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Short Communication

Self-efficacy: Empowering parents of children with cystic fibrosis

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Abstract

Background: Can parent engagement in the development and delivery of educational materials for cystic fibrosis (CF) promote increased self-efficacy and confidence in self-management skills? Standard therapies for a child with CF frequently involve pulmonary treatment, medications, and behavioral and nutritional interventions. Parents report that the prescribed CF care can be overwhelming. Previous research at this pediatric CF Center indicated the parental perception of the difficulty in managing CF-related nutrition therapy. Parents' nutrition knowledge was an initial target of this continuous quality improvement (CQI) project with a long-range aim of increasing children's median body mass index (BMI) percentiles for patients at this pediatric CF center.

Methods: The local CF Parent Advisory Council, CF parents and staff collaborated on this family-centered CQI project. A CF parent website with weekly email newsletters and a facebook page were developed and evolved with input from parents. Parental feedback was gathered through electronic surveys, written questionnaires, focus groups and informal interviews. A convenience sample of parents participated in pre- and post-intervention surveys to determine change in self-confidence in effectively managing their children's CF treatment regimens. Results were also compared with responses from a larger previous survey.

Results: Parental knowledge of nutrition facts and medical nutrition therapy for CF did not increase significantly over the course of the CQI project. Surveyed parents reported increased confidence in their self-management skills. Although mean BMI percentiles have increased at this center, they remain below the national average.

Conclusions: Parent-driven educational strategies provide an opportunity to promote reliable CF-related information in parent-preferred formats that enhance self-management skills in caring for children with CF. Parental confidence to follow CF center recommendations increased between 2004 and 2011. Although many factors may impact confidence, parent satisfaction with the creation of electronic resources and engagement in the CQI process were intangible, but important outcomes.

Keywords: Quality improvement; Pediatric; Family-centered care

1. Background

An accredited, pediatric Cystic Fibrosis Center (CFC) and local CF Parent Advisory Council (PAC) collaborated on a continuous quality improvement (CQI) project to empower parents with knowledge, self-efficacy, and peer support to enhance the nutritional status of children with CF. The Intermountain CFC in Salt Lake City, Utah, serves approximately 250 children aged 18 years and younger (representing ~180 families) in a large catchment area in the western USA.

Prior to this CQI project, the CFC identified improved growth as a center goal. The PAC prioritized the development of a website to: 1) connect and support parents with reliable, positive and current CF information and 2) promote self-efficacy. The CFC and PAC determined that a joint effort could target both groups' objectives.

Optimal growth and nutrition status predict better lung function and longevity for children with CF [1–3]. According

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to the 2007 Cystic Fibrosis Foundation (CFF) Patient Registry Report, patients at this CFC had a median body mass index percentile below the national average, 41.6 versus 47.3 [4]. Although the CFC had focused on improving weight gain and growth by opening more clinic appointments, improved nutrition screening process, and educational handouts, progress remained slow [4].

The nutritional status of children with CF relies on parents' abilities to effectively manage dietary and behavioral issues [5]. Previous research at this center suggested opportunities for improvement in parents' knowledge and confidence in their ability to manage nutrition concerns for their children with CF [6]. Parents reported more confidence in their abilities to manage tasks such as respiratory therapy, oral and inhaled medications, and minor illnesses at home than nutrition-related CF issues [6]. Interviews with families suggested a perception that tasks tend to be more concrete and less emotional than management of nutrition-related issues such as weight gain, differing dietary recommendations for various family members, and behavioral issues around eating [6].

Self-management is essential to effective care of chronic illnesses, resulting in improved patient outcomes [7–9]. The promotion of self-efficacy extends beyond traditional knowledge-based education to encompass problem-solving skills. Successful self-managers apply knowledge to effectively resolve real-life situations that matter to the child and family. Effective self-management of a child's chronic disease extends beyond typical parenting skills to include symptom monitoring, treatments, medications, specialized nutrition, physical and psychosocial issues, and financial planning. Family-centered care and collaboration among healthcare providers and families are key in successful promotion of self-management [10].

2. Methods

The CFC dietitian (CMM) and social worker (DH) were non-voting CFC representatives to the PAC and acted as liaisons with the other CFC staff. CMM designed, conducted, and analyzed surveys of parents. A PAC member (NB) was responsible for the website development. PAC members (all parents of children with CF at the local CFC) participated in reviewing surveys, determining actions, and developing website content. Formal PAC meetings were conducted bimonthly with frequent phone and email communication between CFC and PAC. Institutional Review Board approval was obtained for this CQI research.

The PAC used a nominative problem-solving process to identify parents' concerns regarding their management of their child's CF care. Participative research methods defined parents' perceived needs for CF education and their preferences for receiving the desired information.

Feedback from CF parents was solicited throughout the project. Parents attending CF clinic were queried by the CFC dietitian for the strategies successful in resolving nutrition issues for their child that they would like to share with other parents. These strategies were posted weekly as a short "Tip of the Week" to the website and distributed to parents via email. Electronic and printed surveys, focus groups, and informal interviews were conducted to determine parents' preferences for information content and format. Table 1 describes a timeline of the project along with interval outcomes. Sections of the CQI were previously reported in abstract form [11–13].

A validated, written survey, the Mountain West CF Consortium Questionnaire (MWCFCQ), measured parents' nutrition knowledge and confidence in CF management. Results from 305 CF parents' responses to the multi-site (UT, CO, NM, AZ) MWCFCQ in 2004 were used as a baseline [6]. A convenience sample of 30 parents (not PAC members) was recruited at CF clinic visits to complete pre- and post-intervention MWCFCQs. Knowledge was assessed with multiple choice questions in two domains: 1) Nutrient content of commonly-used foods, and 2) CF-related medical nutrition therapy (MNT). Confidence or self-efficacy was ranked in three different domains of CF care: 1) "CFC recommendations" – the quality of the CFC staff's recommendations and parents' ability to follow them, 2) "Tasks" – ability to manage CF tasks (e.g., pulmonary therapies and medications), and 3) "Nutrition" – ability to manage MNT and food-related behaviors. Examples of questions for each domain are, "How confident are you that you: 1) are able to follow all the recommendations from the CFC?" 2) "…can manage the respiratory treatments that have been prescribed for your child with CF?" and 3) "…can manage the weight gain for your child with CF to achieve the best growth possible?" A Likert-type scale allowed respondents to select from 0, "Not at all confident" to 10, "Completely confident." One sample *t* tests were applied to the comparison of baseline to pre-intervention results and paired sample *t* tests were applied to the pre–post intervention comparisons (n = 21).

3. Results

Through the nominative problem-solving process, the PAC identified parental issues to address: 1) feeling isolated due to infection control concerns, 2) being overwhelmed by CF care, 3) uncertainty about the reliability of myriad sources of CF information, and 4) for some families, physical and/or emotional distance from the CFC. The PAC determined that a reliable, local website could ameliorate these concerns.

A summary of interim surveys with responses and outcomes is listed in Table 1. Over the course of this CQI project a CF parent website, weekly email newsletters ("Tips") and a CF parent Facebook page were established and modified with parent and CFC staff input. Most recently, a mediashare site was added to house videotaped parent educational presentations and non-commercial CF demonstration videos (e.g., "How to clean nebulizers.")

3.1. CF parent knowledge on MWCFCQ

Of the 30 parents who consented to participate in the mailed survey, 27 returned the pre-intervention MWCFCQ and 21 completed the post-intervention MWCFCQ 18 months later. Demographics for pre- and post-intervention respondents are compared with respondents to the 2004 MWCFCQ in Table 2. Fifteen of the 21 parents who returned both pre- and