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Review

Cystic fibrosis foundation position paper: Redefining the cystic fibrosis care team

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ABSTRACT

Interdisciplinary teams care for people with cystic fibrosis (pwCF) at specialized treatment centers. These teams have laid the foundation for the cystic fibrosis (CF) care model responsible for gains in health outcomes and quality of life within the CF community. However, the landscape of CF care is transforming, invigorated by new technologies, accessibility of cystic fibrosis transmembrane conductance regulator (CFTR) therapies, and increased utilization of telemedicine. In light of these advances, it is appropriate to re-evaluate the CF care team structure. This position paper offers guidance for the structure of a CF care center designed to meet the evolving needs of the CF community. Fundamental to the proposed center structure is recognition of pwCF and their families as integral members of their care teams, underpinning the necessity for shared decision making, awareness of social determinants of health, and active partnership between all healthcare professionals involved in the care of pwCF.

1. Introduction

Specialized CF care centers have long been staffed with interdisciplinary teams collaborating to provide comprehensive care for pwCF. This approach has improved health outcomes for complex chronic conditions (e.g., sickle cell disease, HIV, and cancer) through specialized and coordinated care [1,2], and has been transformative for CF, significantly increasing survival rates over time [3]. As pwCF manifest multi-system complications related to CF, including pulmonary and nutritional issues, the CF team members historically included a physician (typically a pulmonologist), program coordinator, nurse, respiratory therapist, dietitian, and social worker. Other disciplines and

Abbreviations: APP, Advanced Practice Provider; CF, Cystic fibrosis; CFF, Cystic Fibrosis Foundation; CFRD, Cystic fibrosis-related diabetes; CFTR, Cystic Fibrosis Transmembrane Conductance Regulator; FTE, Full time equivalent; GC, Genetic Counselor; GI, Gastroenterology; MHC, Mental Health Coordinator; NBS, Newborn screening; PCMH, Patient-centered medical home; PC, Program Coordinator; PCP, Primary care provider; PD, Program Director; PhT, Pharmacy technician; PT, Physical therapist; pwCF, people with CF; SW, Social Worker.

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specialists have been engaged (e.g., endocrinology, gastroenterology, mental health) to address CF complications that are increasingly prevalent as the population ages [4,5].

Initiation of treatment with novel CFTR modulators has benefited many, but not all, pwCF by reducing hospitalizations, improving nutritional status and lung function, and extending survival. Consequently, the CF population, especially adults, is growing and experiencing better health, leading to new and diverse healthcare demands [6,7]. These improvements in outcomes and changing needs provide an opportunity to re-evaluate the composition of the CF care team.

The CF Foundation (CFF) intends for this position paper to summarize available evidence, synthesize expert opinion, and provide clinical guidance for the composition of the care team at an accredited CF center in the United States; however, this guidance may be applicable to address the evolving needs of pwCF worldwide. Roles are defined, recommendations for qualifications of team members are provided, and optimal level of effort estimated. The final composition of each care team must be adapted to the size and needs of the CF program and its institutional setting, and ultimately, the specific care team for each pwCF may vary depending on individual needs. This document does not present accreditation guidelines for US programs; however, the paper describes an ideal state for the care of pwCF across the US.

2. Methods

Through a request for applications, the CFF convened an interdisciplinary committee consisting of CF care team members, caregivers of pwCF, and adults with CF that brought together clinical expertise and the lived experiences of pwCF and their families. The CF Care Model Committee reviewed literature relevant to the topics discussed below for each discipline with the goal of guiding potential adaptations to the CF center staffing and services. The committee was tasked with identifying healthcare team members and ancillary services essential to optimal CF care delivery.Further details regarding selection of committee and process for determining recommendations are found in the supplemental material.

3. Specialized CF care center

CF care centers offer specialized evaluation and management focused on timely diagnosis, optimizing growth and development, minimizing disease progression, and preventing/treating CF

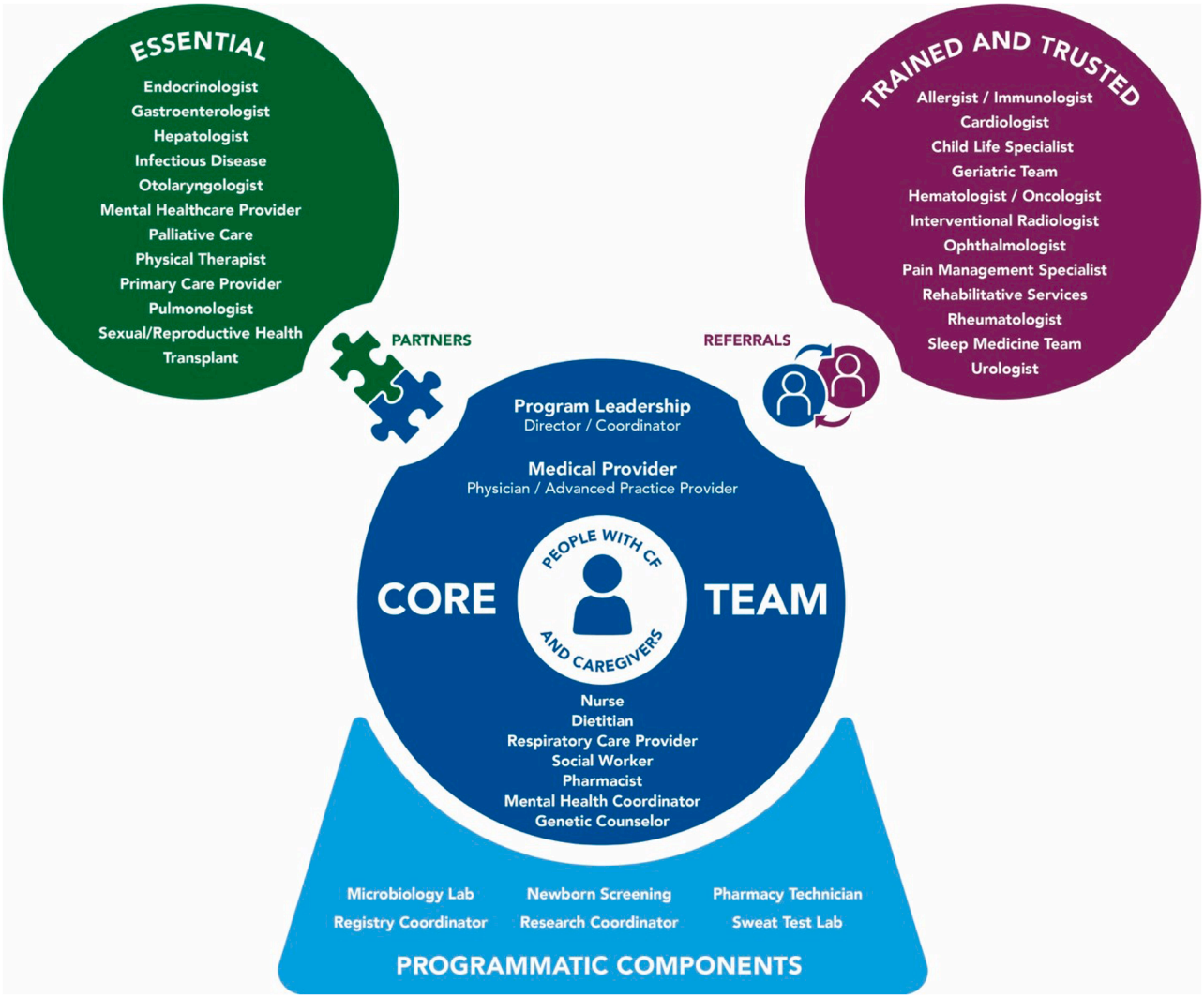

Fig. 1. Structure of a CF Care Center

Figure legend (figure in color): Visualization of the CF care center model that illustrates the level of interaction between all CF care team members involved in pwCF's care. Members of the core team encircle the person with CF and their caregivers, having the greatest level of interaction. The core team is supported by a foundation of programmatic components. Essential partners collaborate with the core team to address health complications that many, but not all, pwCF experience. Trained and trusted specialists (Table 2) serve as a referral source for the core team as they are familiar with CF and its less frequent complications (Supplemental Table 3).

complications that support pwCF in living longer, healthier lives. The **Core Team** (Fig. 1) members are primarily responsible for monitoring and treating CF-related health issues for all pwCF seen at the center. They are supported by 1) **Essential Partners,** 2) **Trained and Trusted Referrals**, and 3) **Programmatic Components** of the CF care center whose roles have been defined (Table 1). These elements are necessary to ensure comprehensive, evidence-based care. Some of these roles may be fulfilled by more than one discipline, but we acknowledge that in some jurisdictions, certain responsibilities must be performed by individuals with specific licensure.

The outpatient staffing requirements for CF care centers depend on the number and complexity of pwCF served. Duties typically extend beyond clinic hours to encompass unscheduled calls, insurance approval of treatments and tests, education for pwCF and caregivers, treatment implementation, coordination of care between the CF team and other healthcare providers, and the facilitation of care between the inpatient and outpatient settings (Fig. 2). Most CF centers are comprised of pediatric and adult programs. Primarily based on the number of patients served, smaller centers may have team members serving both programs, while others have separate pediatric and adult care teams. Historically, one full-time equivalent (FTE) for each clinical role had been advised for every 100–200 pwCF, which is consistent with international consensus recommendations [8,9]. Suggested outpatient staffing ratios are included in (Supplemental Table 1). It is essential to recognize that care team members may have the flexibility to fulfill multiple roles, as outlined here, provided that the sum of the recommended FTE of these roles does not exceed the FTE allotted for that individual's CF team role. FTE recommendations are based on outpatient clinical effort to provide CF care; however, leadership or programmatic responsibilities should also be considered.

Current projections suggest there will be a rise in the number of pwCF receiving care at CF centers due to overall improved survival rates [6]. Pediatric program sizes are expected to remain stable as the number of newly diagnosed infants roughly matches the number of pwCF transitioning into adult care programs, whereas adult programs are anticipated to grow over the next two decades, indicating an increased need for adult CF care team members [6]. Adult care programs should plan for an increased number and/or effort of team members to address the growth of the adult CF population.

4. Patient-centered medical homes

Patient-centered medical homes (PCMH) are known to improve outcomes and enhance the quality of care for individuals with chronic conditions [10] and multiple medical complications [11]. These models offer comprehensive outpatient services, covering acute, chronic, and preventive care [12]. For many pwCF, the CF care center has effectively served as a PCMH, providing elements of primary care within the context of a limited life expectancy [13]. However, despite their background in general pediatric and/or adult medicine, CF medical providers may not be fully equipped to manage all the primary care needs of an aging and growing CF population. PCPs, such as physicians or advanced practice providers (APPs) trained in pediatrics, family medicine, or internal medicine, typically oversee these aspects of care; yet health complications specific to CF often exceed the scope of primary care and require specialized attention at a CF care center.

As such, we emphasize the need for partnership with primary care providers (PCPs) in the care of pwCF. Whether embedded in the CF core team or involved as an external partner, the PCP must have clearly delineated duties separate from the core team's responsibilities, informed by strong bidirectional communication with the core team. Equally important is educating pwCF on the importance of the PCP for implementing preventative care. Preventive care practices should be applied to pwCF similarly to that of the general population except in instances where complications of CF demand more intensive screening (e.g., diabetes, colorectal cancer, osteoporosis, mental health) and guidelines differ from those for the general population. Therefore, proactively establishing relationships between CF centers and PCPs is increasingly important as they care for the healthier and older CF population. This collaboration is further described in **Essential Partners** (below), but the CF team will continue to act as a medical home for pwCF.

5. Core team

High-performing CF programs require capable leadership that fosters communication, collaboration, and adherence to evidence-based standards of care amongst the CF care team and pwCF [14]. Effective leadership, provided by Program Directors (PD) and Program Coordinators (PC), is crucial for team dynamics, competency, and a culture of quality improvement. Physicians serve as PDs, and PCs are often trained as nurses, but the latter may have any clinical background. As these team leaders serve as the main liaison between pwCF, caregivers, and other healthcare providers to direct and coordinate CF care and treatment decisions, their FTE must account for their important administrative responsibilities.

The CF medical provider is a physician or APP with CF expertise who evaluates pwCF through initial diagnosis of CF and subsequent visits, educates pwCF and caregivers, and makes treatment decisions. They are usually trained in family practice, pediatrics and/or internal medicine, and in many cases, pulmonary medicine. Ongoing CF workforce recruitment and retention will be needed to ensure adequate training and program sustainability [6].

With their disease-specific knowledge, CF nurses act as key contacts for pwCF and their families, helping to provide essential CF education, reinforce care plans, and triage clinical concerns. Their responsibilities often include medication education, coordination, communication triage, and interactions with educational and occupational institutions related to CF health issues. Incorporating nurses into medical teams enhances clinical outcomes and reduces institutional financial burdens [15].

The CF dietitian is vital in addressing the diverse nutritional needs of pwCF. Nutrition significantly impacts overall health, with a noted correlation between nutritional status and pulmonary function [16,17]. Although historically focused on addressing undernutrition with a high fat and sodium diet, changes in body mass composition associated with CFTR modulator usage have shifted focus towards promoting a healthy nutritional profile requiring nuanced dietary, pancreatic enzyme replacement, and micronutrient management [17-19]. Dietitians play a crucial role in CF care by managing intertwined health risks such as

Table 1
CF Care Team personnel roles.

Core Team	Essential Partners	Trained and Trusted Referrals
Healthcare team members whose services are **required** to provide routine clinical care that supports the health and well-being of all pwCF.	Healthcare team members with expertise in CF who have a close working relationship with the core team to help manage CF-related complications that many, but not all, pwCF experience.	Healthcare team members who may have more limited expertise in CF, but whose services can be requested on a referral basis to assist in managing less common CF complications, as well as non-CF related complications. Communication regarding an individual's specific CF clinical course is necessary. Further CF education may be required depending on the level of CF experience.

Table legend: Definitions of CF care team personnel roles identified by committee members to assist CF care centers with managing personnel and outpatient referrals, when needed.

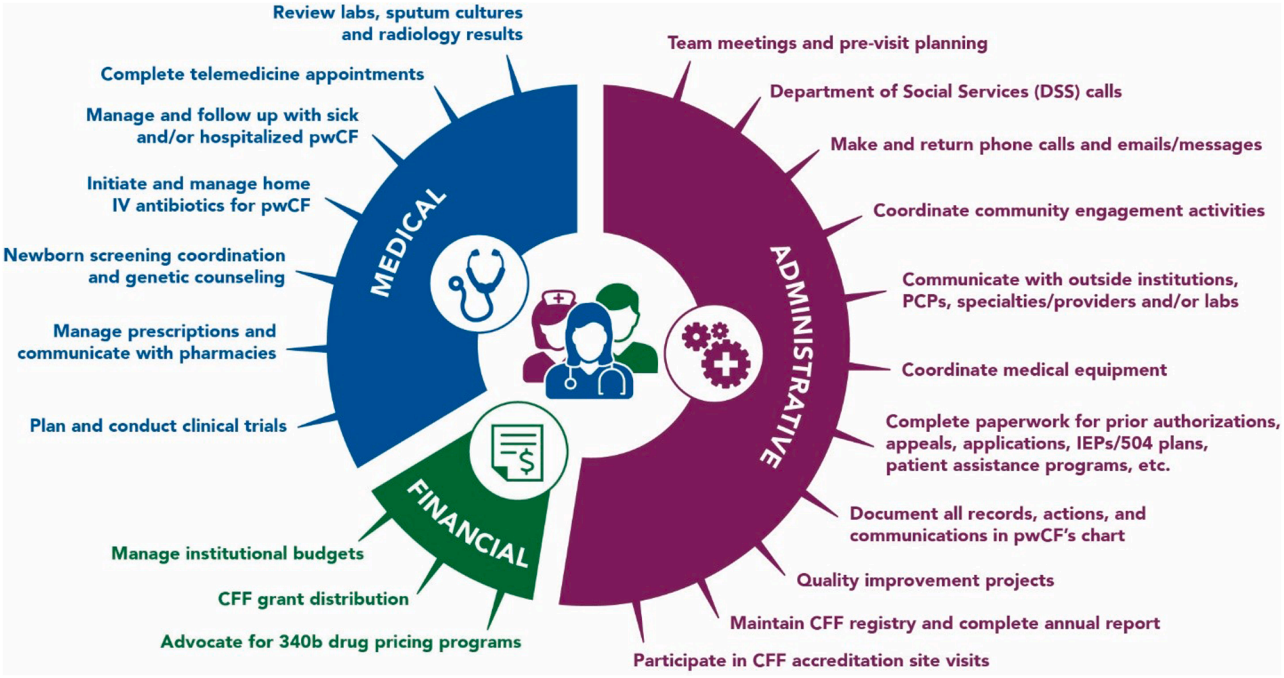

Fig. 2. Essential Tasks Conducted by the CF Core Team Outside of Clinic Visits
Figure legend (figure in color): Diagram of tasks completed by CF core team members between clinic visits divided into medical, administrative, and financial responsibilities. This illustration includes many common tasks but is not a comprehensive list of all responsibilities critical for appropriate patient care.

CF-related diabetes (CFRD) and age-related cardiovascular disease through dietary planning, highlighting their adaptation to the evolving needs of pwCF.

Respiratory care providers, whose role is typically fulfilled by respiratory therapists or physical therapists, are team members responsible for overseeing pulmonary therapies such as airway clearance and inhaled medications. Education on and maintenance of durable medical equipment and respiratory support devices (e.g., supplemental oxygen) are also critical responsibilities [20,21]. Some perform pulmonary function testing and/or support home spirometry monitoring. Despite decreased inhaled therapy use, a strong emphasis remains for education about respiratory health and ensuring therapeutic competency, including spirometry performed at home [22-24].

PwCF and their caregivers encounter routine daily stressors (e.g., safe and stable housing, nutrition and food access, transportation, social and economic mobility) intertwined with complex disease-specific biopsychosocial challenges that have a direct and significant impact on health outcomes and wellbeing [25-28]. The core CF team includes a social worker (SW) who serves in a crucial multifaced role to proactively identify and address psychosocial and environmental factors for each person seen in the CF Center [9,29,30].

The addition of a CF pharmacist to the CF core team has improved outcomes for pwCF [31]. Pharmacists provide individualized medication counseling and education for pwCF and their caregivers to support care plans [32,33]. They also perform medication reconciliation, ensuring medications are safely prescribed and drug interactions considered, a vital role given the increasing complexity of medication management for the more heterogeneous CF population [34,35]. Pharmacists can effectively mitigate barriers to CF treatment plans by increasing access to medications in a safe, appropriate, and cost-effective manner [36–38,132]. Additionally, pharmacists may serve as the liaison for the CF core team and inpatient and outpatient pharmacies. The role of the CF pharmacist continues to evolve, and in certain locations, pharmacists with advanced practice designations may provide medication management services and preventative healthcare services and screening that include writing or modifying prescriptions and ordering lab testing for medication monitoring [31,39,40]. The integration of the pharmacist role into the CF care team may vary by institution, taking into consideration resources available to ensure the frequency and quality of services match the needs of pwCF within each CF care center (Supplemental Table 2).

To provide robust and systematic clinical attention to the elevated mental and behavioral health needs of pwCF [41,42], the inclusion of a mental health coordinator (MHC) on the core team is needed to complement the role of the SW. The MHC role is made distinct from that of the SW [43] so that sufficient and equitable support is provided for the diverse psychosocial needs of pwCF, which can be challenging particularly for medium to large CF centers. In accordance with the CF mental health guidelines [43], annual screening for anxiety and depression is recommended for pwCF ages 12 and above (as well as caregivers when indicated). When symptoms are elevated and needs are identified, additional assessment and referral for evidence-based treatment are appropriate next steps. The MHC may be a licensed clinical SW, psychologist, counselor, APP, or psychiatrist [8,43]. Age-related stressors may lead to additional mental health concerns, highlighting the ongoing need for sufficient support for both the SW and MHC roles within the Core Team, ideally allowing the MHC to provide interventions if qualified to do so [44].

Access to genetic counseling services for pwCF and their families has long been valued [45,46]; however, given the complexity of *CFTR* gene variants and the increase in family planning among pwCF, including access to a CF genetic counselor (GC) on the core team is now recommended [47]. The rise of carrier and universal newborn screening (NBS) with *CFTR* gene sequencing [48,49] has identified more people with rare or complex *CFTR* variants encompassing CF diagnoses, CFTR-related metabolic syndrome/CF screen positive, inconclusive diagnosis (CRMS/CFSPID), CFTR-related disorders, and CF carriers. For individuals with abnormal results, access to GCs at CF centers has been linked to earlier accurate diagnoses and better clinical outcomes for pwCF and family members [50-52]. GCs can also counsel parents of children with CF and pwCF in making reproductive health decisions across the lifespan [53-55]. With novel therapies targeting specific

genetic variants, accurately identifying and understanding *CFTR* variants is crucial to ensure appropriate access to transformative treatments. GCs are well-positioned to inform pwCF about individualized treatment options and to guide enrollment in clinical trials for genetic based therapies [55,56]. The process of engaging GCs at CF centers will likely be center-specific, leverage the use of telemedicine, and employ multiple models of service delivery [57,133,134] (Supplemental Table 2).

6. Essential partners

Essential partners (Fig. 1) are healthcare providers whose expertise is needed because of complications that are highly prevalent in pwCF (Supplemental Table 3) and for which there are better outcomes when managed by those with specific knowledge and expertise in CF. These specialists should have a strong working relationship, bidirectional communication, and function as an extension of the CF care team. In some cases, they may see patients alongside the core team in CF clinics in an integrated model.

All pwCF benefit from age-specific preventative care, including developmental assessments, vaccinations, sexually transmitted infection counseling and screening, cancer screening (e.g., breast, cervical, testicular, colorectal, prostate, skin), cardiovascular risk screening, and acute care evaluation (e.g., otitis media, pharyngitis, injuries). Age-appropriate primary care encompasses general health screenings, routine immunizations, and management of general health conditions such as hypertension and hypercholesterolemia. The PCP should be considered an essential partner by all CF care teams because having a regular relationship with a PCP will have a strong positive impact on the lives of pwCF [58]. There are several models in which the CF center can engage with a PCP, and centers may utilize multiple models to adapt to the varied needs of their CF population (Supplemental Table 2). Regardless of the model employed, it is critical that CF care teams work with pwCF and caregivers to provide basic CF education to PCPs, clearly delineate responsibilities, and communicate effectively with involved PCPs to coordinate synergistic care through shared decision making.

Endocrine-related issues, such as CFRD [59], bone disease [60], delayed puberty [61], and growth hormone deficiency commonly affect pwCF [62] (Supplemental Table 3). In particular, the prevalence of CFRD increases with age and is associated with worsened pulmonary health and reduced survival [63], prompting guideline recommendations for routine screening, diagnosis, and management [64].There is no evident reduction in these complications with the use of CFTR modulators [42,65]. Furthermore, the growing concern for nutritional gaps in the CF population, along with aging as a risk factor, supports the ongoing need for endocrinologists' evaluation and management of CF [66,67].

PwCF experience a high prevalence of gastrointestinal (GI) issues (Supplemental Table 3) [68,69] that are often complex, underscoring the significance of gastroenterologists in the management of CF. Although CFTR modulators have shown promise in reducing bouts of acute pancreatitis and improving exocrine pancreatic function in the very young, their long-term impact on GI symptoms and complications, including colorectal cancer, remains uncertain [70,71]. Further research is required to better understand age-related GI issues in CF, both on and off CFTR modulators.

Liver disease/cirrhosis remains the third leading cause of death in pwCF in the US [42]. To date, there is no evidence that CFTR modulators reduce this risk, and some patients cannot take modulators due to liver-related adverse effects [72]. PwCF with hepatobiliary involvement should be referred to a hepatologist for evaluation and monitoring of both CF-related and unrelated liver issues [72]. Those with advanced CF liver disease benefit from close monitoring by a hepatologist knowledgeable about CF-related liver disease and, if necessary, referral to a liver transplant center.

Persistent airway infection is a hallmark of CF lung disease, and although CFTR modulators have reduced infection burden and exacerbation frequency, infection remains a concern for pwCF [73-75]. Antibiotics are necessary to combat pathogens like *Pseudomonas aeruginosa, Burkholderia* species, methicillin-resistant *Staphylococcus aureus*, and non-tuberculous mycobacteria, among others [76,77]. Given the ongoing concern for antibiotic resistance, antimicrobial stewardship is important to preserve effective treatments and minimize toxicities, particularly with an aging population. Collaborating with infectious disease specialists familiar with CF can yield valuable insights.

The high prevalence of anxiety, depression, and quality of life concerns within the CF community highlights the need for reliable access to mental healthcare providers, such as psychologists, psychiatrists, social workers, and licensed counselors [78,79] through connected referral pathways if the program's MHC does not provide these services. Close communication between the mental healthcare provider and the core team is essential for ensuring that care is holistic and that all biopsychosocial needs are met [80].

Chronic rhinosinusitis is a common extra-pulmonary complication of CF (Supplemental Table 3) characterized by nasal obstruction due to polyposis and sinusitis resulting from thickened secretions and impaired mucociliary function [81]. Effective management by otolaryngologists (ENT) is crucial for improving symptoms and optimizing pulmonary function and post-lung transplant outcomes [82,83]. Although CFTR modulators have resulted in a reduction of sinus disease burden, sinus disease and loss of smell remain problematic for many [84,85]. Dysphonia and hearing loss are also common in CF, often due to toxicities of CF therapies, further warranting otolaryngology engagement [86].

Palliative care to address symptom burden should be available throughout the entire life span, adjusting intensity to match individual needs with a goal of improving quality of life [87]. With advancements like CFTR modulators, pwCF's needs and priorities have evolved [88]. CF care teams should partner with palliative care colleagues to provide screening and personalized care [89,90].

As the CF population ages and overall health improves, physical therapists (PTs) can address diverse needs, including bone and cardiovascular health, alongside traditional areas of expertise such as neuromusculoskeletal assessments, body composition [91], pain management, balance/vestibular functioning, and pelvic floor strengthening. PTs serve as exercise experts who can integrate exercise into pwCF's care throughout life [92]. They tailor individualized programs for pwCF encompassing strengthening, flexibility, endurance, posture re-education, and as mentioned in the Respiratory Care Provider section, may inform on airway clearance exercises and device training [21]. Additionally, PTs play significant roles in pre-transplant preparation and post-transplant recovery [93].

When neither the program director nor core medical provider is a pulmonologist, CF teams should include a pulmonologist as an essential partner. Pulmonologists have historically been integral to the care of pwCF, given that lung disease is a key complication of CF and will continue to be so despite widespread availability of CFTR modulators [94]. Their unique skills include interpreting specialized testing, such as pulmonary function and exercise testing, performing bronchoscopy, and evaluating pulmonary complications that affect pwCF, such as asthma, bronchiectasis, hemoptysis, pneumothorax, and recurrent infections [95]. Importantly, they are also responsible for managing advanced lung disease in pwCF and discussing referral for lung transplantation [96].

With improved survival in CF, a growing adult population is interested in parenting. CFTR modulators have been linked to enhanced female fertility and increased pregnancies, although there is no apparent effect on male infertility [97]. CF centers should be prepared to address these topics as needed and refer patients to sexual and reproductive health specialists for puberty, contraception, assistive reproductive technologies, menopause, gender specific care, and hormone replacement [98]. Before family planning, pwCF should undergo reproductive counseling in addition to genetic counseling, partner carrier screening, male and female fertility assessment, and a review of pregnancy related

health risks, as well as risks/benefits of CF medications during pregnancy and lactation [53,54]. Access to comprehensive obstetric care is crucial for pregnant pwCF, with maternal-fetal medicine specialists playing a vital role, especially for those with advanced lung disease [96].

Lung transplant remains an option for individuals with respiratory failure due to advanced CF lung disease [96,99-101]. Timely referral to a lung transplant center is crucial for evaluation and listing [101]. Seamless referral is facilitated by established relationships and processes with regional transplant programs. Post-transplant care should integrate specialized CF care with transplant care so that clinical outcomes are improved [102]. Special attention should be given to frequent post-transplant cancer screening, given the risks associated with chronic immunosuppressive therapy [103,104].

7. Trained and trusted referrals

Trained and trusted providers have a fundamental understanding of CF, but the frequency at which they treat pwCF is not high. They may not be at the same institution as the core CF care team but have been identified by the core team as trusted colleagues (Fig. 1, Table 2) because of their understanding of CF care needs and established relationships with the care team. This list is not exhaustive as individual pwCF may have unique needs not included in this referral list. Referrals coming from the CF program should include communication regarding an individual's needs and education about CF when needed based on the specialist's level of CF experience.

Table 2
Trained and trusted referrals.

Specialist	CF-Specific Care Needs
Allergist/ Immunologist	• Increased risk for allergic bronchopulmonary aspergillosis and antibiotic hypersensitivity [114,115]
Cardiologist	• Increased risk of age-related cardiovascular disease with longer life expectancy and high prevalence of CFRD • Increased rates of hyperlipidemia, and hypertension with aging [116]
Child Life Specialist	• Increased biopsychosocial needs in childhood require developmentally appropriate support in coping with and processing issues related to CF, medical procedures, and the medical environment [8]
Geriatric Team	• Increased complications of aging such as the interplay of multiorgan system disease, polypharmacy, frailty, mobility, memory impairment, and dementia/delirium [116]
Hematologist/ Oncologist	• Increased risk for colorectal cancer in older pwCF which add to the general risk of age-related cancers routinely screened by a PCP [116]
Interventional Radiologist	• Increased complications of massive hemoptysis and/or pneumothorax [117]
Ophthalmologist	• Increased risk for cataracts in pwCF under the age of 18 years who are on CFTR modulators • Increasing concern for ocular toxicities related to future therapies [118,119]
Pain Management Specialist	• Increased pain which results in impaired quality of life, poorer health outcomes, and increased mortality • Increased risks for pain medication side effects [120]
Rehabilitative Services	• Increased exposure to ototoxic medications, procedures, surgeries require both short term and long-term recovery • Increased feeding difficulties and voice disorders [121, 122]
Rheumatologist	• Increased risk of developing conditions such as vasculitis and inflammatory arthropathy for pwCF [123-125]
Sleep Medicine Team	• Increased risk for poor sleep quality and sleep disordered breathing, nocturnal cough, upper airway obstruction (sinusitis/polyps), and lower airway obstruction [126,127]
Urologist	• Increased prevalence of urinary incontinence from childhood • Increased risk of urinary and kidney stones particularly for those with severe genotypes [128–131]

Table Legend: Trained and trusted referral's disciplines listed with the CF-specific care needs for which they may see pwCF (Supplemental Table 3).

8. Programmatic components

There are team members and services that contribute to the care of pwCF by supporting the general operations of the CF care team but may not be directly involved in patient care themselves and are thus considered programmatic (Fig. 1).

The CFF Patient Registry is vital for detecting clinical trends, planning clinical trials, developing care guidelines, and improving quality of care [105]. The registry coordinator ensures appropriate informed consent and enrollment into the patient registry, and timely and accurate data entry [106]. Research coordinators can also take on data entry, but their primary role is to screen and discuss clinical trial enrollment opportunities with the CF care team and eligible pwCF. If the center conducts CF clinical trials, this coordinator may be responsible for regulatory approvals, and study initiation and conduct. For smaller programs without strong research infrastructure, a coordinator to discuss available regional clinical trials and facilitate referrals is critically important.

A pharmacy technician (PhT) can take medication histories, coordinate medication refills, and assist in mitigating cost related medication barriers by obtaining prior authorizations amongst other tasks. Care models that have integrated PhTs into the CF care team and/or specialty pharmacy have demonstrated benefit, allowing pharmacists to take on larger clinical roles [107] while increasing patient access to medication [108] and thereby supporting pwCF in being able to take their medications [36,37].

Finally, the CF core team should closely partner with microbiology laboratories [109-111] institutional sweat testing laboratories, and state newborn screening (NBS) programs to ensure that CF standards are upheld and properly implemented [112].

9. Conclusion

This position paper addresses changes in the CF population's demographics and care needs by reassessing the structure of the traditional CF care team. Despite the benefits of CFTR modulators, there is no evidence that the health needs of pwCF will decrease over their lifespan. Many health needs persist, and some have evolved, suggesting the need to retain the existing CF team structure. Moreover, pwCF not on CFTR modulators, will continue to rely on the traditional care team for management. This paper attempts to anticipate future needs of a growing, changing and aging population of pwCF and the accompanying new challenges to CF care. The CF team structure will need to be flexible in order to meet the dynamic needs of this changing population. The evolution of CF in the past decade warrants the recommendation of additional team members for either the core team or the list of essential partners and trusted referrals. The integration of pharmacists, MHCs, and GCs into healthcare teams has been achieved through various models and is expected to be tailored to each CF center (Supplemental Table 2). An essential inclusion in this position paper is the recognition of the PCP's role in the care of pwCF. Increasing general care needs in the setting of complex disease underscores the importance of bidirectional communication and role delegation between each PCP and the core team.

Although these recommendations are for the composition of the care team at a specialized CF center, we must also recognize the role of the pwCF and families in the management of CF and clinical decisions. By using shared decision making to incorporate individual goals and needs into care plans, pwCF and their caregivers are also members of the core team, and the specific constitution of their personal care team may vary based on health status.

Challenges will inevitably arise as the recommendations from this paper are implemented, but solution-oriented creativity will allow

individual centers to develop strategies to adjust to their unique circumstances (e.g., level of staffing, financial support) and CF population. For example, barriers to accessing specialized care for pwCF exist due to the varied distribution of specialists across geographic regions. Some specialties are woefully understaffed (e.g., pediatric pulmonologists, genetic counselors, and mental healthcare providers), so increasing telemedicine usage and expanding roles for APPs trained in CF specialty care has the potential to bridge distances between providers and pwCF [113,114]. Some strategies may increase clinical efforts of core team members and add to workloads delegated to leadership and programmatic components of care. Therefore, the determination of center staffing must account for each team member's comprehensive responsibilities as well as the census and specific patient population within each CF center to prevent overburdening of the critically important CF care team.

Author contributions

All authors contributed to the manuscript. All authors aided in the development of the entire manuscript. All authors approved the final manuscript.

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Declaration of competing interest

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- Charlotte Close, MS, Certified Genetic Counselor±
- Jennifer Kyle, Individual with CF
- Stephanie Filigno, Psychologist
- Rebekah Flowers Brown, MD
- Patrick Flume, MD
- Danielle Goetz, MD
- Luis Gonzalez, PharmD±
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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.jcf.2024.09.011.

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