

Complementary Alternative Medicine (CAM), Cannabis, and Therapeutic Diets in Cystic Fibrosis (CF): Perspectives of Persons with CF, Caregivers of Persons with CF, and CF Healthcare Providers

Lam M^{1,2}, Bradshaw S^{2,3}, Anderson K^{1,2}, Sharpe A², Jackson K^{2,3}, Hall-Lipsy E¹, Bowen A², Phan H^{1,2,3,4}

¹The University of Arizona (UA) College of Pharmacy, ² UA Pediatric Pulmonary Center, ³ UA College of Agriculture & Life Sciences, ⁴ UA College of Medicine, Department of Pediatrics



BACKGROUND

- Cystic fibrosis (CF) is an autosomal recessive disorder that affects the cystic fibrosis transmembrane regulator, causing abnormal chloride ion transport resulting in thick, obstructive mucosal secretions resulting in a multi-organ system disease, including respiratory, gastrointestinal, endocrine, and reproductive organ systems¹
- The use of CAM, cannabis, and therapeutic diet may be increasing in popularity due to various reasons including increased availability and legalization
- Previous studies report that up to 73% and 20% of persons with CF use CAM and cannabis, respectively²⁻⁵
- There is currently a lack of data describing and comparing the various perspectives regarding safety and efficacy of CAM, cannabis, and therapeutic diets within the CF community

SPECIFIC AIMS

From perspectives of adult persons with CF, caregivers of persons with CF, and CF health care providers:

- Describe current practices of 1) CAM, including supplements, herbal products, 2) cannabis, 3) therapeutic diets, as part of daily CF care
- Evaluate perceptions of 1) CAM, including supplements, herbal products, 2) cannabis, 3) therapeutic diets, as part of daily CF care
- Compare perceptions of open communication and co-production of CF care with regards to 1) CAM, including supplements, herbal products, 2) cannabis, 3) therapeutic diets
- Describe sources of information for 1) CAM, including supplements, herbal products, 2) cannabis, 3) therapeutic diets

METHODS

Design: survey study with branch logic, using QualtricsXM®, using multiple choice/response and Likert scale questions; offered opportunity to participate in raffle for an Amazon \$40 gift card; series of three survey to be released over 2019

Population: adult persons with CF, caregivers of persons with CF (including parents, guardians, family, partners/spouses, etc.), CF healthcare team members (provider (MD/DO/NP/PA), pharmacists, nutritionists, nurses, care center coordinators (all disciplines), behavioral health professionals (all disciplines)

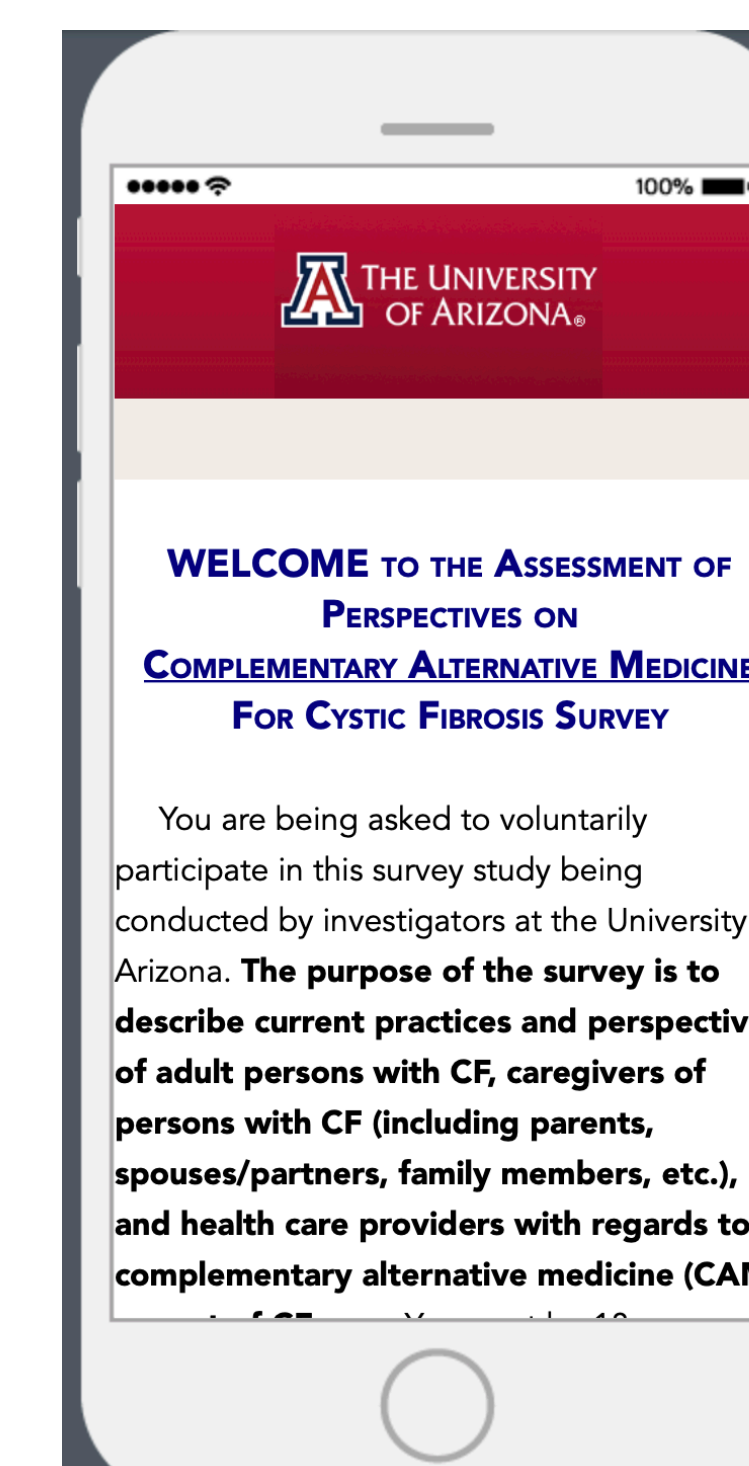
Inclusion Criteria: age 18 years or older, amongst population described (above), agree to participate

Exclusion Criteria: does not meet inclusion criteria

Primary Sources of Participants: CysticLife, CF Foundation listservs (for CF healthcare team members), CF Foundation Community Voice

Data Collection: Use and type of CAM/Cannabis/Therapeutic Diet, perceptions of benefits and risks, perceptions of communication and coproduction of care, sources of information, demographics (including rural status)

Statistical Analysis: Descriptive statistics, including Chi Square/Fisher's Exact, Kruskal-Wallis; Multivariate regression; Alpha priori set at 0.05; use of STATA Version 15.0



PRELIMINARY INSIGHTS

- Many adult persons with CF and caregivers of persons with CF report use or considered use of CAM as part of daily CF care
- There are various reported types of CAM used with the most common being vitamins, herbal/plant supplements, essential oils, and probiotics

FUTURE DIRECTIONS

- CAM survey to remain open until April 2019
- Future release of Cannabis and Therapeutic Diet Surveys in Fall and Winter 2019

LIMITATIONS

- Length of survey and possible survey fatigue (recently released a CF Medication Education Survey), limiting response rate
- Snap shot of information, difficult to measure changes in the population over time

REFERENCES

- Elborn JS. Cystic fibrosis. *The Lancet*. 2016;388(10059):2519-2531.
- Tanase A and Zanni R. The Use of Complementary and Alternative Medicine Among Pediatric Cystic Fibrosis Patients. *The Journal of Alternative and Complementary Medicine*. 2008; 14(10):1271-1273.
- Giangioppo et al. Complementary and alternative medicine use in children with cystic fibrosis. *Complementary Therapies in Clinical Practice*. 2016; 25:68-74.
- Fride E. Cannabinoids and Cystic Fibrosis: A Novel Approach to Etiology and Therapy. *Journal of Cannabis Therapeutics*. 2002; 2(1):59-71.
- Stern et al. Recreational use of psychoactive drugs by patients with cystic fibrosis. *J Pediatr*. 1987;111:293-9.

PRELIMINARY RESULTS (CAM as of 3/23/2019)

Figure 1. CAM Survey Participants, N = 174

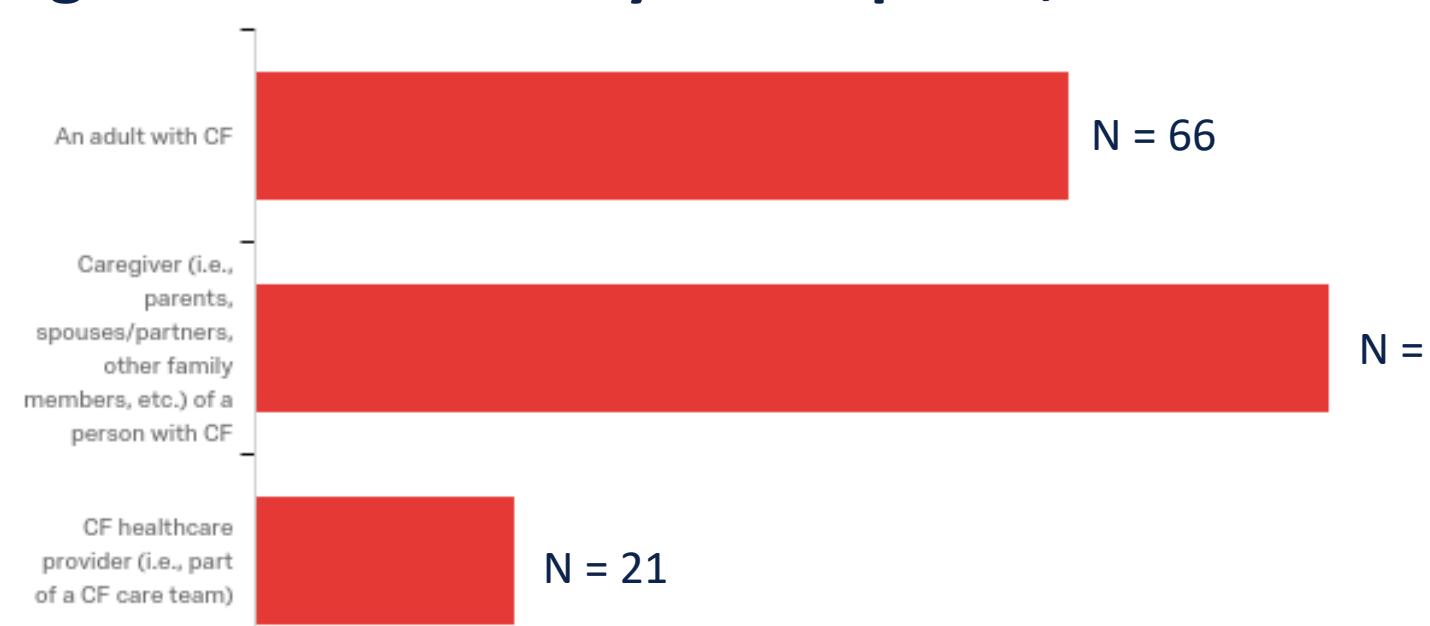


Figure 2. CAM Use/Consideration of Use, Adult Persons with CF

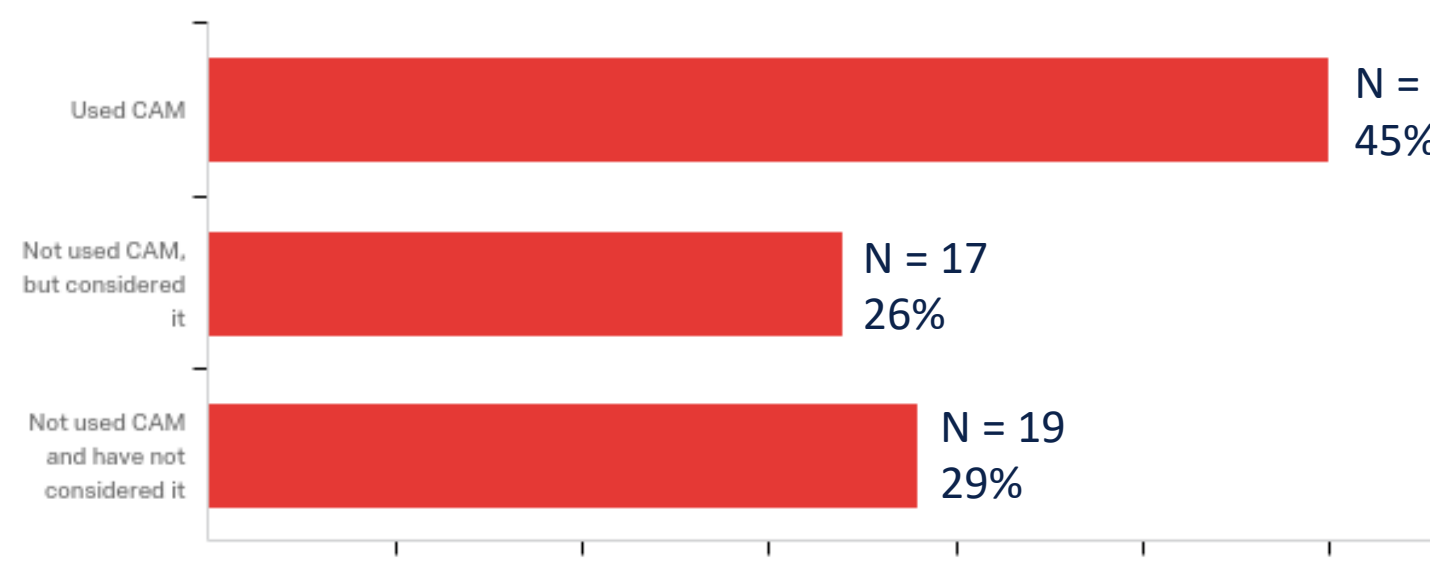


Figure 3. CAM Use/Consideration of Use, Caregivers of Persons with CF

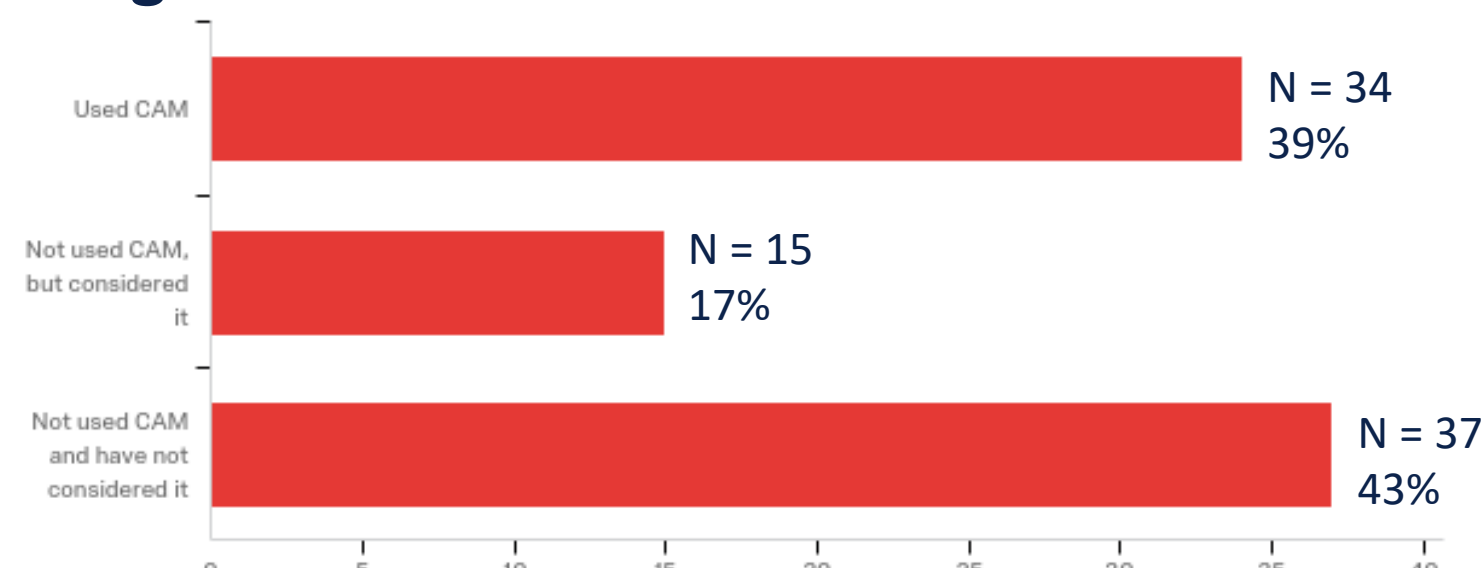


Figure 4. Types of CAM Used in Daily CF Care, Adult Persons with CF

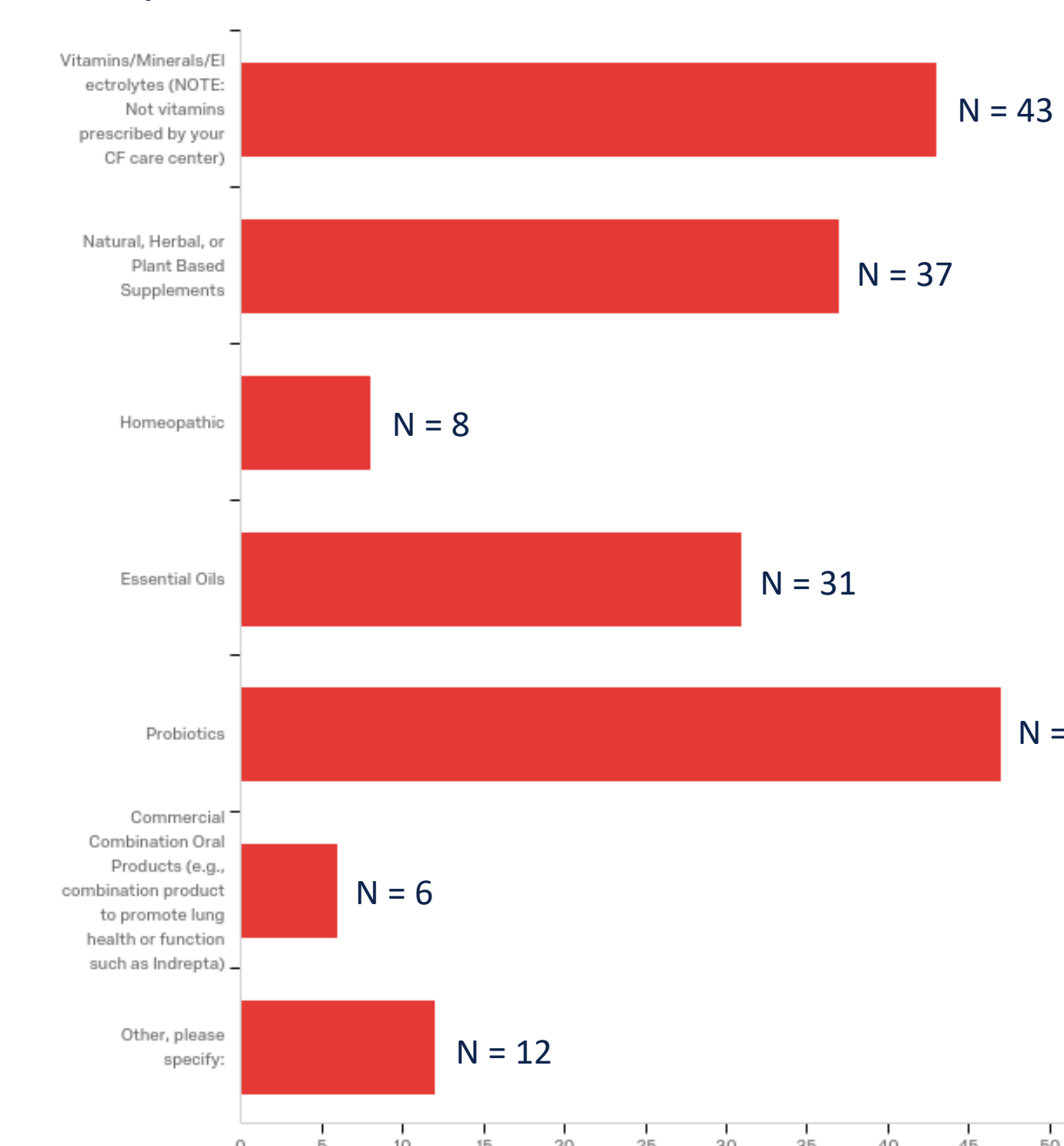
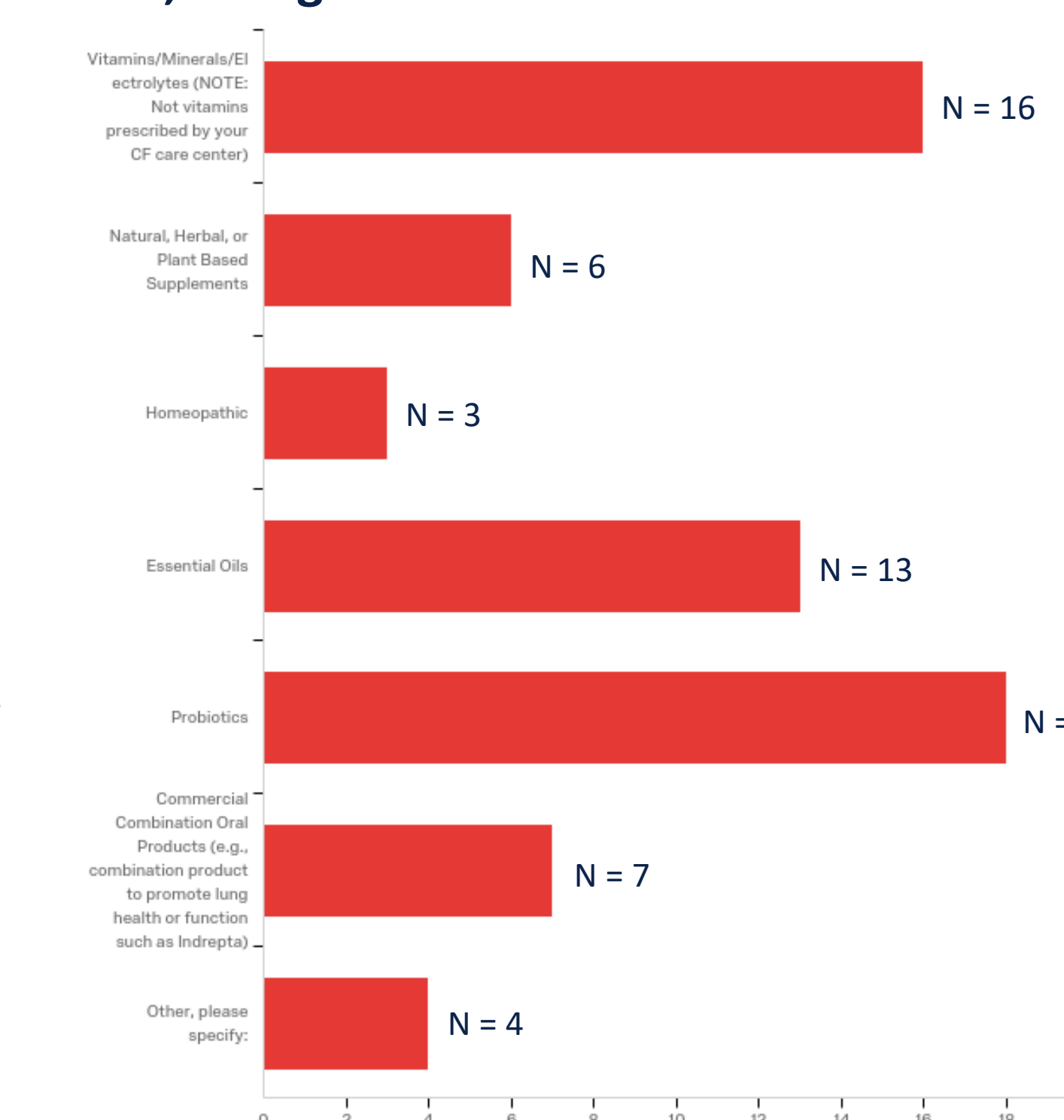


Figure 5. Types of CAM Used in Daily CF Care, Caregivers of Persons with CF



ACKNOWLEDGEMENTS

With gratitude, we would like to thank:

- CysticLife
- CF Foundation Community Voice
- CF Foundation, Discipline Listservs

Project and Trainee Grant Support:

- UA College of Pharmacy Area Health Education Center (AHEC) Grant
- This project is/was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number T72MC00012, University of Arizona Pediatric Pulmonary Center for grant amount \$1,700,000. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

DISCLOSURES

Lam M: nothing to disclose
 Bradshaw S: nothing to disclose
 Anderson K: nothing to disclose
 Jackson K: nothing to disclose
 Sharpe A: nothing to disclose
 Hall-Lipsy E: nothing to disclose
 Bowen A: CF Foundation grant support
 Phan H: CF Foundation grant support (STRC, Outpatient Pharmacy Services); Consultant - Vertex Pharmaceuticals, Wolters Kluwer

Project Contact: Hanna Phan, PharmD, FCCP, FPPAG
 hphan@pharmacy.arizona.edu