

Current Landscape and Future Directions of Patient Education in Adults with Interstitial Lung Disease

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ABSTRACT

Background: Understandable, comprehensive, and accessible educational materials for patients with interstitial lung disease (ILD) are lacking. Patients consistently ask for improved access to evidence-based information about ILD. Nonetheless, few research studies focus directly on developing and evaluating interventions to improve patient knowledge.

Objective: We describe the current landscape of patient education in ILD, identify gaps in current approaches to information delivery, and provide frameworks to address these challenges through novel educational tools.

Methods: A literature review was conducted in collaboration with a medical librarian (M.R.D.) in April 2022 using Ovid MEDLINE (1946–), Embase (1947–), Cochrane Central (1993–), and CINAHL (1961–). Search terms included “interstitial lung disease,” “pulmonary fibrosis,” “patient education,” and “information seeking behavior” (*see* the data supplement for full search terms). Reference lists from selected articles were used to identify additional studies.

Results: Currently, patient education is commonly combined with exercise regimens in pulmonary rehabilitation programs in which benefits of the educational component alone are unclear. Few studies investigate improving knowledge access and acquisition

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for patients with ILD and their caregivers regarding self-management, oxygen use, and palliative care plans. Online distribution of health information through social media runs the risk of being unregulated and outdated, although it is an avenue of increasing accessibility.

Conclusion: By expanding access to novel ILD-specific education programs and accounting for social determinants of health that impact healthcare access, patient education has the potential to become more attainable, improving patient-centered outcomes. Further research into optimal development, delivery, and efficacy testing of patient education modalities in ILD is warranted.

Keywords:

education; fibrosis; digital health; quality of life; self-management

BACKGROUND

Interstitial lung disease (ILD) is a chronic lung disease characterized by inflammation and/or fibrosis of the interstitium and alveolar parenchyma (1). Patients experience variable clinical courses dependent on both the etiology and phenotype of the ILD, as well as other individual patient characteristics (2–4). A person may develop ILD as a result of an environmental or occupational exposure, a systemic connective tissue disease, or an unidentifiable cause, as in the case of idiopathic pulmonary fibrosis (IPF) (4–8). Patients who live with ILD experience varying degrees of symptomatology, including chronic dyspnea, cough, and fatigue, which have the potential to interfere with daily activities and quality of life (2, 6, 9–11).

Receiving a diagnosis of ILD often precipitates a degree of anxiety and uncertainty in many patients as they grapple with the possibility of a life-limiting illness that carries a great degree of morbidity (12–14). Confidence in managing a chronic disease is in part due to access to high-quality information about the natural history of the disease, symptoms, treatment, and self-management. At times, the diagnostic process alone remains elusive for clinicians, patients, and their caregivers, leaving room for further uncertainty. The mainstay of pharmacologic therapy for patients is either

immunosuppression or antifibrotics, which are often associated with intensive drug monitoring and potentially intolerable toxicity profiles (15). At times, deciding which medication to initiate (if any at all) is challenging, sometimes requiring input from multiple specialists and preferably using shared decision making with patients. Those who require supplemental oxygen are burdened with a separate layer of questions related to the delivery device and equipment, frequency of use, and coping with the life-altering addition of this therapy (16).

Patients living with ILD have expressed their degree of uncertainty, lack of knowledge, and difficulty coping with their diagnosis (17). Information insufficiency has also been cited as a problem in systemic diseases associated with ILD, leading to fear and insecurity about care recommendations (18). Patients have alluded to the possibility that this uncertainty may be partially remedied by arming them with a better understanding of their disease and its management (17, 19, 20). In a systematic review of 35 studies evaluating patient needs in pulmonary fibrosis (PF), items within information and education domains were the most frequently cited (21). It should be noted that these needs have not lessened since introducing new therapies (22), and many would argue that these gaps have increased in this setting as

patients grapple with decisions regarding treatments and their potential side effects (23). The *American Journal of Managed Care* reports the average specialty physician office visit length to be 21 minutes, which is insufficient time to provide comprehensive ILD care and adequate patient education to allow meaningful shared decision making (24). According to interdisciplinary experts and the American Thoracic Society, disease-specific knowledge is a key patient-centered endpoint in ILD. Access to accurate and understandable information addressing questions patients have about their disease is key in mitigating this sense of uncertainty (25). Importantly, there must also be the ability to uptake and retain the presented information. Further research into optimal development, delivery, and efficacy testing of patient education modalities in ILD is among the high-priority patient-centered research goals in ILD (26). Although there has been investigation into optimal ways of providing disease-related information and improving patient understanding of chronic disease, little work has been devoted to this in ILD (27). In this review, we examined the current landscape of patient-centered education in ILD, identified the gaps in our understanding, and suggested potential innovations in delivering and measuring disease-specific information uptake in ILD. We highlighted the work that has already been performed in patient education in ILD and successful patient education interventions in other chronic (lung) diseases, as well as how we can build on this to apply it to patients living with ILD. Last, we considered the role of online resources and digital platforms and their effects on patient-reported outcomes, such as health-related quality of life (HRQoL), self-efficacy, and patient satisfaction.

METHODS

A literature review was conducted in collaboration with a medical librarian

(M.R.D.) in April 2022 using Ovid MEDLINE (1946–), Embase (1947–), Cochrane Central (1993–), and CINAHL (1961–). Search terms included subject headings and keywords for the concepts of “interstitial lung disease,” “alveolitis,” “pulmonary fibrosis,” “sarcoidosis,” “patient education,” and “information seeking behavior” (*see* the data supplement for full search strategies). There were no language, publication date, or article-type restrictions on the search strategy. Reference lists from selected articles were used to identify additional studies. Retrieved studies were screened for inclusion using Covidence systematic review software. Additional details of the literature search are available in the data supplement.

Current Platforms for Education in ILD *Education in pulmonary rehabilitation.*

Nonpharmacological interventions have become essential to manage aspects of ILD that are important to patients (e.g., symptoms, functional status, quality of life) that may not be improved with traditionally prescribed pharmacologic therapies. One of the main nonpharmacologic interventions employed in ILD is pulmonary rehabilitation (PR). PR combines a structured exercise program with some degree of patient education (28). The use of PR in ILD has imparted many benefits that lessen the disruption of the disease in daily life. For example, PR has been found to improve functional capacity, dyspnea, and HRQoL (28). Education from PR programs can promote self-management as well as inform patients about proper oxygen use, navigating daily life, and improving physical functionality (29, 30). Patients also expressed wanting to know more about the results of their pulmonary function tests as they relate to their disease state and preparations for end-of-life care (31). Notably, PR programs often group patients with different lung diseases, but

some patients and healthcare professionals desire a separate program specific to ILD, particularly for the education component (31, 32). In regard to specializing education, patients noted that programs gave information about chronic obstructive pulmonary disease (COPD) that would not directly apply to their experiences with ILD (32). For example, inhaler education may not be relevant for everyone with ILD, and different types of ILD cause unique effects, such as an increased need for oxygen therapy or addressing mobility in patients with rheumatologic diseases such as systemic sclerosis-associated ILD (32). In addition, because many studies on the efficacy of PR in ILD focus on the combination of exercise and education together, it is difficult to determine how the education component alone impacts HRQoL (29, 30, 32–34). Although a study of COPD found that education did not improve outcomes as a standalone intervention, further research is needed to explore whether this applies to ILD and how to enhance patient-centered outcomes with innovative education platforms (35).

Electronic delivery of health information.

Informational tools include but are not limited to leaflets, websites, and smartphone apps that offer the potential of customized health information (36). For example, digital platforms involving interactive and three-dimensional content were found to engage patients and instill confidence in their self-management skills while offering reliable health information (37). The importance of providing reliable and patient-friendly health information relates to the vastness of inaccurate resources found on the Internet. Unfortunately, many patients with chronic disease report difficulty finding accurate information and problems comprehending and discerning the reliability of information on the Internet (38). Because most sources are in English, knowledge acquisition can be

limited, necessitating the broadened translation of educational materials (19). Furthermore, on one hand, the Internet has been documented to be a poor place to obtain information about ILD because of incomplete, inaccurate, and outdated content (39, 40). On the other hand, in terms of efficacy and modality, studies have shown that virtual training for both COPD and asthma is as effective as in-person education and can be repeated at home, allowing refresher courses and costing less, all while improving technique in the COPD study (41, 42). This flexibility in modality represents the potential for extending access to patient education programs to patients with ILD with less access to transportation or who live far from the program. Currently, there are several digital platforms from a variety of for-profit and nonprofit organizations that address the needs of patients with ILD and their caregivers (Table 1).

YouTube is a platform commonly used for information about treatment. A study examining YouTube videos as a source of patient information about IPF found that videos had low views overall (43). However, the videos with the most views often promoted products advertised as cures for the disease that have little evidence to support efficacy or, in some cases, have evidence against their use in IPF (43). Another complicating factor is YouTube's unregulated algorithm that prioritizes videos based on search rank, viewership, and interactions under videos, exposing patients to potentially less reliable health information (43). Because many patients will continue to rely on the Internet for health advice, digital platforms delivering customized and trustworthy health information represent promise in reducing misconceptions and the burden of disease management (44).

In addition to online videos, verified social media platforms, for example, allow patient

Table 1. Examples of current online educational resources geared toward patients with ILD

Source Name (Internet Link)	Content Type	Description	Benefits	Challenges	Date Last Updated
American Lung Association (https://www.lung.org/lung-health-diseases/lung-disease-lookup/interstitial-lung-disease) (108)	Website	Features lookup tool for specific ILD, facts about each ILD, treatment options, caregiver advice, and questions to ask doctor.	Outlines causes, diagnostic processes, and treatments for each ILD with patient- and caregiver-specific pages. Some ILDs have videos and more resources to join patient support groups. Translation available in English, Spanish, French, German, Russian, Chinese (simplified), Arabic, Filipino, Korean, and Vietnamese. Information reviewed and updated by review panel.	Limited multimedia (no videos on some ILD pages).	Unknown
CHEST Foundation (https://foundation.chestnet.org/patient-education/) (109)	Website	Contains patient-centered information for different ILDs with an overview of each condition, its diagnostic tests and symptoms, and specific resources for further reading.	Features articles authored by physicians. Provides access to webinars on navigating life with ILD.	Not available in different translations. Not the most up-to-date information (webinars dating to 2018, articles from 2020).	11/20/2020
European Lung Foundation (https://europeanlung.org/en/information-hub/lung-conditions/interstitial-lung-disease/) (110)	Website	Provides overview of causes, treatment, prevention, and additional resources for different ILDs.	Has option to share and browse patient experiences. Translations available in English, Spanish, French, Portuguese, German, Russian, Greek, Polish, and Italian.	Not every ILD (RA-ILD) has patient experiences highlight.	8/8/2023
MedlinePlus (https://medlineplus.gov/ency/patientinstructions/000016.htm) (111)	Website	Explains overview of what to expect at home and in the hospital, how to self-manage the illness, tips to prevent other infections, and oxygen use.	Addresses oxygen use, tips on nutrition, recommended exercises, advice on adapting to living at home, more informational tabs on specific ILD, includes Spanish translation.	Does not describe progression and corresponding symptoms/tips to adjust to them.	1/20/2020

Table 1. Continued.

Source Name (Internet Link)	Content Type	Description	Benefits	Challenges	Date Last Updated
National Jewish Health (https://www.nationaljewish.org/patients-visitors/patient-info/patient-education-and-support) (112)	Website	Contains free downloadable materials for patients and caregivers, explains tests, patient education classes and support groups, individualized programs.	Describes stages of IPF, downloadable booklets, group education classes, podcasts and videos on topics relevant to ILD such as exercise, COVID-19, and living with IPF.	Group classes not ILD-specific.	Unknown
PA-IPF Support Network (https://paipfsupportnetwork.org/education/) (113)	Website	Affiliated with Wescoe Foundation for Pulmonary Fibrosis. Provides overview of IPF and PF, seminars and webinars, and podcasts for educational topics for both patients and caregivers.	Allows knowledge distribution to patients through multiple media outlets, such as webinars, educational seminars, support groups, and podcasts.	Not available in different translations.	9/12/2023
Pulmonary Fibrosis Foundation (https://www.pulmonaryfibrosis.org/patients-caregivers/education-resources/other-educational-resources) (114)	Website	Includes guides on caregiving, discussing PF with friends and family, oxygen use, and treatments, including clinical trials and lung transplants.	Includes Spanish translation and some guides in Simplified Chinese, Russian, Hindi, Arabic, Portuguese, French, and Mandarin. Tips on traveling with oxygen, how to find clinical trials guide, preparing and adjusting to lung transplant, telemedicine-specific guides.	Not available in different translations for caregiving materials.	2022
UCSF Health ILD Nutrition Manual (https://www.ucsfhealth.org/education/ild-nutrition-manual) (115)	Website	Lists manuals of sample foods for eating healthy with ILD and managing the effects of prednisone and weight gain.	Discusses nutritional aspect of managing ILD, includes recipes for ways to ensure comprehensive nutrition.	Not available in different translations.	Unknown

Table 1. Continued.

Source Name (Internet Link)	Content Type	Description	Benefits	Challenges	Date Last Updated
Boehringer Ingelheim (https://www.boehringer-ingelheim.com/podcasts/progressive-fibrosis-ild/journeys-through-pf) (116)	Podcasts	Podcast series that features physicians, researchers, patients, and their families sharing insights on diagnosis and treatment, mental health, support groups, and connective tissue–related ILD.	Integrates many perspectives to give comprehensive overview of key aspects of disease management. Includes other conditions that intersect with ILD. Highlights patients’ experiences.	No readily available transcript for those who are hard of hearing, only available in English.	7/14/2023
PA-IPF Support Network (https://omny.fm/shows/pa-ipf-support-network-podcast) (117)	Podcasts	Monthly podcasts covering education for patients and caregivers, diagnosis, palliative care, and intersexuality intersections.	Features physician guests, covers variety of topics from diagnosis to end of life.	No readily available transcript for those who are hard of hearing, only available in English.	8/24/2023
Breathe Support (https://www.facebook.com/pfwarrrior) (118)	Social media	Facebook group for peer support for patients with PF.	Allows patients to share their experience and gain peer support from other patients, highlights current clinical research projects for patient involvement.	Unknown monitoring of information and interactions, only available in English.	8/23/2023
PF Warriors (https://www.facebook.com/pfwarrrior) (119)	Social media	Facebook group for PF, IPF, and other lung diseases that features educational meetings and patient interactions through support groups.	Promotes educational meetings with healthcare professionals, encourages patients to engage and discuss their experiences, displays current studies on ILD.	Unknown monitoring of information and interactions, only available in English.	8/23/2023
Pulmonary Fibrosis News (https://twitter.com/pulmonaryfibros?ref_src=twsrc%5Egoogle%7Ctwcamp%5Eserp%7Ctwgr%5Eauthor ; https://www.instagram.com/pulmonaryfibrosisnews/?hl=en) (120, 121)	Social media	Twitter/X and Instagram platforms with current research about PF.	Features current research with tips on lifestyle changes to help patients and current clinical trials.	Not available in different translations.	Twitter/X: 8/22/23; Instagram: 4/14/23

Table 1. Continued.

Source Name (Internet Link)	Content Type	Description	Benefits	Challenges	Date Last Updated
Canadian Pulmonary Fibrosis Foundation (https://twitter.com/THE_CPF?ref_src=twsrc%5Egoogle%7Ctwcamp%5Eserp%7Ctwgr%5Eauthor ; https://www.facebook.com/TheCPF/) (122, 123)	Social media	Twitter/X and Facebook accounts that include campaigns for awareness and patient and caregiver support meetings.	Involves caregivers in educational meetings, includes current research findings.	Not available in different translations.	Twitter/X: 7/26/23; Facebook: 8/24/23
European Pulmonary Fibrosis Federation (https://www.facebook.com/EUIFFF/ ; https://twitter.com/eu_ipff?lang=en ; https://be.linkedin.com/company/eu-pff) (124–126)	Social media	Facebook, Twitter/X, and LinkedIn platforms with potential clinical trials for patients and educational meetings and programs.	Features current research and educational meetings and summits. Patient summits translated live into eight languages.	Unknown monitoring of information and interactions.	Facebook: 8/24/23; Twitter/X: 8/24/23; LinkedIn: 8/11/23
ATS (https://www.thoracic.org/patients/patient-resources/fact-sheets-az.php#E) (127)	Educational articles	Educational articles on IPF, HP, and pulmonary function tests.	Focus on action steps, nonmedication interventions, antigen identification and avoidance, and diagnostic tests.	Many only available in English, some in Spanish.	2022

Definition of abbreviations: ATS = American Thoracic Society; COVID-19 = coronavirus disease; HP = hypersensitivity pneumonitis; ILD = interstitial lung disease; IPF = idiopathic pulmonary fibrosis; PF = pulmonary fibrosis; RA = rheumatoid arthritis.

interaction and physicians to reach larger patient populations (44). These platforms (Twitter/X, Facebook, Instagram, chatrooms) offer patients tips on self-management, possible treatments and clinical research trials, and opportunities to engage with other patients. This peer-to-peer level of interaction is valuable in ILD, especially because it serves as a mode of social support and patient empowerment (45). Although there are positive aspects to using social media for education, the presentation of false and harmful information alongside accurate and beneficial materials makes it difficult for patients to determine what information to trust (40). This ambiguity can be particularly harmful if the information contradicts the advice given by a physician (46).

In a content analysis of Facebook pages and Twitter/X posts dedicated IPF, many posts originated from nonmedical professionals, increasing the likelihood of finding inaccurate information (40, 46). Facebook posts featuring helpful and evidence-based advice do not necessarily generate the most attention through post sharing, which may permit outdated and false information to persist (40). This finding is in contrast to the Twitter/X content analysis, where there was less post attention to inaccurate information (46). The differences in post accuracy and attention could be due to the types of information being shared, because Twitter/X features more medical foundations and professionals sharing scientific findings and Facebook is centered on community interactions (46). Although Facebook and Twitter/X posts have similar numbers of harmful information (5% vs. 7%), YouTube outnumbered both platforms (17%), possibly resulting from regulatory policy differences between platforms (46). One necessary improvement to prevent misinformation includes consistent updates to and regulation of online resources in accordance with

current research (19, 47). If clinicians point to specific and verified social media sources or videos, the danger of running into unreliable and unregulated online health information can potentially be mitigated.

Although using the Internet comes with several concerns regarding information accuracy, it can also present helpful advice and immediate information for patients. For example, patients with PF often seek emotional support through online platforms, which allow the expression of their own experiences with the disease, posing questions on current research and treatment, and sharing helpful resources with each other (47). Specifically, peer support groups and resources tailored for patients and their caregivers assist in distributing comprehensive education about the condition (48). Alongside social media and Internet support groups, other methods of seeking emotional support can include being matched with peers over the telephone. The Peer Connect Service was used to establish connections with patients of similar characteristics through telephone conversations (49). Patients appreciated sharing their experiences about living with PF with others while gaining and giving emotional support despite geographic distance, although some wanted to have in-person meetings to further solidify their connection (49). Although patients emphasized the importance of not giving medical advice, patients expressed that talking to someone living with a similar condition gave them insight into how to cope, which could not be gained solely from physicians and nurses (49).

The widespread accessibility of this information and support is especially valuable when ILD progresses and symptoms prevent patients from traveling outside their homes to in-person programming (50). In comparing digital and printed

materials, one must acknowledge the higher costs of printed materials and updating materials. Resources for computer training can allow patients to access telehealth services, which can allow more regular visits to access education from ILD physicians and nurses and accommodate patients and their caregivers struggling with traveling to appointments (51, 52). Telemedicine has also been explored for PR, allowing patients to complete the exercise and education programs without traveling to an external site (53). On one hand, because PR through telemedicine had efficacy similar to that of in-person programs, its implementation could represent an outlet for education programs in ILD (53). On the other hand, digital materials may represent limitations in accessibility, especially for older patients and those of low socioeconomic status, limited mobility, and unfamiliarity with technology (54). However, computer training programs and accessibility to public libraries can bridge these gaps, allowing patients to learn how to access reliable health information online at no cost (55).

In-person distribution of health information. As a result of these limitations on digital health programs, some patients may benefit more from in-person educational interventions that address gaps in their knowledge. Patients report lacking health information at the time of diagnosis, leading to uncertainty about treatment options and disease progression (56). Because ILD is chronic, receiving individualized information from healthcare professionals as the disease progresses is an essential need expressed by patients, including those who eventually receive palliative care (25). Over half of patients report being underinformed about treatments and interventions, as well as lung transplants, which can contribute to increased anxiety because of making challenging decisions in treatment plans (48).

For example, oxygen therapy is a common intervention initiated as ILD progresses (16). Many patients and their caregivers (who serve as an important emotional support during this life transition) feel underinformed about the use of supplemental oxygen (57, 58). As patients with ILD and their caregivers become more informed about treatments such as supplemental oxygen, they experience less anxiety about the disease and more confidence in self-management (59).

In-person education can be provided by clinicians and other trained professionals working in ILD clinics, and more collaboration between several key healthcare professionals can result in better educational attainment (57). In particular, a nurse-led educational intervention (“A Program of SUPPORT”) led to increased knowledge of ILD, its management, and plans for end-of-life care (59). SUPPORT integrates fundamental aspects expressed as unmet needs for patients and their families, including symptom management, disease knowledge, PR, oxygen therapy, end-of-life care, research, and transplant (59). Educating patients on the possible pharmacological treatments and side effects may also help bridge the gaps in knowledge. For example, an asthma inhaler study featured education administered through pharmacists, where personalized instructions were written and distributed on the basis of observations of the patients’ technique (60). This kind of education can be helpful in ILD when patients are unsure of potential side effects and use.

Potential benefits: boosting HRQoL through improved patient education. Implementing patient education programs as a self-management strategy might represent potential avenues for impacting HRQoL (61). Self-management is described as a skill set that can be used to maintain quality of life, often including but not limited to

medication and nutrition care, social support, and disease knowledge (62). Because of the pervasiveness of symptoms in ILD, such as cough, dyspnea, and fatigue, patients often experience reduced HRQoL (11, 63). A Delphi study found that patients with PF and healthcare professionals caring for people with PF came to a consensus that understanding medication use and possible treatments, participating in potential clinical trials, and recognizing the importance of exercise were essential to self-management (64). In addition, patient access to essential health information further emphasizes the need for education in understanding trends and potential prognosis as part of self-management, especially in seeking the support of physicians to interpret the data (65). Although some studies of COPD and asthma (66, 67) reported no improvement in HRQoL, the 6-minute-walk test, and self-confidence after educational interventions, others reported increased exercise capacity (68) and less deterioration in HRQoL than those not participating in the intervention (69). The lack of educational materials covering the psychosocial impact of diagnosis contribute to further worsening symptoms and a lower HRQoL (14). As a result, educational materials focused on elucidating the clinical course of a lesser-known disease, compared with other chronic conditions, could have an invaluable impact on patients' ability to cope with the everyday complexities of living with ILD (31). One study found that patients valued traveling despite progressively declining lung function (20). Therefore, patients wanted educational information on navigating a worsening condition without compromising the activities that contribute to their HRQoL (20).

Another critical component to consider is that patients with low self-activation often have trouble managing their disease,

exacerbating symptoms that decrease HRQoL (70). While no studies have focused on interventions for increasing these two measures in ILD, educational programs aimed at helping patients take control of their disease, especially through patient advocacy programs and empowerment groups, represent the opportunity to provide education, while also giving patients the ILD-specific tools to manage their condition. Notably, many programs have reported positive outcomes in self-management and HRQoL for chronic diseases affecting the lungs, including asthma, cystic fibrosis, and COPD (71–73). These education programs highlight the efficacy of technological interventions, support group therapy, and changes in patient–physician interactions (74, 75). In addition, programs guiding medication use also impact self-management. For example, inhalers are used to dispense medications, making proper inhaler use essential in preventing disease exacerbation (42). However, mishandling of inhalers is common and expected, which has resulted from a lack of understanding of inhaler use (42, 60). Patient education programs commonly used include lectures about COPD, video and in-person demonstrations on inhaler use, relaxation and energy-conserving techniques, and “teach-back techniques,” as well as advice on how to remedy exacerbations in disease (41, 69). In asthma, studies (42, 76–78) have similarly found successful outcomes regarding improved inhaler technique, medication adherence, increased pulmonary function, and increased self-management and HRQoL (77). Overall, improved access to high-quality patient-centered education has the potential empower patients to make informed decisions about their health care, adhere to treatment plans, and lessen the uncertainty and anxiety that results from navigating the effects of ILD on daily life (79).

Social Determinants of Health: Barriers to Improving Health Literacy and Access to Education

Social determinants of health impact healthcare access and disproportionately expose patients to potentially harmful exposures that can develop and worsen their ILD (80). They include but are not limited to education, employment, housing environment, healthcare access, and social support (81). Therefore, it is necessary to investigate their impact on access to educational materials to address gaps in ILD health care. In patients with IPF, inequalities in undergoing a lung transplant are rampant because adequate insurance coverage, higher median zip code income, and shorter distance to a lung transplant site are associated with getting a transplant, and being a non-White patient is associated with lower chances of undergoing a transplant (80, 82, 83). These results are corroborated by studies of patients with COPD, for whom the caregiver's transportation is essential for adherence to care plans and appointments (84). Caregiver reliance potentially represents a gap where patients with ILD who are nonmobile and rely on their caregiver's transportation are disadvantaged when accessing critical health services (85). In COPD, affordable medications are a challenge because of a lack of generic alternatives, and this can be a similar barrier for patients with ILD because of the out-of-pocket cost of antifibrotics (86, 87). In addition, moderate adherence to PR in COPD was correlated with socioeconomic disadvantage when health status was not a factor, furthering the importance of financially accessible treatments for patients (88). It is paramount to further explore the barriers to attaining care for patients with ILD to discern and address the limitations of funding and distributing education programs.

Potential Solutions to Addressing Patient Education Gaps in ILDs

Although there have been several studies investigating patient education in ILD, working toward comprehensive education is still an urgent concern in need of more research (26). Education that discusses different aspects on the spectrum of living with ILD, from diagnosis to end-stage and palliative care needs, should be implemented in patient care. Health literacy is an additional factor that should be addressed in patient materials because lower health literacy in patients with COPD, for example, has been associated with a lower HRQoL and confusion regarding care instructions after hospital admissions (89). To expand health literacy, decision aids may be beneficial, especially for palliative care (90, 91). Furthermore, patients note the need to understand their test results, specifically concerning pulmonary function tests, because these tests can show disease progression (31). Another area to address involves pollutants and antigen exposures that are disproportionately distributed, because patients of lower socioeconomic status are surrounded by highly pollution-emitting areas, such as interstate highways and factories, or use biomass fuel regularly (86). These exposures worsen respiratory function and play a role in health outcomes. However, programs for housing vouchers showed improvements in respiratory function for patients relocating out of high-pollution areas, such as fewer pediatric asthma attacks and more improved overall health for adults, which may be a necessary component to present in educational materials (92). A study focused on investigating the challenges of antigen identification for patients with hypersensitivity pneumonitis found that the greatest barriers to avoiding these harmful exposures were a lack of resources and financial means for patients (93). Improved resources that

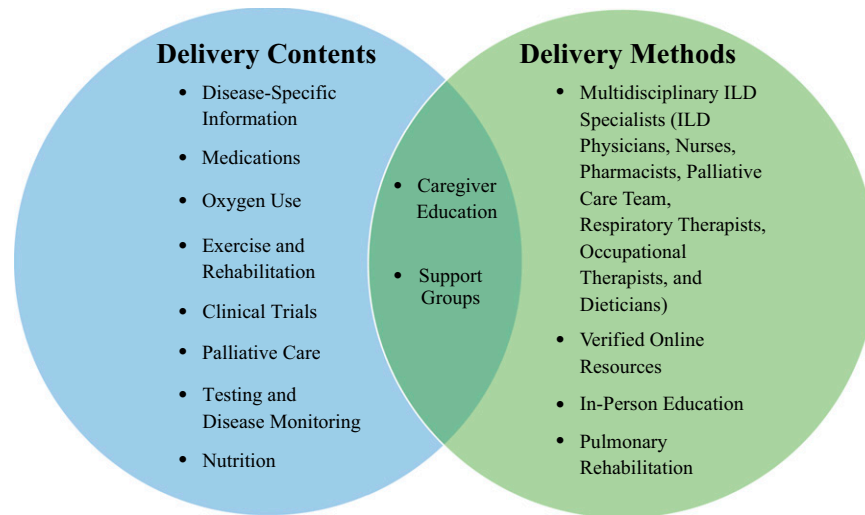


Figure 1. Key educational content and delivery methods for patients with ILD. ILD = interstitial lung disease.

provide information on identifying these antigens and how to avoid them are necessary for improving quality of life and dispelling misinformation (93). Overall, more work needs to be done in this avenue to eliminate the disparities in housing and corresponding exposures that cause and worsen ILD. Providing timely delivery of information relevant to each patient's stage of the disease could expand health literacy and contribute to more efficacious disease management and awareness. Figure 1 highlights some of the potential topics for inclusion in educational resources for patients with ILD.

Nutrition education. Nutrition is an especially understudied topic of ILD and has been identified as an educational topic of interest by patients and physicians (30). Unintended weight loss and malnutrition could occur because of either antifibrotics or other effects of ILD, such as lower mobility (94). For example, in patients with IPF, pirfenidone and nintedanib are two common antifibrotics with gastrointestinal side effects, including nausea, loss of appetite, diarrhea, and weight loss; weight loss was increased for those taking nintedanib (95). Although there are recommendations for diets that can lessen

severe side effects, older adults with pulmonary fibrosis were less aware of different pharmacological and nonpharmacological interventions, including nutrition management (96). Raising awareness about how to prevent malnutrition while receiving antifibrotics represents an avenue for dietitians to be implemented into the multidisciplinary team of ILD educators (97, 98). Therefore, further research is needed on nutrition that may improve HRQoL and the severity of symptoms that can lead to an unfavorable prognosis (99).

Multidisciplinary team of healthcare professionals. As a multifaceted condition, ILD requires the collaboration and coordination of many healthcare professionals in providing comprehensive care, including patient education (100). Side effects of antifibrotics and comorbidities require monitoring and treatment by primary care physicians and can be a source of education for patients learning how to manage the conditions often accompanying ILD (101). In addition, because many patients have expressed wanting information on self-management and end-of-life planning, ILD nurses can guide education on

these topics between pulmonologist visits (14, 59). ILD nurses and nurse practitioners are also essential, together with pharmacists, to provide education on antifibrotic side effects and management (48, 95). Because education is obtained in the clinic, during PR, and at home, the use of a multidisciplinary team of healthcare professionals can promote a community-based approach to education (102). For example, home care often involves coordination among nurse practitioners, respiratory therapists, social workers, dietitians, and occupational therapists (48, 102, 103). This allows prompt, individualized patient education between clinic visits and addresses the need for comprehensive care that patients have expressed, including palliative and psychological care needs (100, 102, 103).

Inclusivity of caregivers. The lack of educational materials leads to confusion among those closest to patients with ILD, emphasizing the need for patient- and caregiver-centered educational materials. Patients note that a lack of understanding of their disease leads to difficulty in explaining their condition to friends and family, who often serve as caregivers (31). Education can make an impact by equipping caregivers with the tools to understand disease progression and manage worsening symptoms (104). For example, many educational studies on COPD involve caregivers with the goal of improving health literacy and consequently health-related outcomes (105, 106). One study (105) found increased caregiver confidence and quality of life alongside a better understanding and fulfillment of their responsibilities, and another study (106) supports this finding, particularly when implementing psychosocial support into PR family education programs. These studies on COPD highlight the versatility of education when incorporating caregivers into educational interventions with a focus on mental

health. Together with disease management, caregiver-focused education may focus on the financial and legal aspects often accompanying loved ones living with a chronic, potentially life-limiting disease (104). In all cases, comprehensive caregiver education will further equip caregivers to help their loved ones and themselves adjust to life with ILD, mitigating some of the uncertainty that comes with diagnosis.

Role of patients in research and implementation of new interventions.

Because ILD is a topic of constant research, patients reported wanting information on current treatments and clinical trials (25, 107). Patients felt in control of their disease when provided with education, because misinformation can lead to false expectations of unproven therapies (107). Support groups, for example, focused on scleroderma offer reliable health information, although it should be noted that educational materials are lacking overall (107). Many patients look for online information on recent research progress from interactive, online platforms, representing another way of encouraging patient involvement in clinical research trials, as well as informing them of trial results (47).

CONCLUSION

Improving education in ILD is a pronounced goal in pursuing further research on improving patients' knowledge acquisition and HRQoL. Although studies implementing education in PR have found positive effects, there is a scarcity of studies focusing solely on education in patients and their caregivers and its impact. In addition, digital modalities will allow validated, updated information to comprehensively cover topics from diagnosis to palliative care, promoting self-management and

self-efficacy. By implementing patient education at specified stages of the disease through a multidisciplinary team of health-care professionals, patients and their caregivers will become empowered to navigate their disease and its progression while maintaining their quality of life. Acknowledging the effects of social determinants of health on attaining health care is also pertinent when designing educational interventions to

ensure access by all patient populations. Future studies that focus on educational interventions from patient and caregiver perspectives will inform the prioritization of education upon diagnosis to mitigate anxiety and confusion throughout the entire treatment and progression of ILD.

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