ILE often described how it was important to them to continue participating in life outside of their home *“I am very active. I garden and … work in the yard, I'm always outside in the summer and in the winter"* (ILE).

However, some ILE described becoming more isolated since beginning their O_2. HCPs recognized the risk of isolation often accompanied with the use of O_2, and discussed the importance of individuals integrating O_2 into their day-to-day life" *Now that they're on oxygen … The more [they] stay home, and don't exercise or don't get out and socialize, that itself has huge consequences on their morale*" (HCP).

ILEs described how they adapted their lives to integrate O_2 so they could continue to participate in life. This included making creative innovations to transport O_2 in their vehicles and make the O_2 devices easier to carry while walking *"I have a little mat that's got a bunch of holes in it with these little plastic rods so that I can lay tanks down (in the car) and secure them in place"* (ILE).

While ILE described methods for integrating O_2 into their lives, both ILE and HCPs recognized this was not always supported in education. One HCP noted that having an individual who is on O_2 and wants to continue being active is quite rare. However, several ILEs expressed how they try to maintain an active lifestyle yet encountered resistance or minimal support about how to do so from a healthcare provider. One ILE described a negative experience with one of the providers from their O_2 company. During one interaction, the ILE communicated their desire to remain active, only to be met with laughter by their oxygen provider: *“I still wanted to go hiking … I still wanted to do the five-kilometer walk that I do with my husband … and they (oxygen provider) just kind of laughed at that"* (ILE).

Lastly, some HCPs mentioned that the assessments currently being done to determine participants' O_2 needs did not replicate life outside of their homes and underestimated their O_2 needs: *"What we consider a walk … going out to a doctor's office or going shopping that is [not the same walk as] when you assess them just walking in their home*" (HCP).

Education Approaches

Education approaches discuss the underlying methods of education that participants highlighted. This included empathy and empowerment, experiential learning, and peer support.

Empathy & Empowerment

ILEs often became emotional when discussing O_2 and what it means to them. For example, when one ILE-ILD was asked what prevents them from increasing their oxygen flow rate as prescribed, they became emotional and stated: *"accepting how sick I am*" (ILE). Similarly, HCPs recognized the symbolic representation of O_2 in ILE-ILDs disease progression and understood that the denial associated with using O_2 may lead patients to use O_2 inappropriately or not at all: *"I think it is denial of where they are in their disease stages"* (HCP).

Some ILE described how they became quite depressed when they started using O_2 with some ILE stating it was because people could now visibly see how sick they were. Some HCPs also recognized how emotionally difficult starting O_2 could be: *"It's time that we talked about oxygen. And that can be hard for patients because they know that their disease is getting worse"* (HCP).

HCPs acknowledged that the process of using oxygen can be emotional and that listening to the patient and respecting their autonomy is an essential part of supporting them: *"We want to fix the problem. We don't always respect what they want. So, taking that time to listen and ask those questions, educate them, but … you know, respect what they want.*" (HCP).

While HCPs acknowledged the symbolism of O_2 and understood the reasons behind denial, they also noted the absence of empathy and compassion in the approach to education. One HCP described how HCPs often approach patients by looking to fix problems rather than offer empathy:

> *It's part of our education to communicate by sticking to the facts … try to be compassionate, empathetic at all times, right? But professionals are not taught that way. In healthcare, we're not taught to communicate, we're taught to fix, right? We're fixed communicators* (HCP).

ILE themselves described how they felt HCPs often focused more on the equipment than caring for the person, and some ILE described feeling dismissed by the health care professionals. Additionally, some ILE felt that health care professionals did not understand what this experience was like for them*: "[Health care professionals] maybe tend to forget how much of a shock it is when [you are] diagnosed … and prescribed [oxygen therapy]"* (ILE).

HCPs identified the importance of empowering the patient throughout the education process so that they feel empowered to make decisions regarding their health:

> *[Health care professionals need to understand] how much power they have over people, and they need to check that power and understand that they need to empower the client instead to take ownership over their therapy (HCP).*

Additionally, HCPs described the importance of integrating a palliative approach throughout the process to support the empowerment and emotions throughout their disease process. In addition, ILE-ILD mentioned when they received their O_2 from a palliative care provider, they felt there was more focus on the person. *"So palliative home care is not an equipment provider, they're a care provider, and that's the difference*." (ILE)

This empowerment translated to ILEs. One ILE described how it was their choice whether or not they continue to use O_2, and that was something they valued *"My motto is live or die. That's my choice. So if I want to live, I use oxygen. If I'm ready to die, unplug it"* (ILE).

While there was a strong overarching pattern of the need for more empathy and empowerment throughout the education process, many ILE highlighted very positive experiences with clinicians and oxygen providers, highlighting the diversity of education approaches in O_2 for ILD.

Experiential Learning

Participants also emphasized the importance of learning from experience and objectively measuring the positive differences in symptoms and abilities when using O_2.

When initiating O_2 for patients, HCPs described the importance of having patients try it out for themselves: "*Patients will start to use it when they notice a difference when they are able to do more with it with like walking further doing more exercising, and ... not have such shortness of breath*" (HCP). One ILE mentioned how the first time they tried O_2 was at pulmonary rehabilitation and how trying exercises with and without it was *“like an experiment*" (ILE).

HCPs suggested that individuals try various activities such as a sit-to-stand exercise or a walk test while using O_2 and using an objective measure, such as heart rate, blood oxygen, validated dyspnea scales, and physical capacity, to show them the potential benefits of O_2. Moreover, HCPs explained that it may take time for patients to perceive the advantages of O_2, and the importance for patients to have realistic expectations when starting O_2. "*It's not like it's a night to day change … what oxygen does is that it brings down the distress on the symptoms. It might improve your ability to function*" (HCP).

Lastly, ILE described how it took time to adjust to their oxygen, but with more time, they figured out the tricks that worked for them: "*It took a while to adjust to the cannulas. At first, when I was sleeping, I used an infant one because it was softer on the face*" (ILE).

Peer Support

ILE and HCPs noted the important role that peer support played in integrating O_2 into the lives of ILE. ILE emphasized the value of pulmonary rehabilitation and support groups as it fostered interactions with individuals in similar circumstances to themselves, often making them feel less isolated in the experience of using O_2 and dealing with the prognosis of ILD. HCP mentioned they commonly witnessed education and support occurring between the participants of support groups: *"I think that there's some education and support that happens among the patients themselves … it happens in our patient support group"* (HCP).

Pulmonary rehabilitation and support groups enabled a setting for ILE to not only receive support from one another, but to also see examples of how they could continue to live a life with O_2:

"Connecting them with other patients who have had similar experiences, who can say, 'I'm still living my life with oxygen … it's like a medication … I take it, it helps me, but I'm still living my life'"(HCP).

Education Content & Approaches

The following themes include the content and approaches of access to reliable and accurate resources, ongoing support from vendors, clinicians, and allied staff and transition from the hospital.

Access to Reliable and Accurate Resources

Participants highlighted the significance and desire for access to reliable resources, given that initiating O_2 entails receiving substantial information in a short period of time. *"We provide them an education package, which I always try to encourage them to read and go through … it's a lot of information all at once"* (HCP). One aspect highlighted by ILE, was the importance of the resources being reliable:*"[You] should get proper information from reliable resources … either a nurse or a doctor or a rehabilitation person" (ILE).*

However, ILE mentioned that good resources, such as a printout or reference to videos, were rarely provided. One ILE shared that their company was not helpful in telling them how to clean their filter, and they had to look up a video online. However, not all ILE felt comfortable receiving information from online sources; many ILE described hesitancy as they were not confident in the reliability: *"I'm always reluctant to do that. Because I'm like, is this a reliable site?"* (ILE).

Ongoing Support from Vendors, Clinicians, and Allied Health Staff

ILE frequently felt the initiation of O_2 within their home was "overwhelming," "chaotic," and information dense. Both ILE and HCP described how follow-ups are an important part of beginning oxygen: *"When a person [has] never been on oxygen, I honestly feel they would need a second time in order to catch it. It's a lot of information all at once"* (HCP).

Participants noted that pulmonary rehabilitation was noted as playing an essential role in ongoing education. HCPs frequently noted the trust and respect often developed within pulmonary rehabilitation was important when working with the fears and concerns of the patient with using O_2:

> *We have that time to develop those relationships if they are refusing to wear oxygen, we can work through that. If they are on the wrong flow, or the wrong piece of equipment, we have that time to help them understand the differences* (HCP).

Additionally, both ILE and HCPs highlighted how the duration between initiation and follow-up by the vendor was too long. One HCP mentioned that while this aspect was done well in the past, the current frequency of follow-ups is less consistent: "*I'm finding that patients are just not being followed up like they used to*" (HCP).

Transition from Hospital to Home

Participants spoke about a lack of education when transitioning from hospital to home with O_2. One ILE and their caregiver described feeling "*scared*" and "overwhelmed" during this experience and that they received no written information: "*No written information and very little to non-existent verbal information* [was given] *… there was nobody to help us to get this tank going like that RT* [respiratory therapist] *just left, she gave us the stuff and left*" (ILE).

The participant described being in *"quite rough shape"* when the oxygen provider arrived at their home three hours after their discharge. Additionally, many HCPs highlighted this as an issue. For example, one HCP stated: *"There is a huge issue with patients being discharged from hospital with oxygen …sometimes we need the bed space … we need to get these patients out of hospital" (HCP).*

Both HCP and ILE proposed solutions to address this gap, including having an information brochure provided to patients upon discharge or having a specified HCP role in the hospital to educate patients in using their O_2.

Comparison of Education Needs in ILD as compared to COPD

Overall, themes generated from ILD and COPD were similar as the themes discussed above. However, there were three areas where education in ILD differed from COPD these included; ILD-Specific Information and Programs, ILD-Specific O_2 needs, and the need for frequent assessments in ILD.

ILD-Specific Information & Programs.

ILE mentioned how they often received information that was not accurate to their situation. One participant described how a clinician told them that they would try to get them off oxygen; however, the participant later found out that would never be possible and felt they had been given a false sense of hope:

> *The pulmonologist said 'we hope to get you off of oxygen when you go home' … and I mean, wow, that would be great. But that wasn't true. And so like, it's not possible to go backwards with lung scarring. So that wasn't actually helpful, because it gives you hope, but then it's not true* (ILE).

Moreover, while pulmonary rehabilitation was identified as helpful, both HCPs and ILE recognized that it was more geared towards individuals with COPD.

> *Sometimes you get patients with interstitial lung disease. And it is different from COPD and a lot of the things that they teach at pulmonary rehabilitation … some patients have said, 'well, it didn't really seem that geared towards me'* (HCP).

One ILE described that they dealt with the education primarily intended for those with COPD by "reversing" the education provided, so it was more applicable to them (ILE). Further, they described how they wanted to participate in a chronic disease exercise program. However, they would have been required to supply their own oxygen, which was not possible given their higher flow rates. Therefore, the participant was unable to attend this program.

Although there were some challenges with non-ILD specific rehabilitation programs, most ILE-ILD spoke positively about pulmonary rehabilitation, even if it was not specific to ILD.

ILD-Specific O_2 Needs.

HCPs highlighted the importance of approaching the education on flow rate slightly differently with patients with ILD than with those with COPD. In ILD contexts, they emphasized using a higher flow rate. This was due to two reasons. The first was related to carbon dioxide retention, which can be more prevalent in individuals with COPD: "There are some (health care professionals) who tell the ILD patient population, 'your carbon dioxide is high' so you [shouldn't'] get too much oxygen" (HCP).

This issue was also common amongst participants with COPD, who discussed the importance of avoiding their oxygen levels becoming too high because of carbon dioxide retention. One ILE-COPD described how they became very sick due to carbon dioxide retention; however, carbon dioxide retention was never mentioned by any ILD participants.

The second reason HCPs emphasized educating ILD patients about using a higher flow rate was due to the rapid desaturation that can occur upon exertion in ILD and how a higher flow rate enables patients with ILD to maintain their function:"[As a nurse in the hospital] the goal was always to go on this lowest amount of oxygen possible … That is not the goal in ILD patients. The goal is … what do they need to function" (HCP).

ILD Specific: Frequent Assessments.

While ILE-ILD and ILE-COPD both expressed the need for more frequent follow-ups, HCPs stressed the importance of more frequent assessments specifically tailored to evaluate oxygen requirements for those with ILD, considering their rapid disease progression and oxygen needs.

"*So a lot of times these patients are not assessed, say beyond once in six months or so. And that's not enough because it will progress … their oxygen needs will progress. And if you don't keep up with the oxygen needs, then the patients will not derive benefit*" (HCP_10).

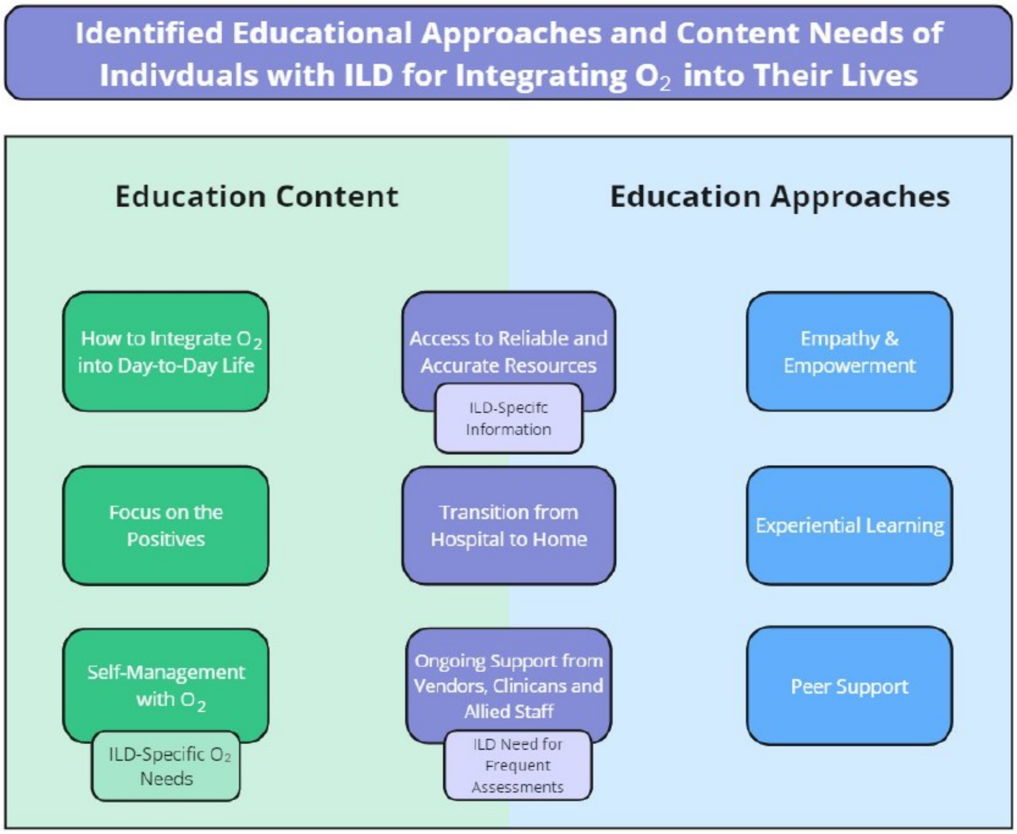

Figure 9. A summary of educational approaches and content identified by ILE-ILD and HCP for integrating O_2 into the lives of Individuals with ILD. The schematic is divided into two halves: education approaches and content. The findings in the purple text boxes encompass both educational approaches and content. Educational content and approaches specific to ILD are noted in the smaller text boxes.

Discussion

Our study is the first qualitative study examining the education needs specific to O_2 in ILD. Overall, there were diverse experiences with education and O_2 therapy. Participants indicated a need for more information on topics like self-management with O_2 and highlighted the importance of experiential learning and the utilization of peer support in the educational process. Participants emphasized the importance of education in maintaining their autonomy and values, stressing that education should be both empathetic and empowering. Comparing the educational needs of individuals with ILD to those with COPD revealed that ILD-specific needs include education tailored to their O_2 requirements, specialized ILD programs and information, and more frequent assessments.

The themes from our study align with the components of the transformative learning theory, which is used to understand how adults respond to and change as they encounter a disorientating dilemma (Mezirow, 2000). Like the transformative learning theory, our findings suggest integrating O_2 is an ongoing process where individuals need support throughout, opportunities to experiment, and empathy and empowerment in learning to use their O_2 (Dubouloz, King, Paterson, et al., 2010; Mezirow, 2000). In the transformative learning theory of chronic illness, peer support and health care professionals play an essential role in the process of transformative learning as it enables [or provides space/opportunity] for critical reflection about one's identity. Therefore, understanding the integration of O_2 as a continuous process and promoting a supportive social environment through ongoing and peer support, may facilitate its incorporation into an individual's life.

The findings from our study, which highlight a need for more education when transitioning from hospital to home, aligns with other literature that has found that only 8% of individuals who use oxygen received information from a clinician, with most information being provided from the oxygen delivery company (Jacobs, Lindell, et al., 2018). This gap may be due to the lack of protocol to guide the discharge of patients requiring O_2. While a 'COPD discharge checklist' is available to ensure patients receive essential information and support for disease management after hospital discharge (Atwood et al., 2022; COPD admission to discharge checklist, 2019), no such checklist exists for patients with ILD within Alberta. This highlights the need for a discharge checklist specific to those with ILD, to guide clinicians and ensure appropriate and thorough education is delivered to the patient upon discharge.

The education content identified includes how to integrate O_2 into daily life and self-management, indicating the goal of maintaining independence while using O_2. While individuals living with ILD expressed a desire to integrate O_2 into their day-to-day lives, healthcare providers noted that many people using O_2 tend to stay at home and become isolated. This aligns with previous literature, which found individuals with ILD report lower opportunities and participation in recreation and leisure activities when compared to healthy controls (Vries et al., 2001). This may not only be due to the symptoms associated with ILD, but the physical burden of the O_2 device, which can increase dyspnea and reduce exercise capacity (Ramadurai et al., 2018). Therefore, when first initiating O_2, practitioners should discuss O_2 delivery options with patients to reduce the physical burden of O_2, support independence, and promote the integration of O_2 into everyday life.

Healthcare professionals observed that portable oxygen concentrators were frequently used by patients despite often not providing an adequate flow rate for those with higher oxygen needs. Conversely, ILE-ILD acknowledged the limitations of portable oxygen concentrators in meeting their oxygen requirements but opted to continue using them. This aligns with the literature that found that 47% of users of portable oxygen concentrators noted that they still used a portable oxygen concentrator, despite knowing it did not maintain their recommended oxygenation (Dakkak et al., 2021). This could be attributed to the many barriers of gas cylinders such as transportation and fears of explosion (Moretta et al., 2021; Tikellis et al., 2022). Similar to other studies, ILE-ILD highlighted the social stigma associated with O_2 use (Tikellis et al., 2022). Given that portable oxygen concentrators are more discreet than oxygen cylinders, this preference may stem from a desire to avoid attention in public places. Therefore, while practitioners should continue to discuss the importance of maintaining oxygenation, discussions around an individual's fears and concerns about devices should also be addressed.

Throughout our study, healthcare professionals emphasized the importance of highlighting the benefits of O_2 when educating patients. However, they also noted that the scarcity of high-quality evidence can complicate this discussion. This aligns with findings from other literature, which identified the lack of ILD-specific evidence as a barrier to O_2 use and prescription (Yet H. Khor et al., 2017b).

Current guidelines recommending O_2 in ILD are based on low-quality evidence, necessitating discussions that rely on expert opinion and data extrapolated from COPD (Jacobs et al., 2020). Therefore, given the lack of available evidence on the benefits of O_2 in ILD, findings from our study further underscore the need for more outcome data on O_2 use in ILD to better support education about its benefits in this patient population.

Education Needs Specific to ILD vs. COPD

Overall, the themes of education needs related to O_2 were similar in COPD and ILD. However, there were some distinct aspects specific to ILD. ILE-ILD mentioned the need for more ILD-specific information related to the duration of O_2 use and emphasized importance of ILD-specific programs in the education process. This aligns with a previous investigation focusing on the educational requirements of individuals with non-COPD chronic lung diseases and those diagnosed with COPD, which also identified common themes between the two groups, but noted specific educational needs related to non-COPD conditions(Granger et al., 2019)These included a need for additional information on treatment plans and cough management (Granger et al., 2019). ILE-ILD also reported that clinicians frequently confused them with patients with COPD and were provided information that was relevant to COPD and not ILD. This may be explained by other literature which found a lack of clinician awareness around ILD, including ILD-specific guidelines (Bonella et al., 2016). Therefore, there exists a pressing need for enhanced awareness and acknowledgment of ILD-specific educational content with respect O_2 use.

One area HCPs highlighted as approaching differently in ILD as compared to COPD was education on O_2 flowrates. HCP described how they frequently recommended patients with ILD to maintain a higher oxygenation compared to COPD. This was done for two reasons. HCPs stated that individuals with ILD are less likely to experience hypercapnia with O_2 use. This statement aligns with the literature that considers hypercapnia as only part of the end-stage for ILD (Plantier et al., 2018). The other reason provided by HCPs was that individuals with ILD develop hypoxemia more rapidly upon exertion. In a trial that compared levels of desaturation throughout a six-minute walk test between ILD and COPD of various stages, researchers found that it was more common to experience hypoxemia with exertion and desaturation occurred more rapidly in ILD (Du Plessis et al., 2018). However, other literature suggests that the over-administering of oxygen may be harmful because of the role of reactive oxygen species (Kallet & Branson, 2016). Several trials have indicated hyperoxia to be associated with negative outcomes when acutely provided oxygen; however, no studies looking at O_2 use in ILD and hyperoxic lung injury exist (Kallet & Branson, 2016). Therefore, before implementing educational recommendations for higher saturation levels in ILD patients receiving O_2, future research on the outcomes of hyperoxia is needed.

Lastly, both HCP and ILE-ILD identified a need for more frequent assessments due to the often higher oxygen needs and rapid progression of the disease, with ILD having a poorer prognosis than COPD (Afonso et al., 2011; Chen et al., 2021). Therefore, as ILD often progresses faster than COPD, there may be more of a need for reassessment and, thus, education related to oxygen needs and flow rates.

Strengths and Limitations

A strength of our study was that participants received their O_2 from several O_2 providers, enabling the exploration of diverse ILE experiences with different O_2 providers. Another strength of our study was the comparison between ILE with ILD and ILE with COPD, which highlighted the differences between the two groups. The use of interpretative description allows the findings to be applied to the intended field, facilitating practical application.

ILE-ILD were recruited either from a support group or from past participants of pulmonary rehabilitation programs. However, this selection method poses a limitation to the study, as these individuals likely received more education on O_2 than those who have never participated in such programs. Consequently, there is a possibility that gaps in understanding among those who do not engage in formalized education settings might have been overlooked. Rural ILE were underrepresented in our study. Considering Alberta's large rural population, recruitment efforts targeted rural ILE by reaching out to three separate rural respiratory therapists; however, these attempts were unsuccessful, which may limit the application of findings to rural settings.

Lastly, caregivers play a significant role in the lives of those living with ILD (Ramadurai et al., 2019). Our study only included one caregiver, who was identified as an important support person for an individual living with O_2. As O_2 devices can be physically burdensome, caregivers often play an important role in the handling and managing of O_2 equipment. Moreover, as the disease progresses, caregivers become more and more involved in the handling of O_2 equipment. One study looked at the specific education needs of caregivers for individuals with ILD and found that education on O_2 for caregivers was insufficient (Ramadurai et al., 2019; Sampson et al., 2015). Therefore, upon completing and reflecting on the findings, it becomes apparent that the involvement of caregivers should have been more extensive in our study.

Implications for Research and Practice

The need for experiential learning and continuous support from peers and clinicians identified in our study, suggest integrating O_2 into an individual's life is an ongoing process. Pulmonary rehabilitation provides ongoing access to resources, opportunities for connecting with others with ILD, and hands-on learning with oxygen therapy. Since pulmonary rehabilitation can meet many of the educational needs identified in our study, referring individuals to these programs may help them better integrate O_2 therapy into their lives.

HCPs and ILE mentioned the value of a palliative approach when working with patients with ILD. Palliative care emphasizes the importance of focusing on an individual's values and goals (Kreuter et al., 2017). A systematic analysis of treatment decisions in palliative care revealed that patients place significant value on having their experiences acknowledged and considered during treatment choices and on having their expertise about their own bodies recognized(Elwyn et al., 2017; Kuosmanen et al., 2021). Furthermore, providing patient education fosters the development of a collaborative relationship between clinician and patient, which is essential for tailoring treatment plans to align with patients' personal goals and preferences (Elwyn et al., 2017). By providing a palliative approach to those whose care goals align with it, education can be seen as a crucial tool for empowering patients and supporting their autonomy as they manage their lives with oxygen therapy.

The findings from our study identified a gap in the current patient education delivered when transitioning individuals with ILD and O_2 from the hospital to home. This issue may stem from the strain on existing healthcare systems and the limited available resources. However, previous research has shown education upon discharge is crucial for reducing hospital readmissions (Oh et al., 2021). In our study, ILE-ILD stated receiving little information upon discharge. This aligns with other qualitative literature where health practitioners note a standard discharge consultation is often not possible given limited available time (Hesselink et al., 2012). Potential options to improve education upon discharge with O_2 could include referral to approved resources (such as a brochure or online video) or a dedicated role in the hospital responsible for education on O_2.

Given our findings, future research should build on these insights by focusing on developmental studies to effectively design and implement these practices. This research should involve collaboration with various stakeholders, including practitioners who deliver the education, policymakers who approve its implementation, and individuals who receive it. Stakeholders would contribute valuable input on the effectiveness and efficacy of these practices. For example, this could involve developing a standardized education checklist that outlines essential items for a respiratory therapist to review with patients at the start of O_2 therapy.

Summary

Our study explored the essential educational content and approaches individuals with ILD and health care professionals consider important for integrating O_2 into the lives of individuals with ILD. The identified content emphasizes maintaining independence and managing day-to-day life while using O_2. We found that educational strategies supporting oxygen use both inside and outside the home should be included in future education for individuals with ILD regarding oxygen therapy. Future research should focus on evaluating and enhancing existing educational practices and incorporating our findings into new practices.

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Chapter 4: Supplementary Discussion

Policy Implications in Alberta

This work has revealed several areas relevant to clinical practice, policy, and rehabilitation. Currently, private vendors in Alberta play a significant role in the O_2 education individuals receive. While a provincial government-associated organization, Alberta Aids to Daily Living (AADL), regulates what education must be provided, this required education is limited to the safety of O_2 use, maintenance of equipment, and assessments are only required once every six months (*Alberta Aids to Daily Living Program Manual Section R – Respiratory Benefits*). AADL mandates that private vendors provide written information for other respiratory devices, such as BPAP, but there are no such requirements for O_2. Additionally, AADL offers a detailed framework for the required education on other respiratory devices, including the discussion of device benefits and potential issues. AADL also includes a provision for assessors to ensure the client understands this information. None of these educational requirements are applied to the initiation of O_2, even though it is a device used up to 24 hours a day. Therefore, the findings from our study should be used to inform provincial regulatory policies concerning the education that private vendors are required to provide individuals who are using O_2.

Online Education

The internet provides patients with abundant health resources, offering written information and multimedia options such as videos and telehealth services (Lewis, 2003). Online education has been used effectively to enhance patients' knowledge and improve symptom control in managing their conditions (Liossi et al., 2018; Whitehead & Seaton, 2016). Moreover, as access to the internet becomes more common with 80% of Canadian households being connected to the internet in 2010, online resources provide an accessible option for educating patients in rural areas of Alberta (McKeown & Lafontaine, 2010). In 2020, around seventy percent of Canadians used the internet to gather health-related information (McKeown & Lafontaine, 2010). However, participants in our study identified hesitancy in using online resources due to the unknown reliability of them. This is similar to other studies that found that patients prefer to get information from their physician rather than the internet (Hesse et al., 2005). When looking at the reliability of health-information on the internet, one study found that online resources directed at managing chronic breathlessness found a range of adherence to American Medical Association reliability benchmarks from 9% for disclosure to 77% for currency of information (Luckett et al., 2016). Furthermore, while online resources are highly accessible, not all patients can critically assess the health information they retrieve, which can sometimes lead to a false sense of understanding. (Tonsaker et al., 2014).

The American Medical Association provides guidelines to assess the quality of online resources. These guidelines discuss important aspects of online resources, including site ownership and any funding involved, and the content should be reviewed by an expert not involved in the development of the resource. These guidelines discuss the importance of resource ease of navigation by including a main page menu and the option to download larger files. Therefore, while online resources can improve access to health education, the quality of resources should be assessed by experts in the field before being utilized in practice for patient education.

Revisiting the Research Approach

The participation for ILE in our study was limited to those who had used O_2 at some point in their disease journey. A previous study found that O_2-naïve individuals desired more information about the indications, usage, and initiation of O_2 therapy prior to its commencement. Additionally, their perceptions prior to starting O_2 often did not align with their lived experience of using O_2.(Yet H. Khor et al., 2017a). Therefore, to improve the initiation process for individuals beginning O_2 therapy, the inclusion of O_2 naïve individuals in our study would have offered insights into the information needed for individuals O_2.

Future Directions

The findings from our study have identified the educational needs of individuals with ILD regarding O_2. Among participants, a wide range of educational experiences were reported. This variation may be due to the inconsistent initiation process of O_2 and differences among provider companies. Future research could investigate the educational practices related to O_2 administration when delivered by different clinicians and companies within Alberta. Such exploration may highlight disparities between educational approaches used by different companies and in various settings.

Our study has identified several areas for potential policy changes to enhance education within the O_2 process. The findings can inform future amendments to AADL policies, aiming to establish provincial standards for educating patients on the use of O_2. Additionally, it is recommended that future studies focus on developing and testing standardized educational protocols to ensure consistency and effectiveness in O_2 education across different healthcare providers and companies. This could involve comparative studies to identify best practices and the impact of standardized education on patient outcomes.

The Current Study within the Context of Rehabilitation Medicine

The World Health Organization utilizes The International Classification of Functioning, Disability and Health (ICF) to understand and organize disability and functioning (WHO, 2013). As a multidimensional model, the ICF aims to highlight the inter-relatedness of body function and structure with the personal and environmental factors, and sees disability as an experience rather than an attribute of an individual (Üstün et al., 2003; WHO, 2013). Incorporating the ICF within rehabilitation research enables for a comprehensive exploration. In ILD, the function and structures of the lungs are impaired, as a result, individuals with ILD experience reduced gas exchange and frequently develop hypoxemia at rest and during exertion (Khor, Gutman, et al., 2021a; Ryu et al., 2007). Moreover, individuals with ILD experience symptoms of dyspnea, chronic cough and fatigue, frequently impairing their ability to participate in activities of daily living (Ryu et al., 2007).

When considering O_2 in the context of the ICF model, O_2 can be described as a facilitator (WHO, 2013). It is frequently recommended to individuals with ILD to reduce hypoxemia and potentially improve function, thus facilitating meaningful interaction in their daily lives (Jacobs, 2019; WHO, 2013). However, the use of O_2 also presents challenges, including the physical limitations of the device and the associated social stigma (Yet H. Khor et al., 2017a). Consequently, integrating O_2 into an individual's life to enhance function and quality of life can be complex.

Education can support individuals using O_2 to help them optimize their function within their environment. From our study, we have highlighted various aspects of education surrounding O_2 in ILD that have been identified as important. Specifically, our finding of education related to using O_2 on a day-to-day basis, highlights the importance of education in supporting the interaction with the environment while using O_2. Many of our insights can be integrated into rehabilitation settings, such as pulmonary rehabilitation, which often spans several weeks and has access to O_2 equipment. This creates a unique opportunity to incorporate peer support, experiential learning, and ongoing support. Thus, the findings from our study can inform future educational approaches to support individuals with ILD in engaging in meaningful activities and daily living, thereby enhancing their quality of life.

Summary

Healthcare professionals and individuals living with ILD have identified key educational content and approaches essential for integrating O_2 into the lives of individuals with ILD. They emphasize the importance of viewing education as an ongoing process and providing information that supports patient independence. While the educational needs of individuals with ILD are largely similar to those with COPD, there is a need for more education specifically tailored to ILD. We suggest that future research trials should incorporate our findings into educational practices to assess their effectiveness and contributions to the integration of O_2 therapy into the lives of individuals living with ILD.

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Appendix A

Guides for Focus Groups

Table A1.

Introduction and Closing Script for Focus Groups

Introduction & Informed consent

- Hello everyone, my name is… and I am currently a Master of Science Student at the University of Alberta. For my masters, I am interested in education surrounding oxygen therapy, and this is why you have been asked to be part of these sessions.
- Before we begin, I would just like to review the informed consent.

Reason:

- So the reason you have been asked here today is to understand the facilitators and barriers surrounding oxygen therapy, specifically the patient education

What you are asked to do and time:

- This session will be no longer than 60 minutes, and I will do my best to ensure we are done on time.
- I will be recording this session so I can review the discussion at a later time.

Information kept private:

- These recordings will be kept confidential additionally, your name will be removed and replaced with a study ID, so that nothing can be traced back to you.
- I also ask that everything said in this focus group remains anonymous, so please do not share any identifying information of others outside of this focus group.

Risks and discomforts:

- It is not possible to know all the risks, but as researchers we have taken the steps to minimize the known risks.

Benefits:

- We hope to that through these focus groups we can learn more about the challenges to oxygen therapy specially around patient education.

For in-person consent forms will be signed

Instructions on Session for Zoom

- When speaking, try to speak clearly and one at a time.
- You can choose to jump into the conversation whenever you would like, or you can put your hand up by selecting the reaction button at the button and clicking "raise hand."
- Please double check you are unmuted before speaking. When muted, the microphone symbol in the bottom left of your screen will have a red diagonal line through it.
- And if you would like you are welcome to turn your camera off

Instructions on Session for In-person

- Because I am recording the audio through a program, please speak as clearly as possible and one at a time.
- You are free to join in the conversation whenever, or you may put your hand up whatever you feel most comfortable with.

Okay, I will now hit the record button.

START RECORDING: (Begin focus group-specific questions)

Closing

- Thank you all for sharing your experiences here today. It was really great to hear all your perspectives.

- As a thank you for your time, I will be sending you a 50-dollar gift card in the Once I have completed all of the focus groups and the data analysis, I will be sending you a summary of the results…

Table A2

Focus Group Script & Questions for ILD & other respiratory conditions

Introductory questions

To begin, let's start with introducing ourselves. First, your first name and then where you are from.

Can you tell me about your experience with your chronic respiratory conditions?
Potential Prompts:

- What it did it feel like to hear your diagnosis?

In what ways does living with your chronic respiratory condition impact your day-to-day activities?
Potential prompts:

- What do you do differently now because of your ILD/COPD?

Intermediary Questions

Can you tell me about your experience with therapies and treatments you have used other than oxygen?

Potential Prompts:

- Which therapies or treatments worked? Which did not?

What did you know about oxygen therapy before starting it?
If you can remember, what was it like to hear oxygen therapy recommended to you?
Potential prompts:

- What kind of feelings did you experience?
- What were some of your concerns?
- What did this conversation look like?
- How did the people close to you respond?

Can you describe the first time using you used your oxygen therapy device?

When learning how to use your oxygen therapy device what did you find helpful? What did you find confusing?

Was there any extra help needed outside of that first visit? If so, where did you go for help?

Looking at your overall experience using oxygen therapy, what day-to-day activities do you do differently now?
Potential Prompts

- Is there anything that is easier to do?
- Is there anything that is more difficult?

If, right now, you ran into a problem or had a question about your oxygen device, who or where would you turn to find the answer? And why?
Potential questions/problems: Unsure if the flow rate is sufficient. How to fly on a plane with your oxygen.

Concluding Questions

If you were talking to someone who was just starting oxygen therapy, what are some tips and/or tricks you would tell them?

If you were to create a crash course on how to use oxygen therapy, what would you include?

Table A3

Guiding Focus Group Questions for HCP's

Introductory questions

To start off, if we could by introducing yourself by providing your name, what area of health care do you work in, and how much experience you have working with chronic respiratory conditions and which conditions.

Intermediary Questions

What is your experience like in assisting patients in using and understanding their oxygen therapy?
Potential Prompts:

- What are some challenges with this?
- What are some things that facilitate this?

What areas of oxygen therapy do you find the most difficult to teach to patients?

When introducing patients to their oxygen therapy, what aspects of education do you find important?
Potential Prompts

- Do you look at their lifestyle?
- Benefits of oxygen therapy?
- Challenges of oxygen therapy?
- Offer other supports?

Where did you get most of your information for supporting patients in using their oxygen therapy?
Potential Prompts

- What could be improved?
- What is helpful?

From your experience, where do you notice most patients getting their information from?

HCP in ILD and other respiratory conditions

When supporting patients in terms of their oxygen therapy, what do you do differently with a patient who has ILD vs if they have a different chronic respiratory condition?
Potential Prompts:

- From your perspective, how are they different?

What areas of knowledge need to be improved to better inform education in ILD/other respiratory conditions in oxygen therapy?

Concluding Questions

What changes would you like to see in the way education is approached in ILD/other respiratory conditions in oxygen therapy?

If you were talking to a new clinician entering the field, what tips would you give for educating patients on oxygen therapy?

Appendix B

Guides for Interviews

Table B1

Introduction and Closing Script for Interviews

Introduction & Informed consent

- Hello everyone, my name is… and I am currently a Master of Science Student at the University of Alberta. For my masters, I am interested in education surrounding oxygen therapy, and this is why you have been asked to be part of these sessions.
- Before we begin, I would just like to review the informed consent.

Reason:

- So the reason you have been asked here today is to understand the facilitators and barriers surrounding oxygen therapy, specifically the patient education

What you are asked to do and time:

- This session will be no longer than 60 minutes, and I will do my best to ensure we are done on time.
- I will be recording this session so I can review the discussion at a later time.

Information kept private:

- These recordings will be kept confidential additionally, your name will be removed and replaced with a study ID, so that nothing can be traced back to you.

Risks and discomforts:

- It is not possible to know all the risks, but as researchers we have taken the steps to minimize the known risks.

Benefits:

- We hope to that through these conversations we can learn more about the barriers to oxygen therapy specially around patient education.

For in-person consent forms will be signed

Instructions on Session for Zoom

- When speaking, try to speak clearly as possible.
- Please double check you are unmuted before speaking. When muted, the microphone symbol in the bottom left of your screen will have a red diagonal line through it.

Instructions on Session for In-person

- Because I am recording the audio through a program, please speak as clearly as possible and one at a time.

Okay, I will now hit the record button.

START RECORDING: (Begin interview specific questions)

Closing

- Thank you for taking the time and sharing your experiences here today. It was really great to learn from you.
- As a thank you for your time, I will be sending you a gift card in the mail, does that work for you?
- Once I have completed all of the focus groups and the data analysis, I will be sending you a summary of the results…

Table B2

Guiding Interview Questions for HCP's

Introductory questions

To start off, if we could by introducing yourself by providing your name and what area of health care you work in how much experience you have working with chronic respiratory conditions and which conditions.

Intermediary Questions

What is your experience like in assisting patients in using and understanding their oxygen therapy?
Potential Prompts:

- What are some challenges with this?

Can you run me through what it would like for you to introduce oxygen therapy to a patient?

- How much time does it take?
- What areas do you really emphasize?

What areas of oxygen therapy to you think patients struggle with the most?
When introducing patients to their oxygen therapy, what aspects of education are important?
Potential Prompts

- Do you look at different levels of activity and titration?
- Benefits?
- Challenges?
- Offer other supports?

Where did you get most of your information for supporting patients in using their oxygen therapy?
Potential Prompts

- What could be improved?
- What is helpful?

From your experience, where do you notice most patients getting their information from?

HCP in ILD and other respiratory conditions

When supporting patients in terms of their oxygen therapy, what do you do differently with a patient who has ILD vs if they have a different chronic respiratory condition?
Potential Prompts:

- From your perspective, how are they different?

What areas of knowledge need to be improved to better inform education in ILD/other respiratory conditions in oxygen therapy?

Concluding Questions

What changes would you like to see in the way education is approached in ILD/other respiratory conditions in oxygen therapy?

If you were talking to a new clinician entering the field, what tips would you give for educating patients on oxygen therapy?

Table B3

Interview Questions for ILD & other respiratory conditions

Introductory questions

To begin, can you share a little bit about yourself? Where are you from and how long have you been living with ILD/COPD?

Can you tell me a little bit more what it was like to first receive your diagnosis of ILD/COPD?

Potential Prompts:

- What were your initial thoughts?
- What did you know about ILD/COPD prior to your diagnosis?

Is there anything you do differently in your day-to-day activities because of your ILD/COPD?

Potential prompts:

- Is there anything you do differently now because of your ILD/COPD?

Intermediary Questions

Can you describe the therapies or treatments you have used other than oxygen therapy and your experience with them?

Potential Prompts:

- Which therapies or treatments worked? Which did not?

Did you know anything about oxygen therapy before starting it?

If you can remember, what was it like to hear oxygen therapy recommended to you?

Potential prompts:

- What kind of feelings occurred?
- What were some concerns?
- What did this conversation look like?

Can you describe what it was like when you first started using your oxygen therapy device?

Potential Prompts

- Is there anything that you had a difficult time with?
- Is there anything that you were not sure about?

When learning how to use your oxygen therapy device either from the oxygen company or a health care provider, what did you find helpful? What did you find confusing?

Was there any extra help needed outside of that first visit? If so, where did you go for help, and what did this look like?

Looking at your overall experience using oxygen therapy, what day-to-day activities do you do differently now?

Potential Prompts

- Is there anything that is easier to do?
- Is there anything that is more difficult?

If right now you ran into a problem or had a question about your oxygen device, who or where would you turn to find the answer? And why?

Potential questions/problems: Unsure if the flow rate is sufficient. How to fly on a plane with your oxygen.

Concluding Questions

If you were talking to someone just starting oxygen therapy, what tips and/or tricks would you tell them?

What would you include if you were to create a crash course on how to use oxygen therapy?

Appendix C

Health Care Professional Demographic Surveys

FOCUS GROUP PARTICIPANT QUESTIONNAIRE -Healthcare Providers

Please complete the following questions. If you do not wish to answer any of the questions, please leave them blank.

1. What is your clinical profession?

☐ Family Physician ☐ Registered Nurse/Nurse Practitioner ☐ Pharmacist

☐ Respirologist ☐ Respiratory Therapist ☐ Physical
Therapist

☐ Physician (other specialty): _________________________ ☐ Other: _________________________

2. What gender do you identify with?

☐ Man ☐ Two-Spirit ☐ Woman

☐ Non-binary ☐ Non of the above, I identify as:

3. What is your cultural background? Choose all that apply.

☐ African ☐ Hispanic or Latinx ☐ Middle Eastern

☐ European ☐ Asian ☐ Prefer not to answer

☐ First Nations or Indigenous ☐ Other (please specify) _________________________

4. In which of the following settings do you work (please check all that apply)?

☐ Inpatient/acute care/hospital ☐ Home oxygen company/vendor

☐ Community/primary care ☐ Pulmonary lab

☐ Outpatient clinic ☐ Other:

5. How many years of clinical experience do you have?

6. How many years of clinical experience with (treating, caring for) Interstitial Lung Disease do you have?

____

7. Which AHS zone do you work in?

☐ North ☐ Edmonton ☐ Central ☐ Calgary ☐ South ☐ N/A

8. Do you have any other comments you would like to share about oxygen therapy for ILD that you do not wish to share in the focus group? If so, please provide them below.

Appendix D

Demographic Survey for Individuals with a Lived Experience

UNIVERSITY OF ALBERTA
UNIVERSITY OF CALGARY

FOCUS GROUP PARTICIPANT QUESTIONNAIRE –Individuals with Lived Experience

Please complete the following questions. If you do not wish to answer any of the questions, please leave them blank.

1. For how long have you/the individual you provide care for had a chronic respiratory condition?

☐ less than 6 months ☐ 6-12 months ☐ 1-2 years

☐ 2-5 years ☐ more than five years

2. What gender do you identify with?

☐ Man ☐ Two-Spirit ☐ Woman

☐ Non-binary ☐ Non of the above, I identify as: ______________________

3. What is your cultural background? Choose all that apply.

☐ African ☐ Hispanic or Latinx ☐ Middle Eastern

☐ European ☐ Asian ☐ Prefer not to answer

☐ First Nations or Indigenous ☐ Other (please specify) ______________________

4. Which zone of Alberta do you live in?

☐ North ☐ Edmonton ☐ Central ☐ Calgary ☐ South ☐ N/A

5. Would you say you live in rural or urban Alberta?

☐ Rural ☐ Urban ☐ Unsure

6. How long have you been using oxygen therapy? Or how long did you use oxygen for?

☐ Less than 6 months ☐ Between 6 months – 1 year ☐ More than one year

7. Which company provides your oxygen therapy?

☐ Dream Sleep Respiratory ☐Freshair Respiratory Care Inc. ☐Medigas

☐Advanced Respiratory Care Network ☐Vitalaire

☐ Other (please specify) ________________________

8. Do you have any other comments you would like to share about oxygen therapy that you do not wish to share in the focus group? If so, please provide them below.

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