

Navigating School While Living with Cystic Fibrosis

Katelyn Heimbruch, MD, PhD¹; Sarah Strong, MEd²; Matt Wackler, MHSA, PMP³; Marissa Taylor, MPH⁴; Qing Duan, PhD⁵; Stephanie Filigno, PhD^{3,6,7}; and Michelle Hjelm, MD, MMM^{3,7}

¹ Pediatric Residency Program, Cincinnati Children's Hospital
² Center for School Services and Education Research, Cincinnati Children's Hospital
³ Division of Pulmonary Medicine, Cincinnati Children's Hospital
⁴ Cystic Fibrosis Foundation
⁵ Division of Biostatistics and Epidemiology, Cincinnati Children's Hospital
⁶ Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital
⁷ Department of Pediatrics, University of Cincinnati College of Medicine



Introduction

- Cystic Fibrosis (CF) is a chronic, genetic disorder characterized by mutations in the Cystic Fibrosis Transmembrane Regulator (CFTR) gene.
- Quality of life for people with CF (PwCF) continues to be affected by the significant burden of keeping up with this chronic disease despite improvements in treatment [2].
- Children with CF (62%-82%) are at moderate-to-high educational risk [3].
 - Educational risk calculations include:
 - Need for school accommodations
 - Special education services
 - School performance and advancement
 - Attendance
 - Relationships within the school environment [4].
- CF care providers (social workers, physicians, nurses, and psychologists) often assist patients and their families with school needs [5-8] including:
 - Completing documentation
 - Providing advocacy tools or coaching to families
 - Contacting schools directly to provide education and resources

This study aims to explore the intersection of CF management and educational attainment, by asking the following questions:

What are the perspectives of PwCF and their caregivers on the CF care team's role in their educational success?

What barriers to education do PwCF experience due to complications from their disease?

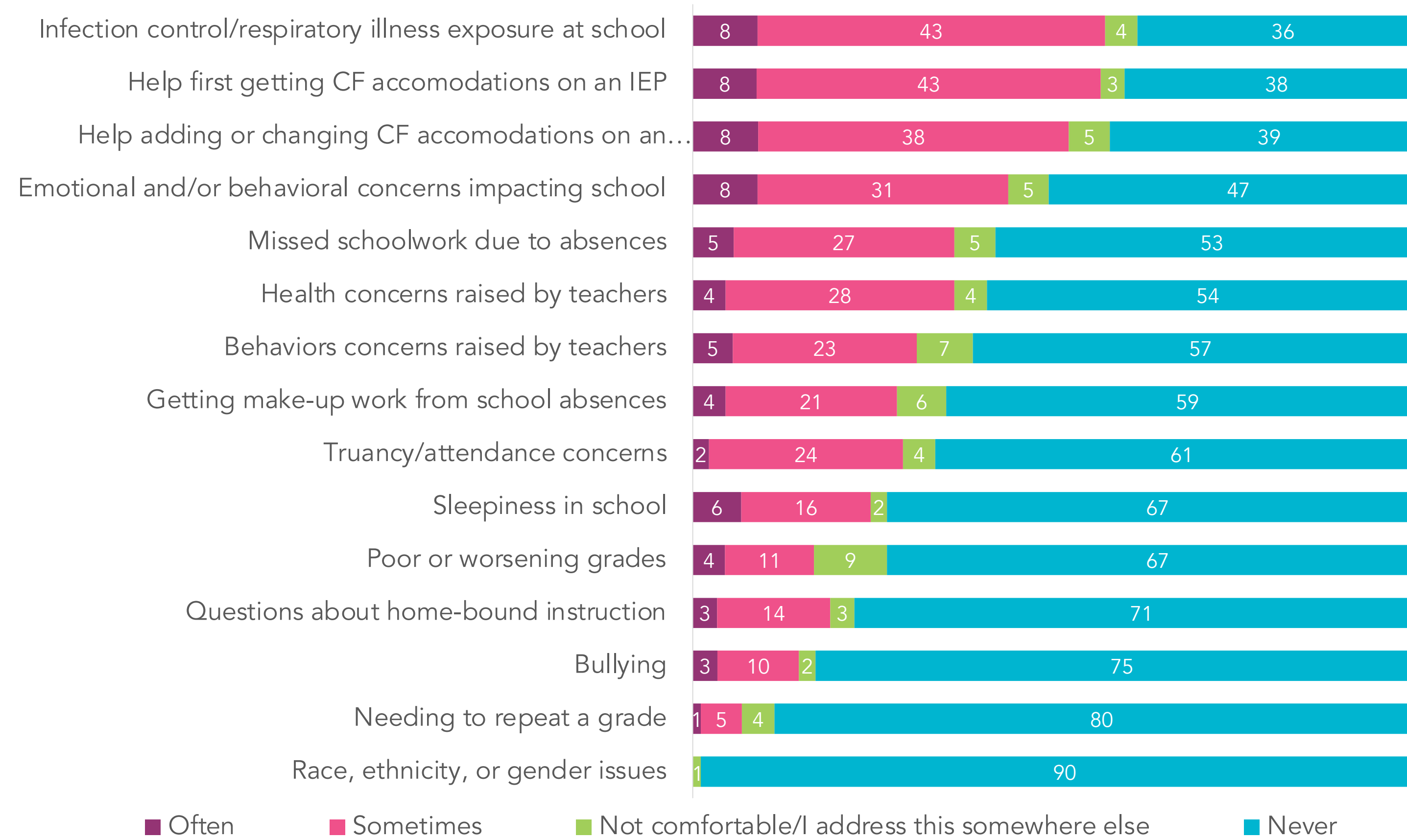
Methods

- A cross-sectional, survey-based study was conducted in August 2024. The survey was comprised of 24-25 questions.
- The electronic survey was distributed using the CFF's Community Voice and via CF care teams.
- To avoid recall bias, only adults with CF between the ages of 18-20 were able to complete the survey.
- Caregivers receiving the survey were encouraged to complete the survey with input from their children with CF but were not required to do so.
- This study was approved by the Cincinnati Children's Hospital Institutional Review Board.

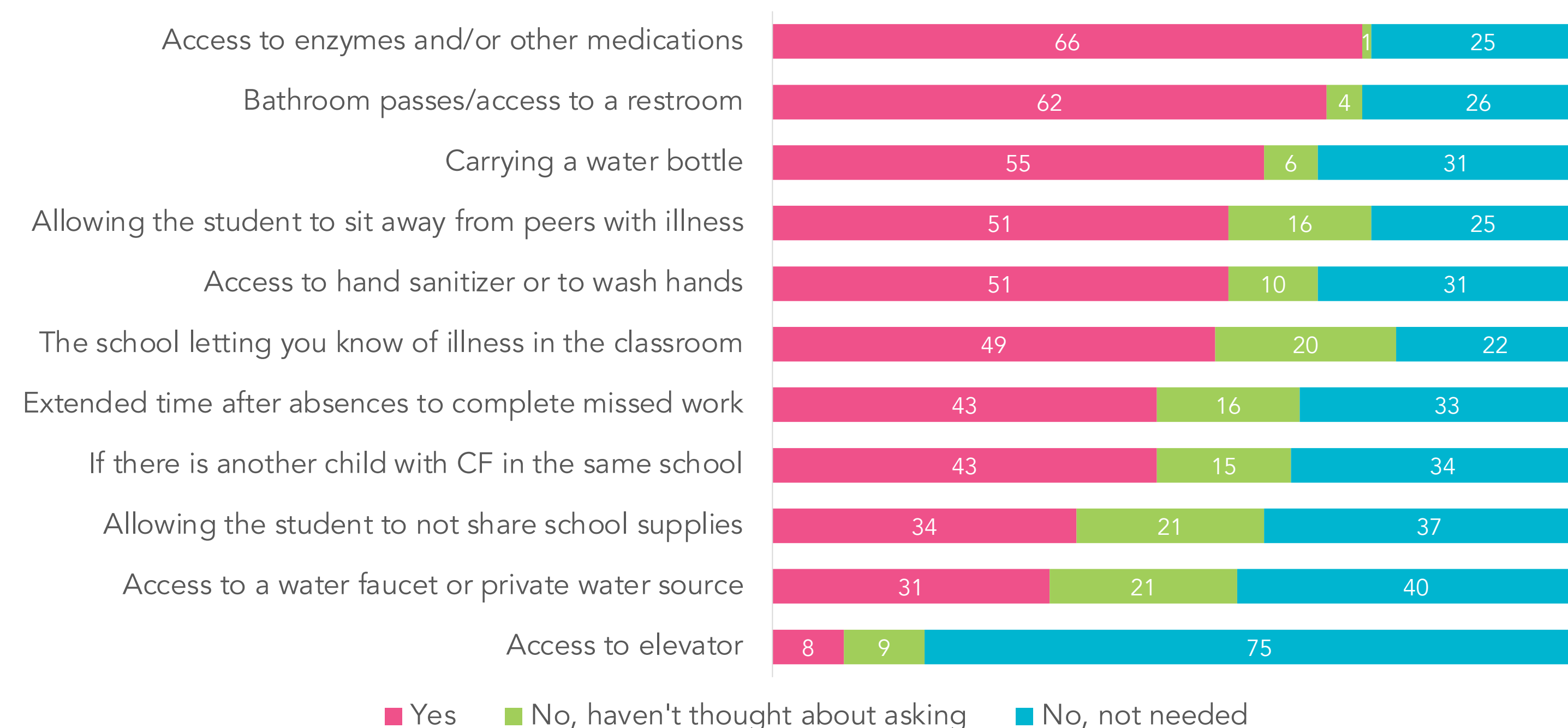
Respondent Demographics

- 234 responses to the survey, with 146 complete responses, including 10 PwCF (ages 18-20) and 136 caregivers and/or caregiver plus PwCF pairs (ages 12-17)
- Over half (63%) of caregivers completed the survey with input from their child
- Caregivers indicated the eldest child with CF in their household ranged in age from age 6 – 17, with an average age of 10.3 and a median of 10
- Fourteen caregiver respondents (10%) indicated there were 2 children with CF living in the home
- Majority selected White as the ethnicity/race their child identified with, others identifying as Hispanic/Latino, Black/African American and Jewish
- Respondents represented 28 unique states
- Majority of respondents indicated they were involved in traditional schools; other respondents indicated they were in private schools, home schooled, or in online public school

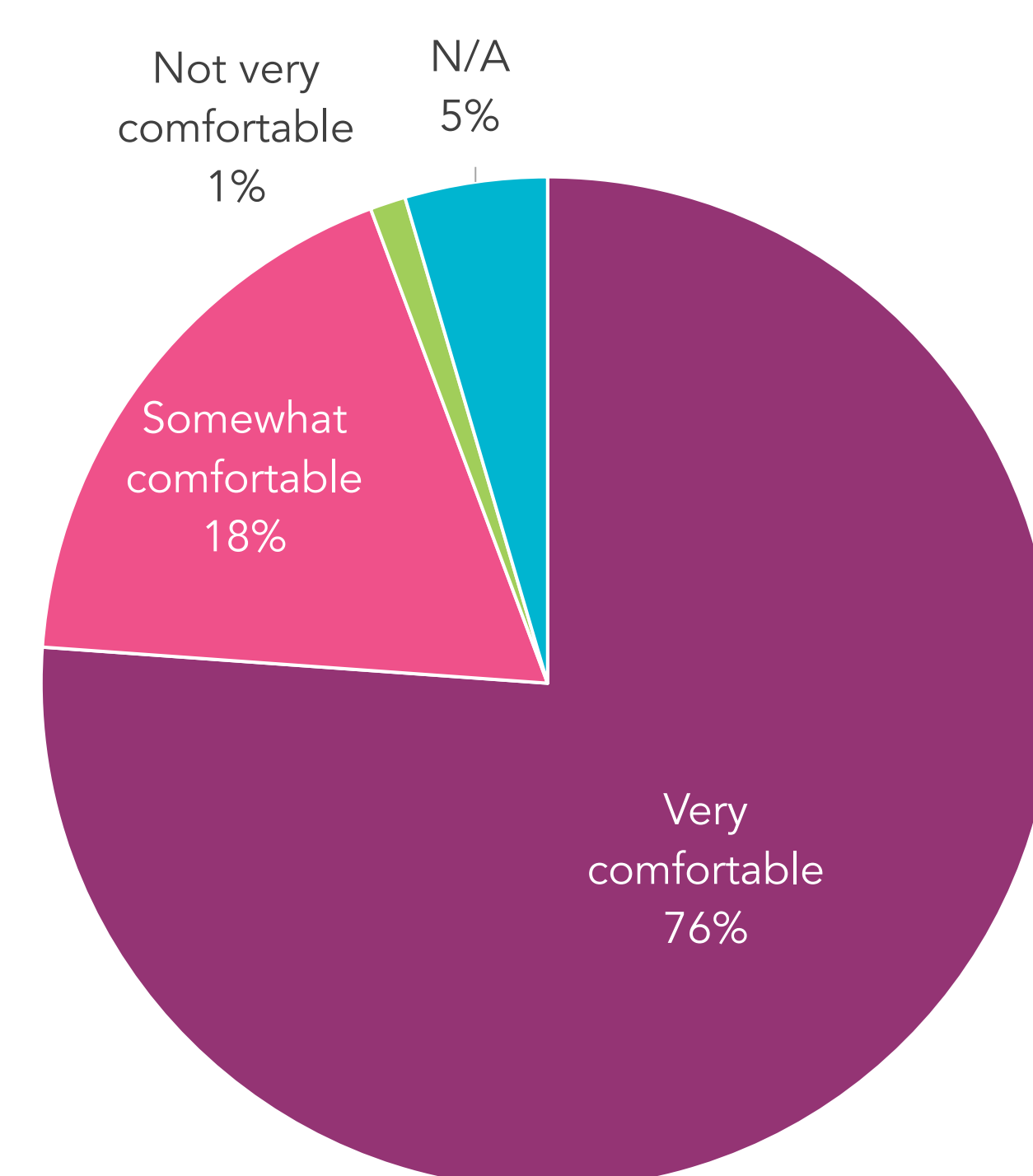
How often have you brought the following school concerns to the attention of your CF care team?



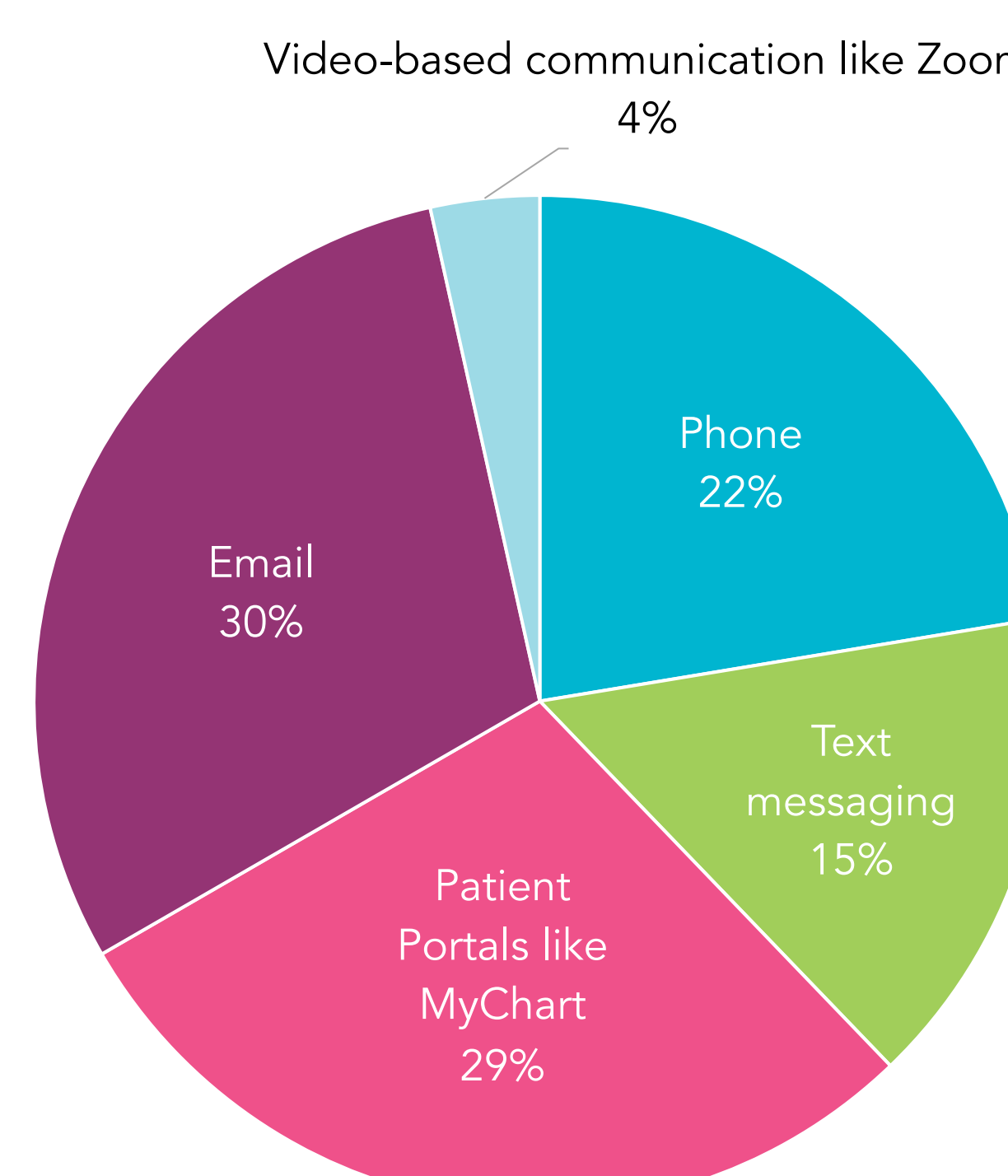
Have you ever talked to your CF care team about any of the following school accommodations?



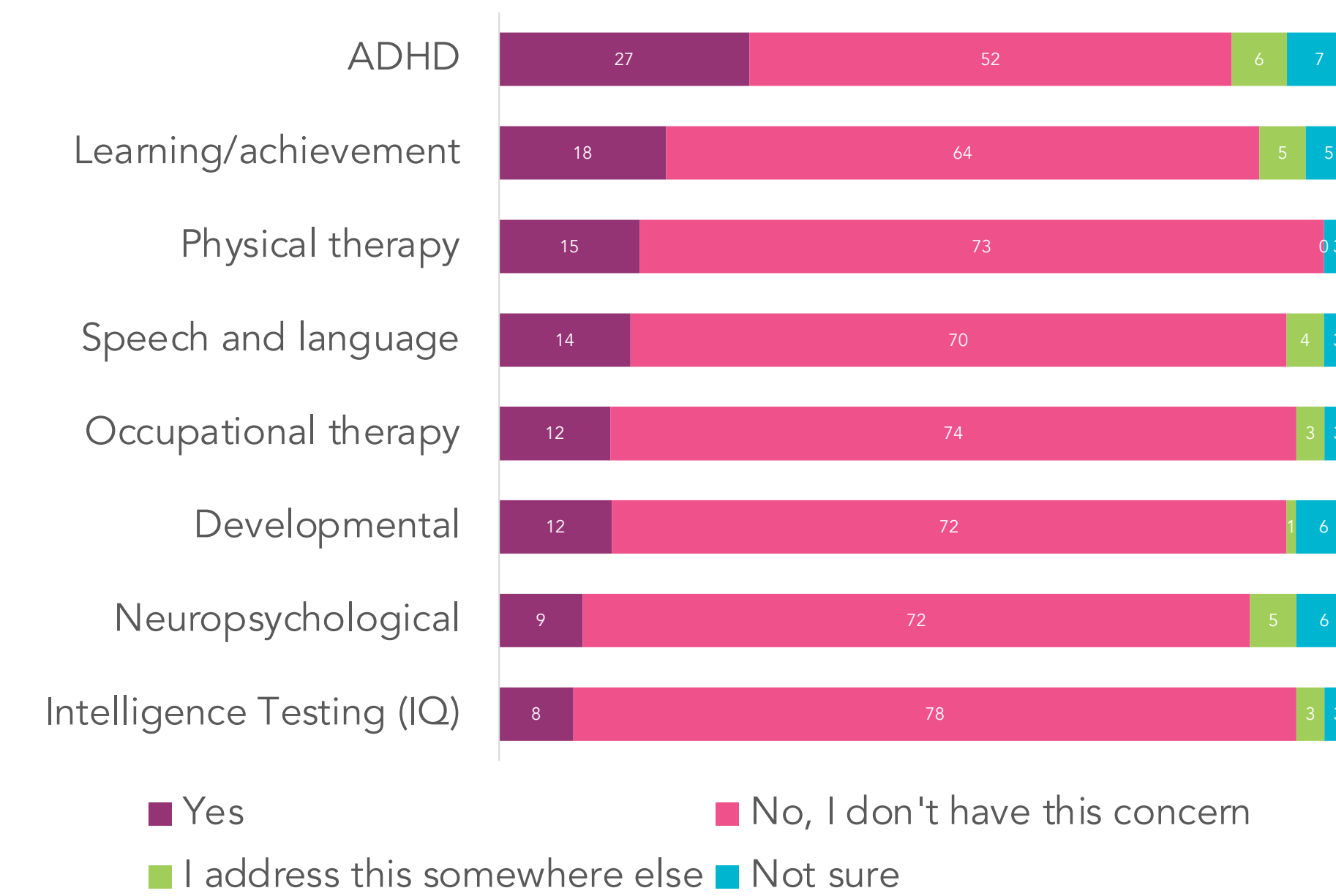
How comfortable are you asking for school support from your CF care center during a clinic visit?



How do you prefer to communicate with your CF care center outside of clinic appointments?



What referrals have you discussed with your CF care team?



Common words from free text responses about the biggest challenge PwCF face at school

Conclusions & Discussion

- This is the first assessment of school-related issues from the perspective of PwCF and caregivers of PwCF.
- Caregivers and PwCF report they are comfortable addressing school related issues with their CF care teams, although many report this could be improved if CF care teams were the ones to initiate conversation on these topics.
- Our survey also highlighted the importance of awareness of other pre-existing school-related resources such as cff.org, Facebook groups, and school nurses.
- CF care center or school-based psychologists are also part of a PwCF's school-support team.
- More of a focus on transition to post-secondary school options is especially important as more PwCF are transitioning to adult providers closer to age 18.

In summary, this study gives insight into the tasks which CF care teams should be most prepared to help their patients. A centralized hub of resources that PwCF and their caregivers can use to address school-related issues would be beneficial to many if not all PwCF. Ideally, this resource would include specifics surrounding educating schoolteachers and administrators about the educational implications of CF, a list of potential accommodations helpful for PwCF, and resources about how to be evaluated for and update an IEP. With the help of these resources and information identified in this study, the quality of life of PwCF could be greatly improved by aiding in the school success.

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