

PFF Summit 2023 Abstract

TITLE: “TAKING A DEEP BREATH: ASSESSING THE BENEFITS AND CHALLENGES OF SUPPORT GROUPS FOR PATIENTS LIVING WITH PULMONARY FIBROSIS AND THEIR CARE PARTNERS”

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Idiopathic Pulmonary Fibrosis (IPF) is a progressive lung disease characterized by scarring of the lungs with no known cause or cure. Upon initial diagnosis, patients are given 3-5 years to live and often can feel isolated and depressed. Support groups can provide valuable resources of supportive care while navigating this devastating disease. However, there is little known about the way patients and care partners get information, attend, and engage in support groups.

The objective of this survey is to determine support group effectiveness by surveying patient and care partner satisfaction with their involvement in a support group.

We developed a 21-question survey utilizing Google Forms that was distributed via email and to all (18) virtual monthly support groups within 3 states between the months of February and March 2023. Six questions associated with mutually exclusive benefits to quality of life were asked, with respondents given a five-point “Likert-Style” rating scale to select from (0= Never, 4=Always). The aforementioned benefits to quality of life covered in the survey include support, knowledgeability of diagnosis, confidence, awareness of secondary resources, and a sense of advocacy.

We received 63 responses from the 265 patients and care partners (23.8%) who received the survey. From these responses, we are able to establish non-causal inferences from each question. We can infer that our support group members feel more supported, knowledgeable, confident, and stronger advocates for themselves after attending a session, compared to the time before they joined the Wescoe Foundation (WFPF) support group network. Secondly, we also observed that 74.6% of respondents said they prefer Virtual or Hybrid support group delivery. This finding goes against the stereotype that older individuals are technology-averse. Lastly, we found a correlation in satisfaction when controlling for respondent sex. We observed that, on average, respondents who self-identified as female reported being 13% less satisfied compared to their male counterparts. This observation is interesting, as WFPF is a 100% female-managed and operated non-profit organization. Further research will be necessary to better understand this secondary result.