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worldwide, people with cystic fibrosis (CF) may be uniquely susceptible to negative health impacts because of the common high cost of their medications, treatments, and insurance, as well as frequent doctor visits and hospitalizations. We sought to better understand current SDH research within the CF community and the prevalence of screening for social risk factors at CF programs by completing a landscape analysis.

Methods: The landscape analysis consisted of an Internet search of existing research on social risk factors in the CF community and a survey question sent to CF programs nationwide. Research articles were identified via database searches of PubMed, ScienceDirect and Google Scholar using combinations of key words, including cystic fibrosis, social determinants of health (or SDH), social risk factors, and specific words pertaining to each of the 5 SDH domains. Studies were also identified via the reference lists of reviewed research. The survey was sent to 1400 CF clinicians in February and March 2021. Survey participants were asked to identify social factors they are currently screening for and to describe their screening methods.

Results: There is at least one research publication specific to CF within each of the 5 SDH domains. The most studied SDH domain in CF is economic stability, with 16 studies identified in the last 20 years specifically focused on socioeconomic status. From the CF program survey, 94 programs responded. Social risk factors within the economic stability domain were screened most often (89% of CF programs reported screening for food insecurity, 63% employment, 63% finances, 30% affording utilities). Social risk factor screening occurred within other SDH domains as well, including education access and quality (57% reported screening for school/education), neighborhood and built environment (63% screen for housing; 56% transportation; 24% exposure to violence; 15% internet access; 9% neighborhood safety), and risk factors that span multiple SDH domains (87% screen for emotional wellness; 24% other).

Conclusion: Research strongly suggests that social risk factors affect health outcomes of people with CF. While research specific to the CF community exists in each of the 5 SDH domains, more research is needed to understand health outcomes in relation to social risk factors, particularly in under-represented populations. Furthermore, screening at CF care centers is occurring but is inconsistent. There are opportunities to increase and improve standardized SDH screening at CF care centers. Additional research is also needed to understand interventions, both within the CF community and the general population, that can be applied to CF and have the potential to reduce the impact of social risk factors on people with CF.

Reference

1. Healthy People 2030. U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. 2020. <https://health.gov/healthypeople>.

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Creation of the Cystic Fibrosis Food Security Committee

C. Clemm¹, K. Reno¹. ¹*Health System Innovation and Navigation, Cystic Fibrosis Foundation, Bethesda, USA*

Background: A person is considered food insecure when access to enough affordable, nutritious food to support a healthy lifestyle is limited. Food insecurity is linked to stress, depression, anxiety, poor health, and skipping medication to save money. People with cystic fibrosis (CF) face unique challenges that make them more likely to experience food insecurity, such as needing more calories to maintain growth and nutrition, the cost of CF care, and CF treatments taking many hours each day, leaving less time to plan and prepare meals. The CF Food Security Committee (FSC) was developed to better understand and address food insecurity in the CF community through a multilevel approach using the unique CF care center network and model. The goals of the FSC are to increase awareness of food insecurity among clinicians and the community, improve understanding of the impact of food insecurity, develop educational resources for clinicians and the CF community, connect to existing community resources, decrease stigma associated with food insecurity, and catalog and share best practices inside the CF care center network

Methods: In 2017, food insecurity was identified as a problem from Compass data and discussions with CF clinicians. Two informal surveys, a literature review, and a landscape analysis confirmed the need to address food insecurity in the CF population. In fall 2018, FSC members were

selected after completing interviews as part of a force field analysis. Through 2019 and 2020, the committee developed a research agenda, created and shared educational content, began writing a quality improvement change package, and increased awareness of food insecurity at NACFC. In late 2020, the committee expanded, adding additional community members and incorporating patient advocacy work.

Results: The work of the FSC has increased awareness and interest among CF families, clinicians, and researchers, as evidenced by the increasing number of abstracts submitted to NACFC (2 in 2017 to 13 in 2020), the incorporation of food insecurity into CF Foundation national studies (such as the CF Health Insurance Study and State of Care survey), and an increase in the number of food-related calls to Compass, which led to enhanced training for the team. The FSC has developed 8 resources, including a quality improvement change package, a quality improvement quick guide, 5 informational handouts for clinicians or CF families, and a food assistance resource flowchart. The FSC collaborated in 2020 with the Partnerships Enhancement Program to develop a food insecurity discussion guide. The committee also regularly includes resources and interventions from care centers in the My.CFF resource library.

Conclusion: A focused committee of CF clinicians and community members is effective in identifying needs and finding solutions to enhance understanding of the effects of food insecurity in CF. The committee has identified variance in the needs of people with CF and interventions required. While the work of the FSC has met many of their goals, some gaps remain. More research is needed to understand screening and interventions most effective in CF care. Additional educational materials to support care teams and the CF Community are needed to decrease stigma and continue education. Opportunities to explore interventions through local partnerships may be helpful to target the needs of local communities. Finally, while food insecurity is one social factor being addressed, the FSC recognizes there are more social factors that affect CF care.

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Perceptions of telehealth of patients with cystic fibrosis and their caregivers during the COVID-19 pandemic in Australia

R. Ruseckaite¹, J. Herdman¹, S. Ahern¹. ¹*Public Health and Preventive Medicine, Monash University, Melbourne, Australia*

Background: Telehealth has been defined as the use of medical information exchanged from one site to another through electronic communication to improve a patient's health. In Australia, telehealth for management of cystic fibrosis (CF) has been predominantly used for outreach care in regional and rural areas. However, in March 2020, the nationwide restrictions imposed by the COVID-19 pandemic necessitated the abrupt and unprecedented transition of CF care almost exclusively to telehealth. As a result, face-to-face clinic visits were replaced by telehealth visits for a majority of patients across CF centers. In some instances, clinical measurements were acquired from telehealth consultations. The aim of our study was to explore patients' and their caregivers' perception of telehealth services during the COVID-19 pandemic.

Methods: Semistructured qualitative interviews were conducted with patients or their caregivers. An interview guide was developed that focused on experiences of telehealth and clinical data collection via telehealth services. Data were audio-recorded and transcribed. We analyzed data into topics and subtopics using conventional content analysis.

Results: Fifteen participants, 6 patients and 9 caregivers, were interviewed. All participants were adults; 2 were male. The mean (SD) age of people with CF was 40.2 (6.9). Caregiver mean (SD) age was 41.8 (6.7). In general, most study participants thought that telehealth services were as effective as clinic visits. They also believed that telehealth services were more accessible during COVID-19 than routine clinic visits. Conversely, some participants expressed concern about the disadvantages of telehealth services, including lack of physical examination, access to hospital equipment, and immediate admission to the hospital if necessary.

Conclusion: Participants highlighted that telehealth was an excellent option to monitor patient conditions but that meeting clinicians face-to-face in clinic was still essential. More research is needed to compare standards of care and clinical outcomes for patients with CF using telehealth versus clinic-based care.