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The *EMPOWER* (Enhancing, Managing, and PrOmoting *WEll-being and Resiliency*) Program within The Jaffe Food Allergy Institute – A person-centered care initiative

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Abstract

The *EMPOWER* program was launched to provide patient and family-centered care, which includes emotional support and consultation to children who suffer from food allergy and their parents. It resides within the Jaffe Food Allergy Institute in the Department of Pediatrics at the Icahn School of Medicine at Mount Sinai in New York, USA. Patients' perspectives are central to program development. Patient and family feedback has been incorporated into all operational and developmental aspects of the emerging program. This approach is frequently recommended but rarely practiced. [1,2] This manuscript presents the original aims of the program, the way those aims were approached, and the progress to date. Research results, as well as information about programmatic processes, are presented, with the intent of providing useful information to readers who might be interested in creating similar person-centered programs.

Keywords

Food Allergy, Patient and Family Centered Care, Screening, Anxiety, Clinical Care, Research, Patient and Family Feedback

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Introduction

Food allergy affects about 4-5% percent of children and adolescents, [3] and 3-4% of adults, across the US. To ensure safety, individuals with food allergy and their immediate family members need to endure substantial restrictions to their life-style (including dietary restrictions, restrictions in travel, and others). The challenges involved in living with food allergy are similar to the challenges associated with having any chronic medical illness with the caveat that food allergy is an episodic condition that may cause no apparent ailment except when active. Thus, those necessary, extensive life-style restrictions sometimes seem to be without apparent "reason" for the restrictions – until one actually experiences an event, ranging from a rash to a fatal anaphylactic reaction. This conundrum (a life-threatening illness which on one hand has little morbidity in between episodes, but on the other hand requires sustained changes to the affected individual's, and his/her family's, life-style) poses a specific challenge to children and adolescents and their families. As families struggle to maintain a life-style that is as normal as possible while also

trying to maintain safety, decisions are challenging to make and many times fraught with doubt. Lack of agreement or certainty about the definition and maintenance of safety (what should be considered safe and what is not), the degree to which children should be allowed to make decisions about their safety as they grow older, and even whether treatments should or should not be administered (i.e., using a self-carried autoinjector containing epinephrine, a medication required to treat severe reactions) frequently leads to distress. In turn, distress may impair quality-of-life, strain relationships with children, spouses, and even health care providers, and may also lead to less than ideal disease management. Indeed, investigators across countries, [4-7] have documented that in the face of this uncertainty, families yearn for guidance and support. Families report heightened levels of distress, especially in relation to having experienced an upsetting event such as anaphylaxis. [8] During adolescence, distress and perhaps confusion or avoidance responses may lead to failure to follow medical recommendations or treatment. [9]

The person-centered approach to care can be summarized with the phrase attributed to the philosopher

Ortega y Gasset, “I am I and my circumstance” [10], which means, in the context of program development, that one’s personhood, and by definition also one’s needs, stem from a variety of factors that include a person’s circumstances as well as her or his biology. Recognized deficiencies in health care include neglect of the holistic needs of people who receive care and the fragmentation and inadequacies of health and social services. [10] Food allergy is a case in point. The biological morbidity is only one aspect affecting the quality of life of the patient and her or his family. While much is being done to address the physical phenomena associated with food allergy, including research about its prevention, maintenance treatment and even cure, surprisingly little is done to alleviate the associated distress. Even though patients and families clearly ask for more support, and in spite of the fact that there are proven methods to address distress in other settings, [11-14] there is a dearth of mental health experts who have specific knowledge about food allergy. Those needs mainly simply do not get addressed. But even if the importance of the emotional well-being of the patient and family is in fact acknowledged, families in need of support at most may be referred to a mental health professional in another center. This fragmented approach is inconsistent with “person centered care” as it inconveniences the family and may result in a referral to a practitioner with little experience in handling the unique challenges posed by food allergy.

Dedicated clinicians and researchers at the Jaffe Food Allergy Institute at the Icahn School of Medicine at Mount Sinai embarked on an effort to define and clarify the “full person” concerns and service needs of pediatric food allergy patients and their families. Based on initial research and surveying patient needs, [15] *Enhancing, Managing, and PrOmoting WELL-being and Resiliency (EMPOWER)* program was launched in June 2010, with a generous gift from the Jaffe Family Foundation, and a later complementary gift from the Pine/Segal family. Several key factors have contributed to the development and maintenance of this initiative: the availability of multidisciplinary expertise within the same institution and Department, a patient population that had clearly identified a need for this aspect of care, and the availability of training programs that can provide the seeds for a future generation of experts. Since this initiative sprouted from (was conceived, funded, and inspired by) patients and families of patients, the priority has been a concrete and sustained effort to incorporate patient feedback in every step of the creation of this program.

EMPOWER

The program outlined two main goals: 1) Provision of clinical care, and 2) Research and training. To ensure that families participated in decisions related to the building and implementation of the program, the following consultations and collaborations were undertaken in an attempt to build a patient-centered program: a) initial national needs assessment in the population of interest; b)

multi-year study of pediatric patients and families within the Jaffe Food Allergy Institute, the specific site for program implementation; c) continuing patient and family feedback via ad-hoc interviews, and written review of program materials by local and national patient-advocacy groups. Feedback from clinicians regarding program creation, implementation, and adjustments was encouraged, as well.

Goal 1: Provision of clinical care

The most immediate goal of the program was to provide pre-emptive and reactive care to affected families in a comfortable setting. Intended clinical care aims included screening with a focus on health and prevention rather than on pathology, ad-hoc and scheduled consultations, provision of expertise in cases in which treatment should include a multi-team approach, provision of referrals in cases that need further care, and generally offering a service in which liaison with other agencies (i.e., schools) will be not only be possible but a part of usual care if needed.

To develop the clinical components, *EMPOWER* initially embarked on a needs assessment. Over 400 families attending food-allergy themed conferences nationwide were recruited to voluntarily participate in a survey. The respondents clearly stated a need for mental health consultation and care that is accessible and involves a minimal amount of scheduling. [15] To complement and build on the input from the members of the national patient advocacy organization, *EMPOWER* researchers surveyed 250 families in the Jaffe Food Allergy Institute, looking to identify the most important topics that need to be addressed. The results of this study are still being analyzed; one published finding was that bullying is frequent and of concern in this population. [16] Taking those results into account, in concert with expert input from the Jaffe Institute clinical team, the *EMPOWER* team provides consultations with a mental health provider with a focus on improved access and continuity of care, and liaison services with other agencies, particularly other providers and schools (to address the concern of bullying). In addition, a screening program was initiated with the intent to screen patients for symptoms that they might not otherwise discuss with their physician during their appointments.

Specific measures of success were set once program components had been identified. They include: a) Creation and maintenance of an effective scheduled and ad-hoc consulting service, and provision of care commensurate with the time/effort provided by the funds; b) Establishment of a clinic-wide screening effort; and c) Provision of liaison services with other entities.

Goal 2: Research and training priorities

Research initiatives are a part of the Jaffe Institute’s mission and a part of the *EMPOWER* team’s focus. The

EMPOWER program funding and structure allows some capacity for supporting innovative initiatives so as to ensure that research is flexible, responsive to emerging needs, and nurtures not just established trajectories but also the next generation of ideas and experts. To support innovation, the *Challenge Research Program* was created which supports a stipend for an innovative research project offered by a trainee. The proposal is opened only to trainees who spend a period with the Jaffe Institute's *EMPOWER* team and offers an incentive for those trainees to engage in creative thinking about the issues that they encounter. The *EMPOWER* program hosts trainees from a pediatric medical residency program, a pediatric psychology externship program, and a pediatric / psychiatry / child psychiatry Triple Board medical residency program.

The specific measures of success include: a) Publication of at least one peer reviewed manuscript in a medical journal per year; b) Creation and maintenance of at least one IRB-approved research protocol per year; c) Presentation of the research in national forums; d) Attracting top-caliber trainees to the team; e) Invited talks / manuscripts on the research topic; and f) Participation in and assistance to patient advocacy groups.

Outcomes to Date

More than 700 patients and/or families have participated in program development and research efforts via surveys, or in-person interviews. Brief results are summarized below.

1. *Survey findings.* A survey of 454 parents of children with food allergies was completed at national Food Allergy & Anaphylaxis Network (FAAN) meetings. The survey data have been presented in two national scientific meetings and two FAAN meetings, and have now been published. [15] One finding was that mental health consultations were deemed to be of value by most parents, but were seldom sought. This supports the original idea behind the *EMPOWER* program, to provide consultations rather than wait for self-referrals to a psychiatrist. An in-depth survey of 250 families seen at the Jaffe Institute was completed and initial results published. [16] One finding was that bullying of food-allergic children is common and is associated with significant decrease in quality of life. Therefore, bullying, along with other salient topics, were later incorporated into a question on the screening questionnaire. Additionally, because health-related quality of life is a key indicator of the effect of medical illness and any secondary development of stress or psychological symptoms; [6,17] a section for quality of life assessment was included in both the child and adult screen. Furthermore, since parent stress and child anxiety have been shown to be predictive of health-related quality of life, [18] questions targeting these two constructs were included in the screening questionnaires.

2. *Groups.* Beyond identification of ad-hoc and scheduled mental health consultations for food allergic patients and their families, educational/support groups for adolescents and parents were an anticipated deliverable. However, these groups could not be implemented because patients and families found it hard to arrive at prescheduled group meetings.

3. *Consultations.* Consultations (1-3 encounters) have been in steady demand, and at the time of this publication, the program has provided consultations to about 200 referred cases. Consultations are provided at the discretion of the allergist, in response to screening results, and according to the wishes of the child and family. Every effort is made to provide care that is as integrated as possible with the allergy clinic visit. To achieve this goal, there is a dedicated coordinator with flexible scheduling capabilities, and the consultations are provided in the same physical space. Key to the *EMPOWER* mission, we include an option to request a consultation whether or not the child actually has symptoms (pre-emptive consultation is accepted and encouraged). Treatment for established mental health disorders is not usually provided by the *EMPOWER* team. Rather, an effort is made to refer patients to an adequate provider for mental health interventions, if those are needed. An exception is made in cases in which specific expertise is required that the *EMPOWER* team is uniquely equipped to provide. Additionally, *EMPOWER* provides a liaison with other providers as needed (i.e., discuss cases and guide outside therapists / pediatricians as needed, offer consultations with school personnel upon family request, etc.).

4. *Development and implementation of a screening effort.* The screening component identifies distress and other needs of patients and families as they emerge. Data from the initial *EMPOWER* needs assessments, in addition to previous research conducted by members of the *EMPOWER* team, [15] were analyzed to create a simple screening tool to identify those patients and families who were experiencing distress, signs of anxiety, and/or disruption to quality of life, in addition to those that would benefit for a mental health consultation for other reasons. Continuous patient and family involvement in all aspect of measure development was mandatory (i.e. concept generation, item generation, item reduction, content validation, initial testing, review of results from the first iteration, and modification). Such an approach is recommended for quality-improvement initiatives such as "audit" projects, [19] but is still unusual in screening efforts: in typical measure development, patient involvement rarely occurs during all stages of development, if it happens at all. [2] To develop the *EMPOWER* screening tool, patient involvement could be characterized as collaboration during the concept generation phase, transitioned to a consultative role on item generation led by *EMPOWER* clinical staff and researchers, and returned to a collaborative approach

Table 1. FARE Leader Feedback Results

	Yes n (%)	No n (%)	Don't Know n (%)	No Response n (%)
Parent Screening Form				
<i>Formatting</i>				
Easy to Read	11 (79)	3 (21)		
Appropriate and Clear	13 (93)	1 (7)		
<i>Content</i>				
Instructions Easy to Understand	12 (86)	2 (14)		
Specific Instructions Easy to Understand	11 (79)	2 (14)		1 (7)
Comfortable Answering in Clinic	14 (100)			
Delete or Replace a Question	2 (14)	11 (79)		1 (7)
Add Any Questions	4 (29)	8 (57)		2 (14)
Child Screening Form				
<i>General</i>				
Age Appropriate	11 (79)	2 (14)	1 (7)	
Create 2 Questionnaires	12 (86)	1 (7)		1 (7)
<i>Formatting</i>				
Easy to Read	10 (71)	3 (21)		1 (7)
Appropriate and Clear	13 (93)	1 (7)		
<i>Content</i>				
Instructions Easy to Understand	11 (79)	1 (7)		2 (14)
Specific Instructions Easy to Understand	12 (86)			2 (14)
Comfortable Answering in Clinic	10 (71)	3 (21)		1 (7)
Delete or Replace a Question	3 (21)	5 (36)		6 (43)
Add Any Questions	6 (43)	5 (36)		3 (21)
Managing Anxiety Question Important	13 (93)			1 (7)
Managing Anxiety Question Appropriate	9 (64)	1 (7)	1 (7)	3 (21)

Note: FARE = Food Allergy Research and Education

for initial item reduction and general modifications prior to implementation.

Following the initial measure development with input from one family, the screening tool was then presented to Support Group Leader's and Walk Chairs at the annual Leader's Summit for Food Allergy Research and Education (FARE). The leaders were asked to respond to a survey that evaluated the format and content of both the parent and child screening form. All respondents (n =14) were female, with a mean age of 41. All but one respondent had a child with food allergies and, of those that did, two of them had more than one child that is food allergic.

Table 1 summarizes the general results of FARE leaders' feedback. The majority (93%) reported that the format is appropriate and clear and 79% reported that that the form is easy to read. With regards to the child screening form, 79% agreed that the questionnaire was appropriate for the intended ages; 86% endorsed the idea of creating two separate questionnaires, one for 8-12 year olds and one for adolescents.

Tables 2 and 3 provide the respondents' specific comments regarding questions that should be deleted, in addition to questions or topics respondents felt should be included but were not addressed in the screening measure. Typically item reduction is left to factor analysis and statistical analysis to identify items that are not contributing to the outcome indicator. In this case, however, the outcome indicator was not clearly defined in statistical terms (the "outcome" was to generate a screen that best captures the needs of the food allergic patients; such an outcome is best achieved through consultation with the target audience).

The feedback from FARE will be combined with informal feedback received from patients and families who engaged with the screen during their visit at Jaffe Institute, in addition to quantitative statistics regarding the screening measures utility and effectiveness in routine clinical care with an initial sample of over 500 families in the Jaffe Institute. Together this information will assist the EMPOWER research and clinical team in modifying the screening questionnaires to best target patient and families' needs while also improving its clinical utility and predictive validity in identifying patients and families who might benefit from further mental health consultation. This work is currently being undertaken.

Table 2. FARE Leader Comments – Parent Screening Form

Parent Screening Form	ID	Comments
Questions to Delete	13	"My child can use an Epinephrine Autoinjector on his/her own..." doesn't distinguish between those incapable due to age/maturity and those incapable due to lose consciousness
	14	Circled "yes" that there is a question to be deleted/replaced but does not state which question
Questions to Add	1	Parent's openness to mental health services/options
	2	A blank section for the respondents to comment freely
	6	Parents perception of the child's emotional health
	9	Worry about not being able to respond to medical emergency with child (give Epinephrine Autoinjector)
	13	Circled "yes" that there is a question to add but did not provide one
	13	Avoidance of social situations due to child's FA

Note: FARE = Food Allergy Research and Education; FA = food allergy

Table 3. FARE Leader Comments – Child Screening Form

Child Screening Form	ID	Comments
Questions to Delete	14	Would not work with child who has difficulty with self-expression or self-awareness
	2	"I'm a worrier" is not necessary if the 2 Q's above it are answered
	7	"Have trouble getting along with kids" sounds like the child's fault
	14	Ask Q's under "How I get along with others" section 2 ways: (1) way it is currently presented and (2) where each Q ends with "because of my FA"
Questions to Add	5	Embarrassment of having a reaction in front of friends
	6	Worry about having a reaction and needing to use an Epinephrine Autoinjector
	9	How much worry interferes with paying attention in class
	9	Do they think they are not invited because of FA?
	9	Feel they can't go anywhere because of FA?
	12	Q about vacation and dating
	14	Ask if feel different/isolated/unincluded
	14	Give space for child to write or draw freely about how they feel

Note: FA = food allergy; yo = year old; Q = question

5. *Training.* The intent of *EMPOWER* to provide holistic patient care called for training a multidisciplinary cadre of students and professionals. There have been a large number of trainees that have been involved with the program ranging from pediatric fellows to doctoral students to undergraduate students, and from various disciplines accentuating the integrative and multi-disciplinary collaboration needed to address the holistic needs of the targeted patient population. Trainees have won several awards for their work.

A research project identified gaps in clinicians' ability to recognize anxiety in their patients and evaluates a training program that enhances clinician's abilities. *EMPOWER* staff embarked on, and are testing,

innovative methods to help clinicians be more attuned to patients' level of anxiety in the clinic.

Challenges

Despite the growing attention to patient-centered development care models, it has become clear that the American health care system is ill-suited to provide coordinated, patient-centered care. In spite of several attempts to get some reimbursement for the *EMPOWER* program's clinical initiatives, health insurance companies would not reimburse the consultations. Reasons cited range from the fact that "two services were rendered in the same day (the visit with the allergist and the visit with the mental health provider) and only one of those can be

reimbursed, to simply denying care because it is not covered. In one instance, even when a specific plea was made by the patient, the allergist, the head of the allergy clinic, and an independent outside evaluator engaged by the insurance company, the insurance company declined any reimbursement for care. At this point, the only viable way to sustain such a program in the US is through philanthropic support.

Conclusions

The EMPOWER program, a patient- and family-centered care initiative, was inspired by, is funded by, and is continuously benefitting from the input of patients and families. In its third year, it has achieved almost all of its goals, and exceeded quite a few. The program's success validates the Jaffe Family Foundation's, the Pine/Segal Family, the Jaffe Institute's patients, as well as the Institute Director's, conviction that there is a clinical and research need for a program that helps families to address stress responses and proactively tackle emotional health needs without pathologizing them. Patients and their families provided valuable input about the topics that are addressed, how the program addresses them, in what setting, and when. The program has led to research findings that were of sufficient caliber to be accepted by leading scientific journals. Future directions include analysis of outcome measures of specific programs, such as the screening tool and consultations and referral services, with emphasis on quantitative evidence of the program's effectiveness. Continued documentation of patient involvement and evolution of the provision of care and support as more information is gathered are an essential feature of the program. It is a clear example of the principle of "considering the whole person of the patient in context."

[10] Unfortunately, this model of patient-centered care is not sustainable under insurance reimbursement schemes in the US. While the total cost of healthcare could be lower in the longer term by addressing secondary concerns and taking a holistic approach to patient care from a prevention model, a program of this type is not yet covered by current health insurance schemes and must rely on other funding and philanthropy efforts.

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