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Conclusions: Although we did not meet our goal, we were able to maintain overall length of clinic duration despite a global pandemic. Our clinic is no longer required to use strict COVID-19 precautions, so we have returned to our original clinic flow. We will continue to gather data in hopes of decreasing clinic duration and thereby increasing patient satisfaction.

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Quality improvement project: Human milk feeding and lactation support in a large pediatric cystic fibrosis clinic

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Background: Breastfeeding or human milk are recommended for at least the first year of life based on well-documented health benefits for mother and child. Moreover, breastfeeding is often more meaningful to parents than can be expressed simply in terms of health statistics. Conversely, negative experiences from excess pressure to breastfeed have been described. Evidence suggests that bottle feeding and formula supplementation may impede breastfeeding success. Even so, both are typically encouraged by all providers in our clinic because careful monitoring of feeding and a very high-calorie intake are strongly recommended to achieve above-average growth over the first 2 years of life.

Methods: We collected baseline data on infant feeding and lactation support during the first year of life via retrospective chart review. Infants visiting our center from 2016 to 2020 were included. Infants presenting for their first visit after 3 months of age were excluded.

Results: Between September 2016 and September 2020, 49 infants entered care at our center at or near diagnosis and remained in our care until at least age 12 months. The average age of the infants on the first visit was 5 weeks (range 2–12 weeks), and the average age at the second visit was 10.5 weeks (range 8–16 weeks). At the first visit, 29 infants (59%) had had any human milk feeding (AHM) including 17 infants (35%) that were only human milk feeding (HMO); 12 infants (24%) were human milk plus formula feeding (HMF), and 20 infants were formula feeding only (FO). At or before the first CF visit 37 (76%) had some lactation support, and 16 (43%) had used a breast pump. Of the AHM group, 13 families (45%) talked with the CF lactation consultant, and seven (24%) of these used a baby scale at home to monitor intake or weight gain. At the second visit, nine infants (18%) were HMO, and 25 (51%) were HMF. At 6 months, 20 (41%) were HMF, and two (4%) were HMO; the two HMO infants continued HMO until age 12 months.

Conclusions: The rate of AHM feeding at our center at any time during the first year of life is lower than national rates (59% versus 84%). HMO feeding at the second visit was especially low (18% versus ~46% nationally). AHM feeding also rapidly declined after the first visit. In-clinic lactation support was limited. Family input is needed to further characterize parent impressions of lactation support in our CF clinic, as well as any feelings regarding pressure to provide human milk they may have experienced. Next steps: Our QI team plans to obtain patient and family input to describe their experience of current lactation support at our center, including potential negative impacts associated with pressure to provide human milk. We will use our baseline data and the family input to develop change ideas to support desirable outcomes for human milk feeding and a positive experience for families.

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Identifying Knowledge Gaps Using Adapted CF R.I.S.E in a Low Resource Setting

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Background: CF R.I.S.E is a transition program that helps improve self-management, increase baseline knowledge, and ease the transition of cystic fibrosis (CF) patients from pediatric to adult care. The Marmara University CF center is one of the largest centers in Turkey, and although the number of adult patients has increased in recent years, we do not have a structured transition program. We implement the CF R.I.S.E program by making the necessary translations and adaptations during the VIP-F7 training program. We named our adapted transition program KF SOBE. SOBE is a word formed by the Turkish initials for self-care, responsibility, independence, and education. Attaining the necessary knowledge about CF and its management is an essential part of the transition process. Our aim was to understand the baseline characteristics and knowledge levels of our patients to identify education deficits. We accomplished this by initiating the KF SOBE program. It includes assessment of baseline knowledge using 11 knowledge assessment questionnaires (KAQs). To our knowledge, this is the first implementation of CF R.I.S.E outside of the United States and the first in Turkey.

Methods: All Marmara University CF team members and a patient representative from KIFDER (the Turkish CF patient and family association) meet for weekly quality improvement meetings. The clinical microsystems quality improvement methodology was used during this translation and adaptation process of CF R.I.S.E. People with CF (PwCF) aged 16 to 25 that were followed routinely at our CF center were included. After introducing KF SOBE to families and patients in an online meeting, the KAQs were administered to the patients via an online questionnaire within 2 weeks to assess baseline knowledge regarding CF.

Results: Of 81 PwCF who received KAQs, 77 (95.1%) completed all of the questionnaires. The mean age of the patients was 19.4 ± 2.9; 42 (52%) were female. Mean percentage predicted forced expiratory volume in 1 second was 76.3 ± 23.2%. Fourteen (17.3%) were colonized with *Pseudomonas aeruginosa* and four (4.9%) with methicillin-resistant *Staphylococcus aureus*. Fifteen (18.5%) were undergoing modulator therapy. Between 47.9% and 68.3% of responses to the KAQs were correct (Table 1).

Conclusions: The CF R.I.S.E transition program was successfully translated and adapted to Turkish with the guidance of the VIP-F7 program. Our patients' knowledge assessment scores on lung health, airway patency, general health and equipment care, and infection control were good, reflecting the focus of education on these topics in many clinic visits. The knowledge areas that needed to be supported were related to sexual health, college and work, and health insurance. Liver disease and diabetes are not typically discussed unless there is a prior condition. We must support these topics as well. Baseline KAQ results will help us determine knowledge gaps that may hinder successful transition and the need for additional coproduced educational support. Education of adolescents and young adults about the disease is essential to provide self-management skills and facilitate continued success in adult CF programs. We believe that successful implementation of CF R.I.S.E in a low-resource environment, without extra financial support and personnel, sets an example for other countries with similar settings.