

Case study

Experiences that matter

Shaping patient-centered care for cystic fibrosis



Introduction

Cystic fibrosis (CF) is a life-threatening genetic disease affecting nearly 40,000 people in the United States.¹ The disease primarily impacts the lungs but can also affect other organs such as the digestive system and reproductive system. Recent advancements in cystic fibrosis transmembrane conductance regulator (CFTR) modulator therapies have significantly improved treatment outcomes, but challenges persist for patients and caregivers.

Challenges

- **Disease management:** Managing CF is complex and often overwhelming for patients and caregivers.
- **Emotional and psychological burden:** Patients and caregivers face significant emotional challenges, including anxiety, stress and financial burden.
- **Administrative burden:** Navigating insurance, communicating with providers, and managing multiple medications is a significant challenge.
- **Social Determinants of Health (SDoH):** Financial and logistical barriers, such as geographic limitations and financial constraints, impact the ability to manage treatments effectively.

Findings from the research

Patient and caregiver experiences

A qualitative study drawing on the experiences of 23 individuals, including CF patients and caregivers, revealed several key insights²:



Each patient with CF has a unique experience based on genetics, clinical status, coping strategies and SDoH.



Patients and caregivers strive for clear treatment goals that encompass both medical and psychosocial factors.



Patients and caregivers respond best to information that's age-appropriate and easy to comprehend.



The administrative burden of managing CF is significant with patients and caregivers expressing frustration with insurance navigation and therapy coordination.

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Findings from the research (continued)

Three pillars of support systems



Importance of care teams: Patients value cohesive and proactive care teams that communicate effectively and advocate for their needs.



Patient and caregiver engagement: Proactive patients who manage their health care tend to have better relationships with care teams and a more positive outlook on their health.



Role of specialty pharmacies: Specialty pharmacies help with administrative challenges in the onboarding process, enhance communication and provide personalized support for patients and caregivers.

The essential role of specialty pharmacies



Specialty pharmacies are pivotal in enhancing the lives of patients with CF by:

- Gaining access to limited distribution specialty medications
- Helping patients navigate complex insurance benefits processes
- Connecting patients to third-party financial assistance programs, foundations and community resources
- Maintaining proactive communication with patients and caregivers
- Providing personalized medication therapy support for patients' unique needs
- Enhancing education resources for better disease management
- Supporting the transition from dependence to independence in health management for young patients

Conclusion

Effective management of CF requires a comprehensive approach that includes educational, clinical and psychosocial support. Understanding the lived experiences of patients and caregivers is crucial for delivering impactful services. Specialty pharmacies play a vital role in supporting patients by easing administrative burdens and providing personalized care.

Recommendations

- **Health care providers** should build unified, proactive care teams to improve coordination and patient outcomes.
- **Patients and caregivers** should feel empowered to take an active role in managing their health care.
- **Specialty pharmacies** should be integrated into the care team to provide comprehensive support.
- **Tools and resources** to support self-management should be available and incorporated into every treatment plan.
- **Addressing SDoH needs** is fundamental to improving patient outcomes.

By understanding the complex challenges faced by CF patients and caregivers, their health care providers and specialty pharmacies can help develop more effective support systems, ultimately improving patient outcomes and quality of life.

1. Cystic Fibrosis Foundation. <https://www.cff.org/news/2022-07/cf-foundation-estimates-increase-cf-population>. Accessed August 21, 2025.

2. Cystic Fibrosis Patient and Caregiver IDIs Qualitative Summary Report, independently conducted by The Olinger Group, in conjunction with CVS Specialty, Inc., January 2025.

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