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“Educate and Empower: Novel Edu-Therapeutic Model Of Supportive Care For Patients And Care Partners Living With Pulmonary Fibrosis”

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Interstitial lung diseases (ILDs), such as pulmonary fibrosis, involve lung inflammation and scarring, causing breathlessness, cough, and fatigue, with a life expectancy of 2-3 years post-diagnosis, leaving individuals feeling isolated and overwhelmed while navigating this insidious disease. Supportive care serves as the vital channel offering education, support, and resources to patients and their care partners who seek answers and guidance in navigating their journey. Patient experience data shows that integrating evidence-based information with practical support group dynamics, known as the Edu-Therapeutic Model, proves effective for the pulmonary fibrosis patient community. This approach ultimately empowers patients and their care partners to better manage this journey.

The goal of these findings is to share this integrative model, curriculum design, and call to action, advocating for an effective facilitative approach in support group settings.

A 21-question survey was conducted using Google Forms, distributed via email, and to all 18 virtual monthly support groups across three states from February to March 2023. Six questions focused on exclusive benefits to quality of life, employing a five-point Likert-style rating scale (0 = Never, 4 = Always) for respondents to indicate their sentiments. This survey contributes to the assessment of support group engagement and facilitation.

Within the context of support group settings, the results highlight a preference for a virtual delivery, with an in-person setting. Of the 63 patients and care partners who responded to the question, 43 (68.25%) noted preference for virtual (23 Men; 20 Women), 16 (25.40%) noted preference for in-person (7 Men; 9 Women) and 4 (6.35%) noted preference for a hybrid delivery model (4 Men; 0 Women). Additionally, these findings underscore a preference for an

open forum format over structured educational topics. When the same 63 patients and care partners were asked about delivery structure and content preferences non-exclusively, 40 (63.50%) noted preference for open forum, 36 (57.14%) noted preference for symptom management (e.g., managing cough and fatigue), 30 (47.62%) noted preference for Physician Q&A and 25 (39.70%) noted preference for both oxygen therapy and medications. There were also preferences noted for 5 other delivery and content options at a decreased level. This observation is particularly significant, as it implies that patients and their care partners value both the education and dynamics of a group, which has led to using an Edu-Therapeutic Model for facilitation and engagement.

Conducting both a needs assessment survey and introspective evaluations helps ensure the dual efficacy of the educational and therapeutic approach for patients and their care partners. Ultimately, validating the current approach in support group facilitation, using a “playbook” for supportive care, an evidence-based program can educate, support, and sustain patient and care partner engagement and empowerment. For the next steps, partnering with another patient-advocacy organization can help redefine the model and lend to collaborative partnerships to use this model for supportive care. In addition, future studies will need to consider cultural diversity in group dynamics and facilitation.