

Translation And Adaptation Of CF R.I.S.E Transition Program To Turkish

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September 22, 2023

Abstract

Background: Previously, Cystic Fibrosis (CF) patients faced a limited life expectancy, but significant medical advances now highlight the need for successful transition programs from pediatric to adult care. **Methods:** The aim of this project was to implement the CF R.I.S.E. program, a structured transition program, in a CF center with limited resources at Marmara University. The program was adapted and translated into Turkish with the permission of the Cystic Fibrosis Foundation. A multidisciplinary team collaborated in the translation and adaptation process and educational materials were developed for patients and families. **Results:** Successful implementation of the CF RISE program was achieved within six months. A pilot study with randomly selected patients revealed positive feedback indicating the effectiveness and understandability of the program. The program facilitated strong collaboration between pediatric pulmonologists, CF nurses, dietitians and patient representatives. However, challenges were encountered due to the lack of a designated social worker, which affected patients' access to expert guidance on social security and disability rights. **Conclusions:** The CF S.O.B.E. program was successfully adapted and implemented at the Marmara University CF Center in Turkey. The program is expected to have a positive impact on patients' knowledge and self-care skills over a period of 1.5 years. It is aimed to make the program a routine practice in the center and to expand the collaboration with adult clinics. Further studies are needed to assess its long-term impact and applicability in different health settings. The ultimate goal is to disseminate the program's resources and promote structured transition practices nationwide.

1. INTRODUCTION

Cystic Fibrosis (CF) is a genetic disorder with an incidence rate of 1/3000-1/6000 live births¹⁻³. In the 1930s life expectancy for people with CF (pwCF) was limited to just a few years, but medical advancements have increased life expectancy, with modulatory drugs targeting specific gene defects being effective in a majority of the CF population⁴.

Currently, more than half of the CF population in Europe, Canada and North America is over 18 years old, a significant increase is expected in the number of pwCF transitioning from pediatric to adult care^{5,6}. The transition period can be a stressful time for young adults with chronic diseases and can result in poor health outcomes⁷. A structured transition program can help prepare pwCF and their caregivers and lead to higher patient satisfaction, lower anxiety, and greater self-esteem^{8,9}.

When developing a successful framework for transitioning healthcare services for pwCF, it is important to consider strategies that will help prepare pwCF and their caregivers, as well as tools that can track and measure transition progress at various stages ¹⁰.

A comprehensive transition program should involve a well-coordinated approach that includes a clinical summary with contributions from all members of the pediatric multidisciplinary team (nurses, doctors, dietitians, psychologists, social workers, and physiotherapists), an opportunity to meet the adult care team at the adult CF center, and ensuring timely access to an adult care provider^{11,12}. In cystic fibrosis (CF) transfer programs, the involvement of social workers is paramount for a seamless transition from pediatric to adult care. These professionals, form a multidisciplinary transition team, with social workers often serving as the "transition coordinator" for individual patients^{12,13}. As the number of adults with CF increases, comprehensive transition programs and clinics are becoming more common in many countries ¹⁴⁻¹⁶.

CF R.I.S.E. (Responsibility, Independence, Self-Care, Education) is a planned, structured transition program created to improve quality of life, maximize independence, and minimize interruptions in care as a patient transitions from pediatrics to an adult subspecialist^{12,16}. This program has been successfully implemented in the United States since 2015 providing tools and resources to help patients and caregivers understand the disease and develop skills for managing it independently. CF R.I.S.E. aims to provide a gradual and purposeful transition of responsibility over time from support person to patient, while facilitating communication among pediatric and adult care teams, patients, and caregivers ¹⁷. The program has the potential to address the deficits in transition and has been positively evaluated by CF healthcare providers during its implementation period ^{10,12}.

Although adult patients have been increasing steadily over the years, the number of adults with cystic fibrosis in Turkey is relatively lower compared to Europe and North America. Being the largest center in Turkey, there are 424 individuals with CF in Marmara CF center and only 103 (24.3%) are adults. Since there was no structured transition program in our center, we decided to implement the CF RISE program by making the necessary translations and adaptations during the Cystic Fibrosis Foundation (CFF) Virtual Improvement Program-F7 (VIP-F7) training program. We named our transition program CF S.O.B.E, which consists of the first letters of responsibility, self-care, independence and education in Turkish.

Our aim was to convey our experience of the adaptation and implementation process of the CF RISE program in a CF center with limited resources. To our knowledge, this is the first implementation of CF RISE program outside of the US and in another language other than English.

2 MATERIALS AND METHODS

2.1 Setting and design

This is a quality improvement project created within the VIP-7 program in March 2022 at Marmara University (MU) Faculty of Medicine Selim Coremen CF Center. The study was approved by the respective ethics review board of the participating institutes the Ethics committee of Marmara University. (Project No: 07.10.2022.1359). A total of 81 individuals between the ages of 16-25 are followed in our center, 40 people residing in Istanbul who could regularly come to CF clinics were selected for implementation CF RISE. Permission was obtained from the CFF for the translation and usage of CF-R.I.S.E. materials. Written consent was obtained from the participants and their families.

2.2 MU CF Team

MU CF team consists of 5 pediatric pulmonologists, 6 pediatric pulmonology fellows, 2 CF nurses, 1 dietitian, 1 physiotherapist, and 1 patient representative from the Turkish Cystic Fibrosis Association (KIFDER). As part of the CFF QI project, all transition team members regularly attended weekly quality improvement meetings with 2 QI coaches from October 2021-October 2022. A social worker and psychologist are not part of the CF team.

2.3 Step 1: Translation and adaptation

2.3.1 CF R.I.S.E Program

The CF R.I.S.E. program includes 13 Knowledge Assessment Questionnaires (KAQ) and 6 Responsibility Checklists (RCL) forms¹⁸. The purpose of the KAQ is to evaluate the individual's basic knowledge about CF. It covers topics related to lung and liver health, infection prevention methods, pancreatic insufficiency, nutritional principles, endocrinology problems, school, work, financial, and social security. These assessments are introduced gradually. Each module is completed independently by the pwCF without parental or team assistance, to accurately assess areas for knowledge improvement. Once completed, the responsible CF care team member devises a plan to address identified knowledge gaps. After providing the necessary trainings, the modules are reassessed in subsequent visits or in 6 to 12 months to measure progress¹⁸.

The CF RISE program covers six responsibility checklists: 1) Working with the CF care team and other healthcare professionals, 2) Responsibility of CF Treatments, 3) Living with CF, 4) CF Transition, 5) School and Career Plan, 6) Finance and Insurance. These are designed to facilitate the acquisition of age-related self-care skills for everyone. Although KAQs are applied only to patients, RCL forms are collaborative assessments involving a designated support individual and the CF healthcare team to assess and monitor the patient's current level of responsibility. In the RCL forms, patients/parents are required to respond to each question using a Likert scale ranging from 1 to 5. The results of each question are compared between the parent and pwCF, and if there is inconsistency, the individual's level of responsibility for that question is reevaluated¹⁸.

A target responsibility is identified for the next meeting between the transition clinic (TC) representative and the pwCF based on the RCL results. The assigned tasks are recorded in a progress report, signed by both parties, and a copy of the progress report is given to the pwCF. The assigned responsibility is determined based on the individual's needs and level, and the interaction between the TC representative and the pwCF is contractual in nature. The progress of patients is reassessed one year later with renewed RCLs¹⁸.

2.3.2 Translation of CF R.I.S.E materials in Turkish

1- Translation and adaptation: All materials of the CF R.I.S.E program were translated into Turkish by the MU team. Necessary changes were made in the health and finance, business, and college program contents according to the conditions in our country.

2- Translated materials were evaluated for comprehensibility and content by senior team members and a team of volunteers from KIFDER, including a pwCF, a Turkish grammar teacher and two other members of KIFDER. Materials were designed to be understandable at the 3rd or 5th grade level. All translated and newly created materials were shared with CFF.

After the translation of all CF R.I.S.E materials into Turkish, the contents were reviewed by the team members, and adaptations were made according to our country's conditions. Since the College-Business Life and Finance-Social Security KAQs in CF RISE contain questions about the educational and social security system in US, we have created new KAQs suitable for the conditions of our country and the rights of the disabled. The two KAQs of Lifestyle and Mental Health were combined into a new KAQ called "Lifestyle and Mental Health" (Table 1).

2.3.3 Patient Education Materials

Educational resources including patient leaflets, webinars and videos were produced on all topics covered by the Knowledge Assessment Questions (KAQ). As part of the CF S.O.B.E initiative, webinars, patient leaflets and videos, were available online through a website created specifically for this project (16).

2.4 Step 2: Timeline

We planned to reassess patients' knowledge levels regarding the completed topics every 6 months via KAQs. We also planned to identify wrong answers and focus on these subjects in their following clinical appointments provide the correct answers face to face. We created 4 training modules and determined dates for online meetings every 3 months to cover the related content of these training modules. We also aimed to apply two

different RCLs at each appointment and reapply RCLs after 12 months. The timeline created within this scope is provided in detail in Figure 1.

2.5. Step 3: Pilot Study

A pilot study was conducted with a 16-year-old male and a 21-year-old female patient randomly selected by TC team members. During the pilot study, BOTH patients were asked to complete 11 core KAQs and 2 responsibility checklists. Both patients confirmed that the materials were understandable and informative. They expressed their excitement about the implementation of such a program. The pilot visits lasted 30 and 40 minutes respectively. Feedback from the CF team revealed that patients would need an extra 30-40 minutes of in addition to their routine clinical procedures. After the pilot study, the program was introduced to all families and patients through an online meeting.

3. DISCUSSION

In this quality improvement program we aimed to report our experiences regarding the adaptation and implementation process of the CF RISE program in a CF center with limited resources. The successful translation and implementation of the program were accomplished within a six-month period.

The pilot study provided positive feedback from patients, demonstrating their favorable evaluations regarding the content and comprehensibility of the program. Young pwCF described the education they received as "exciting and necessary," stating that it allowed them to better understand their condition and take responsibility for their care. This program was implemented through strong collaboration among pediatric pulmonologists, CF nurses, dietitians, and volunteer patient representatives. We had no financial support or social worker.

Formal transition processes for pwCF have been implemented worldwide since 1982, primarily in the United States and Canada^{16,19}. The United Kingdom has been at the forefront of establishing a transition program in Europe, and studies conducted in in several countries have reported positive outcomes regarding structured transition programs^{15,20,21}. Among these transition protocols, the CF RISE program, developed as part of quality improvement initiatives with resources from the CFF, has been successfully implemented in the United States for many years¹⁷. Therefore, the CF RISE program was chosen as a global example to be implemented in our country, representing the first translation and adaptation of the CF RISE program into a language other than English.

The success of establishing the CF S.O.B.E. program can be attributed to various factors. Active participation of a multidisciplinary team, expertise of subject specialists in developing educational resources, and the inclusion of patient representatives and language educators played crucial roles. Additionally, regular meetings between the transition team and QI coaches from the CFF VIP-F7 program, as well as valuable feedback from patients and families, facilitated continuous improvements and adaptations to meet the needs of patients and the healthcare system.

During the development of this program, a significant challenge encountered was the absence of a designated social worker as a project coordinator. The establishment of transition protocols for adult clinics and their continuous implementation within the hospital setting are critical, and social workers, typically serving as program coordinators in centers where CF R.I.S.E has been successfully implemented for years, play a vital role within the transition team^{12,16,22}. Due to limited availability of social workers and psychologists in our hospital, it was not possible to assign a social worker to the transition project. As a result, a significant portion of our patients did not have access to expert guidance on social security and disability rights. Consequently, pwCF and their families lacked awareness of government regulations concerning social security and disability rights, and their knowledge on this topic was limited. As part of this project, collaboration was established with volunteer experts through the CF patient and family association (KIFDER) to review government regulations regarding social security and disability rights and prepare written materials. A comprehensive online meeting was conducted with the entire transition team to ensure an inclusive approach and facilitate the dissemination of information to all team members.

Collaborative consultations and joint clinics involving professionals from both the pediatric and the adult clinic are often preferred over direct handovers^{12,22}. The next phase of our research involves integrating the adult clinic into the transition program and establishing a fully structured joint transitional outpatient clinic aimed at optimizing the transition process for patients. These clinics would be dedicated to patients who are prepared to transition from the pediatric clinic to the adult clinic at our center.

However, the implementation of the program in a single center may have certain limitations regarding its generalizability to other centers in Turkey. In order to gain a deeper understanding of the program's effectiveness, future studies should emphasize the assessment of its long-term impact on patient outcomes, as well as its suitability for different centers and the healthcare system in our country. With this objective in mind, following the initial evaluations of the CF SOBE program at our center, our aim is to distribute the resources we have to CF centers nationwide and promote the implementation of structured transition practices throughout the country.

4. CONCLUSION

CF R.I.S.E was successfully translated and adapted in our center. The success of the adaptation of CF RISE program can be attributed to the participation of a multidisciplinary team, utilization of educational resources, and regular meetings for feedback and compliance. Based on the program's outcomes, the aim is to share all materials and surveys with other centers, ensure their utilization, and benefit all pwCF.

In the coming period, our center will enroll pwCF aged 16-25 years in the CF SOBE program. The enrolled patients will be reassessed for their knowledge and skills after KAQs and RCLs. People with CF and their families who receive personalized education within the scope of the project are expected to increase their knowledge and skills about CF at the end of 1.5 years. Periodically throughout the project, the individual deficiencies of the patients will be identified through interim information assessments and individual and collective trainings (webinars, etc.) will be organized to overcome the information deficiencies (see Figure 1).

It is aimed that the project will become a routine practice of our center in the coming period. In addition, within the scope of the project, joint visits with adult clinics with limited experience in CF are aimed to increase their expertise in CF disease and active participation of transfer clinics in the project.

5. ACKNOWLEDGMENTS

The authors would like to thank the CFF VIP-7 team, KIFDER volunteers, patients for participating and for their feedback and assistance in conducting the study.

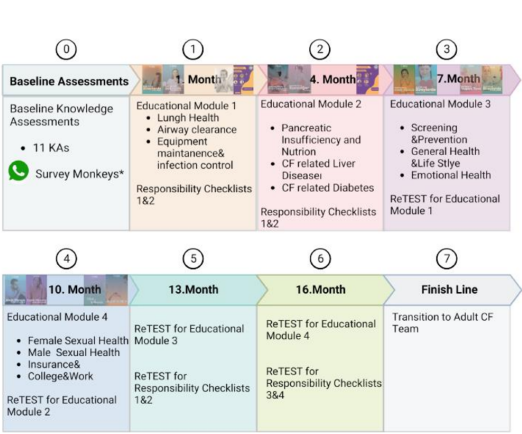
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