Welcoming Feedback: Using Family Experience to Design a Pediatric Weight Management Program

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Abstract

Objective: To describe an approach using principles of experience-based codesign (EBCD) and quality improvement (QI) to integrate family experience into the development of a pediatric weight management program. Methods: Clinic development occurred in 3 plan, do, study, act (PDSA) cycles that were driven by family experience data. During these cycles, families were engaged in feedback sessions that informed program development. Staff reflected on feedback and designed and tested changes that would improve service delivery. Results: The first PDSA cycle resulted in the fundamental program parameters and a formalized patient engagement strategy. The second cycle focused on pilot programming, and feedback was used to develop the structured group program. During the third cycle, feedback sessions were embedded into the structured group programs. Program changes included focusing on health rather than weight-based outcomes, adjusting the timing of program offerings, increasing experiential learning opportunities, and providing more opportunities for peer support. Conclusions: Both EBCD and QI methodologies informed the process of family engagement and program development. This pragmatic approach might be useful for the development of other family-centered pediatric programs.

Keywords

pediatric obesity, patient engagement, patient-centered, quality improvement

Introduction

Treatment models for childhood obesity should include caregivers and families (1). Multicomponent lifestyle interventions utilizing behavioral strategies with family-based and parent-only behavioral treatment types have proven efficacious (2,3). Since families play a prominent role in successful treatment approaches, patient and family caregiver input is critical for the effective delivery of family-based behavioral programs (4,5). Although there has been substantial investment in refining methods for collecting data about patient experience, there is limited understanding of how these data can be used locally to improve the quality of care and the culture of health-care services.

Early in the development of the KidFit Health and Wellness Clinic (KidFit), a multidisciplinary, family-centered, pediatric weight management program, the clinical team adopted the position that families should be engaged in the design of the treatment approach. The KidFit program defined family engagement as a partnership between patients, caregivers, and health-care providers to design care delivery to improve health and wellness (6,7). KidFit's goal

was to effectively integrate the experiences and perspectives of families into the design of services (6-8). The aim of this report is to fill an important implementation gap by describing and appraising our systematic and sequential approach to integrating family experience into the development of a pediatric weight management program. Particular emphasis is placed on describing how this methodology was used to engage families and how family feedback was incorporated into program design at the onset of program planning. This

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pragmatic approach might be useful for the development of other family-centered pediatric programs.

Methods

Context

KidFit is a multidisciplinary pediatric weight management program within Trillium Health Partners (THP) in Mississauga, Ontario, Canada. Trillium Health Partners is the largest academically affiliated, community-based acute care facility in Canada (9), which is located geographically west of Toronto (10), The area is the second most populous health region in Ontario (10) and is ethnoculturally diverse (11).

Trillium Health Partners received funding from the Ontario's Ministry of Health and Long-Term Care in January 2015 to launch KidFit within the calendar year. Following the receipt of funding, a multidisciplinary team was hired including a nurse coordinator, child psychologist, registered dietitian, social worker, activity therapist, project manager, and pediatric endocrinologist. The multidisciplinary KidFit team accepts referrals for children between 2 and 17 years old with obesity (body mass index [BMI] \geq 95th percentile for age and gender on the Center for Disease Control [CDC] growth chart or >97th percentile on the World Health Organization [WHO] growth chart for Canada). This pediatric weight management program is 2 years in length and provides education and counseling to patients and caregivers individually and in group sessions. Currently, the primary outcome measures for the clinic reported to Ontario's Ministry of Health and Long-Term Care include weight, height, BMI, BMI z score, medical and mental health comorbidities, Pediatric Quality of Life Inventory version 4.0 (12), and patient satisfaction scores.

Stages of Program Development

To inform KidFit's approach, the team reviewed the extant literature and determined that a combination of elements of both quality improvement (QI; 13) and experience-based codesign (EBCD) might be an effective approach to engage families in the design process (14). Both methodologies have been used extensively in the health-care setting, and both approaches have specific strengths and limitations. Quality improvement consists of systematic and continuous actions that lead to measurable improvement in health-care services (13). The foundation of QI is the Model for Improvement, developed by Associates in Improvement, which relies heavily on testing changes through plan, do, study, act (PDSA) cycles (13). Experience-based codesign is an approach that seeks to improve health-care services by enabling service providers, users, frontline staff, and management to collaborate together to codesign better services (15). Experiencebased codesign typically involves completing 6 distinct stages: (1) setting up the project; (2) gathering staff experiences; (3) gathering patient and caregiver experiences; (4) bringing staff, patients, and caregivers together to share

experiences; (5) groups work together to codesign; and (6) a celebration/review event (16). Experience-based codesign puts service user voices at the center of the evaluation process (16). This is achieved through listening to the experiences of the people who work in and use health-care services and sharing these experiences with the people who can effect change within services through collaborative work between families, staff, and managers (14). Experience-based codesign methodology has been utilized in a variety of clinical settings including diabetes, mental health, and pediatric areas (14).

During each stage of KidFit development, elements of EBCD and serial PDSA cycles (13,14) were used to design and test changes based on feedback from families. The development of KidFit had a number of stages beginning with the collaborative design of the treatment program with families, followed by its implementation, gathering opinions on the strengths and weaknesses of the program through feedback sessions with families, and review and reflection by staff (14). Qualitative feedback and process measures were tracked to ensure effectiveness of individual PDSA cycles, while incorporating lessons learned during each stage into subsequent cycles. The institutional review board classified this project as local QI, and a formal exemption from the Research Ethics Board [REB] review process was granted. Informed consent was obtained from participants in the qualitative components of the project for the purpose of audio recording for later transcription and analyses.

Data Collection

The method of participant recruitment varied over the 3 PDSA cycles. In the first and second stage, participants were recruited via phone calls placed by the Patient Relations Department at THP. In the first stage, caregivers with children awaiting initial assessment were invited to participate, whereas in the second stage, families who had completed the pilot group programming were contacted to attend the feedback session. In the third and final stage, families who were currently enrolled in the structured group programming were invited to participate in the feedback sessions, and recruitment was primarily completed via announcements made in the first few group sessions. Families were notified in advance that attendance at these sessions was optional, choosing not to participate would have no impact on care, and participation would remain confidential.

The feedback session in PDSA cycle 1 was facilitated by 2 KidFit staff (dietitian and social worker). These staff members received coaching from the project manager, who was skilled in group facilitation and ongoing training occurred by a qualitative researcher at the hospital's research institute, the Institute for Better Health (IBH). In the second PDSA cycle, to protect participant confidentiality, these sessions were led by experienced facilitators not engaged in direct patient care and affiliated with IBH. In the final PDSA cycle, sessions were facilitated by staff associated with KidFit; however, these individuals did not provide any direct patient care. At the beginning

of each feedback session, participants were told about the importance of their feedback, that there were no "right" answers and that the facilitator wanted to hear from everyone.

A variety of data collection methods were used to capture the qualitative feedback from patients and families as well as from KidFit staff. The feedback sessions in each PDSA cycle were audio-recorded and transcribed verbatim. For the latter 2 PDSA cycles, there were also volunteer notetakers present during the sessions, which allowed for the collection of field notes. The results from KidFit staff meetings were captured in extensive meeting minutes, as well as photographs of any affinity diagrams (17) or other visual representations of brainstorming sessions.

Data Analysis

The field notes and transcripts were circulated to the KidFit team, and several intensive planning sessions were held where findings were used to make program decisions and changes. When reviewing transcripts, 2 of the authors (I.S.Z. and J.G.) independently reviewed the data to generate initial codes. The feedback session data were then coded independently (J.G. and I.S.Z.), initial themes were identified, and reports were generated for discussion during KidFit staff meetings. During each PDSA cycle, short reports summarizing key observations from the feedback sessions were shared with family participants as a form of member checking to validate the team's interpretation of the data (18,19).

Results

A summary of the PDSA cycles is outlined in Table 1. A total of 13 feedback sessions were held throughout the 3 PDSA cycles, and the duration of the sessions ranged from 30 to 90 minutes each. The numbers of families invited to participate in feedback sessions during PDSA cycles 1, 2, and 3 were 16, 11, and 30, respectively. Of those families invited, 5 (31%) families provided feedback in cycle 1, 4 (36%) in cycle 2, and 30 (100%) in cycle 3. By the end of the third PDSA cycle, 1 member of each family had participated in at least 1 feedback session. The characteristics of the caregivers who participated in the feedback sessions during PDSA cycles 2 and 3 are reported elsewhere (7). The following sections review the components of each PDSA cycle, emergent themes, and program changes. A summary of the results of the PDSA cycles is provided in Table 2.

Plan, Do, Study, Act Cycle 1: Creating the Culture

The purpose of the first PDSA cycle was to create a culture that valued, obtained, and utilized patient feedback. One of the first steps in this process was the creation of a patient engagement strategy (6,8) to guide the overall approach to program development (Table 3). To develop the patient engagement strategy, a brainstorming session was held with all KidFit staff. Several QI techniques were utilized at this

Table I. Plan, Do, Study, Act Cycle Summary

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PDSA Cycle	Key Elements
Creating the culture	One 90-minute feedback session with caregivers of children awaiting initial assessment Coordinated by Patient Relations Department and facilitated by KidFit staff Session audio-recorded and basic thematic analysis completed
	Patient engagement strategy and key program components developed
2. Testing the strategy	4-week pilot programming developed and trialed with 3 age groups
	Two 90-minute feedback sessions conducted with parents and children who participated in the pilot group programming
	Coordinated by the Patient Relations Department and facilitated by research staff not affiliated with KidFit
	Sessions audio-recorded, memos taken, and basic thematic analysis completed
3. Committing to the	12-week group programming was developed and implemented with 3 age groups
strategy	Ten 30-minute feedback sessions embedded into the 12-week group program
	KidFit staff coordinated attendance and sessions were conducted by staff familiar with the KidFit program but external to patient care
	Sessions audio-recorded and transcribed with basic thematic analysis completed by KidFit team

time, including multivoting and affinity diagrams (17). These methods of facilitation allowed for the development of a document that reflected the team's shared values regarding patient engagement.

The next step in developing KidFit's culture and guiding principles was a feedback session with family caregivers of referred patients awaiting initial assessments in KidFit. The discussion guide for this session was developed by the KidFit staff and was informed by EBCD principles. The questions and prompts focused on the families' prior experiences with and expectations about weight management, language considerations, ideas for important program components, and the overall treatment approach.

The primary themes identified at this stage are listed in Table 2 and included preferences for language not focused on "weight" or "obesity"; the desire for a balance of different program components including nutrition, physical activity, medical education, and social support; and lastly, the need for a portfolio of outcome measures including both weight-based and patient-reported outcomes. Many program changes were made based on the feedback received in this session. Based on this feedback, the name of the program was changed from the "KidFit Weight Management Program" to the "KidFit Health and Wellness Clinic." In addition, participants reported a preference for a holistic approach to health and wellness, rather than a focus on weight-based outcomes (Table 2). While the clinic name

Table 2. Selected Examples of Program Changes Based on Family Experience

PDSA Cycle	Feedback	Representative Quote	Program Changes
I. Creating the culture	Families expressed preferences about the use of language (eg, obesity and body as negative terms, life-long and wellness identified as positive terms)	"As soon as she says the word "am I obese?" and it's like mmmmmm it's like it's all negative all of the sudden and it goes from being positive to negative"	Changed the name of the clinic from "KidFit Paediatric Weight Management Program" to "KidFit Health and Wellness Clinic." Family and staff joint vision statement created: "Small steps, lasting change, and lifelong wellness"
	Families identified key program elements and spoke to importance of social support	"And that would be, be really important for us, for me I will speak for myself, to get information from professionals like you guys on that. How much of it is environment how much of it is their biological makeup?"	
	Families expressed mixed opinions about success (eg, weight loss vs improved lifestyle habits or quality of life)	"I'm interested in the number, I'm confused by it, and I haven't quite figured it out. Dr X said he doesn't want her to necessarily lose weight, he wants her to grow into her weight and I'm thinking what in the world? So I would like a number, even a range, like that would be healthy for her. Yeah, I think that would be a success factor for me, to have her within a range."	Developed key program principles for consistency in treatment approach, measures of success, and to manage family's expectations about weight loss
2. Testing the strategy	Families preferred regular physical activity, less sedentary time, hands-on nutrition education, and communication skills training	"Yeah. I think education is good, but they have so much at school and it needs to seep in. And a long day at school, and I think if you're going to do education, put it into an activity."	Longitudinal programming was developed with mix of physical activity and experiential learning opportunities related to nutrition and communication skills training
	Families expressed preferences for required attendance at group sessions and opportunities for sibling involvement	"For me, I would like the siblings to join in you can bring your siblings for the whole family to join in, like, so that everybody had an education aboutI think it's better if the whole family."	Attendance policy cocreated with families and siblings invited to participate in special events and summer programming
	Families reported that the start time of the group was causing logistical challenges and burden	"Well, I think it's not easy for them because like it's in their schedule too. So I went to every single session but I'm always like 10-15 minutes late because my parents—like they're pushing themselves to get you here."	Timing of the start of group was adjusted to later in the evening
3. Committing to the strategy	Families reported that they were unclear about next steps in the program	"So, I mean, we've got a fantastic program here what's going to kind of happen after graduation, and I guess one of the concerns that I would probably have is, you know, is there something that's going to help us just keep maintaining things?"	Discussed program expectations more with the families currently enrolled in groups and made the expectations clear in information night presentation
	Families expressed a preference for increased group cohesion and additional time for sharing and support	"Many of the strategies that have come up have been from other people around the table and not necessarily just facilitators, and I think that's really, really beneficial because we're the ones who, you know, having the struggles. So as we solve those problems and we develop our own strategies represented, like it really, really helps a lot"	build relationships and educational content was removed to allow for more time for sharing and support
	Families expressed concerns about the timing and logistics of the groups	"Maybe you can run 2 of these classes for people who work on the weekends, people who don't work on the weekdays."	Group start times moved to later in the evening and weekend programming added for increased accessibility

was changed, for clarity purposes the referral form and introductory clinic materials do specify that KidFit works with children with obesity.

During a series of intensive planning sessions, KidFit staff reflected on data from the feedback session and incorporated caregiver perspectives into the patient

Table 3. The KidFit Patient Engagement Strategy.

Why are we creating this patient engagement strategy?

Because in the spirit of codesign, we recognize that the only way to truly create patient-centered care is with the input from the client and family

Because we believe that the patients' input is as important as the expertise of the team

Because we want to promote a desire to participate in the program

Because high levels of patient engagement promote innovation What do we hope to achieve with this patient engagement strategy?

Understand patients and families baseline level of knowledge, strengths, and skills

Understand patients' needs and barriers

Have families and clients as authentic partners in service development and delivery

Have a clear understanding of the patients' motivations for participating in the program

Have an idea of what program logistic patients would prefer (such as times, days, location, frequency of program, etc)

Have continuous system for patient engagement so the program can evolve and improve

Understand how to create a program that is culturally sensitive and accessible for our population

Have patients continue to be involved beyond the length of the program (eg, as ambassadors or peer mentors)

What do we think the underlying principles, or "ways of being" for patient engagement should be?

Truly value and utilize patients' and families' input

To develop authentic patient-centered care, we need to ensure we actually use the information and suggestions from patients and families. We want to avoid tokenism

View patients and families as experts

We need to acknowledge that patients and families are experts on their family and know best how to meet their needs. We cannot assume we know it all

Patient engagement should be an ongoing and sustainable process

Patient engagement should be core to the development and delivery of the program, with mechanisms to ensure it is sustainable for the life of the program

engagement strategy (Table 3). In these sessions, staff had the opportunity to read the transcripts from the sessions and reflect upon the reported experiences of families. From this, the team developed the following key principles: (1) the treatment program would be family-centered, including both caregivers and siblings when possible; (2) the treatment approach would emphasize positive behavioral changes rather than weight loss; and (3) the overall goal of the program would be to help families make small, sustainable, healthy behavioral changes. Experiences captured in the feedback sessions were used to create the following vision statement for the clinic, which utilized language and key concepts identified by families and caregivers: "Small Steps. Lasting Change. Lifelong Wellness."

Plan, Do, Study, Act Cycle 2: Testing the Strategy

In the second PDSA cycle, the team applied the patient engagement strategy and framework to create pilot group programming. This consisted of a small-scale, short-term, trial group program to test the format of the sessions and some initial content that could inform the more structured group programming. During this phase, KidFit began to seek partnership with a local grocery store and the in-store dietitians to provide an experiential learning opportunity for families to gain skills in food preparation and cooking. The KidFit team then piloted 4-week group-based programming for 3 different age groups. Subsequently, 2 separate 90minute feedback sessions were held with family caregivers and patients, who participated in pilot programming. A semistructured discussion guide was developed by KidFit staff members with input from IBH personnel with expertise in qualitative evaluation. Questions were related to the following topics: (1) overall experience with the group program and (2) educational topics covered and learning styles.

The key themes identified in these feedback sessions included the desire for physical activity and experiential learning opportunities, preference for strict attendance policies to promote regular group attendance, sibling involvement, and expressions of logistical challenges including timing and location of groups (Table 2). This feedback gathered had a substantial impact on the format and focus of the structured group program. As a result, when designing the complete curriculum, physical activity was included in most of the weekly sessions. Additionally, more nutrition content was planned including grocery store tours, taste testing, and role-playing activities. Other changes made based on the feedback received included altering start times and group expectations to ensure consistent group participation.

Plan, Do, Study, Act Cycle 3: Committing to the Strategy

The third PDSA cycle allowed KidFit to commit to the approach of incorporating patient feedback opportunities into regular treatment. This enabled KidFit to build a more structured group curriculum consisting of 12 weekly group sessions. During this cycle of program development, community partnerships began to have substantial impact on program development. To improve access to care, the KidFit team sought opportunities to collaborate with the City of Mississauga to allow the majority of programming to be held after hours in local recreation centers more convenient to families. The City staff worked with KidFit to cocreate physical activity programming for the families participating in the group-based programming.

To gain insights about family experience, KidFit embedded patient and family feedback sessions into the longitudinal group programming. Families enrolled in the structured 12-week group-based program (Foundations) had the opportunity to participate in at least 2 feedback sessions during regular

group programming. Embedding the feedback sessions into scheduled sessions resulted in a much higher level of participation and allowed for prompt changes based on family experience data. The semistructured discussion guide for these sessions was developed by KidFit staff members. Questions were related to the following topics: (1) overall experience with the group program; (2) educational topics covered and learning styles; and (3) desired next steps in the program.

In the third PDSA cycle, changes based on feedback impacted both current programming and future stages of curriculum development. As reported previously, (7) caregivers reported that they valued the opportunities for open discussion and time for peer support. The KidFit team addressed this feedback by reducing some educational content to allow more time for sharing and discussion between caregivers. Building on this feedback, the KidFit team designed the second phase of the group-based program (Supported Implementation) as a peer support model during which facilitators would lead group discussions about applying the lessons learned during the first phase.

Discussion

In this report, the methods used to capture and utilize the experiences of families to create and change key elements of the KidFit programming are outlined. Given the lack of guidance in the extant literature, this was accomplished by using both elements of QI and EBCD. After embedding the engagement opportunities in regular program sessions, the team observed a marked increase in participation at feedback sessions and at least 1 caregiver per family was able to share their experience. Although numerous changes were made to program content and mode of delivery, the KidFit team was limited in certain aspects by logistical constraints. Overall, the approach to program development was feasible and acceptable for families and staff and provided valuable insights into the experiences of families in our program.

One of the most substantial impacts on the KidFit clinic resulting from patient feedback was the change in language and key program principles to not focus primarily on weight. This change aligns with a body of research examining weight-inclusive treatment programs, which demonstrates beneficial impact on physical and mental health (20-21). In line with weight-inclusive recommendations (22), the clinic uses person's first language. In addition, the clinic is striving to find appropriate outcome measures that align with the weight-inclusive treatment approach. Currently, the clinic collects data in a number of different domains using the Family Assessment Device (23), the Patient Health Questionnaire—Adolescents (24), and food frequency and physical activity questionnaires which have been developed specifically for the KidFit clinic.

There are a number of well-described facilitators and barriers to making patient-centered changes in health care (25-26), and throughout the process of program development, several of these facilitators and barriers were present. With supportive leadership, staff were able to innovate

without fear of retribution if unexpected results arose. The staff were also supported by existing resources available in the hospital community, including THP's Research Institute, the Patient Relations Department, and the Volunteer Department. Another important facilitator was the QI expertise that was preexisting within the KidFit team, as the physician lead had completed advanced training in QI and the project manager had extensive experience in the hospital's quality department. This expertise enabled the team to develop a family-centered program by using the key principles of EBCD layered on QI for program development.(13) While KidFit did have QI expertise on the team, no members had formal training in the development, implementation, and evaluation of the health education programming. This is an important expertise that was missing during program development, and the team will explore opportunities to work with Medical Education at THP to fill this gap.

A number of challenges arose with both methodological approaches. One of the most significant barriers was the lack of dedicated additional staff or resources. Therefore, factors such as lack of time, money, and physical space were consistent limitations to the overall effort. To mitigate these challenges, a number of pragmatic choices were made when developing the methodology described in this article. The process for EBCD typically involves nonparticipant observation; in-depth interviews with patients, caregivers, and staff; and the creation of a film with "trigger" points or experiences, with the whole process taking about 9 to 12 months to complete (27). Considering the time pressure of having to launch a new clinical service within a calendar year and the resourceintensive nature of the traditional EBCD approach, KidFit was unable to adopt this extensive methodology. Although there have been several previous adaptations to the EBCD methodology (27), such as an accelerated EBCD approach that draws upon archived interview footage (28), this adapted method was not appropriate for program development, as archived interview footage for this population does not currently exist. Rather, by relying on data from recent family experience, we were able to design and test changes during our PDSA cycles to drive program improvement. This pragmatic approach allowed for families to be engaged throughout the process of program development, and their experiences informed each step of the design.

Conclusions

Using family experience data to drive program development resulted in the creation of a multicomponent program promoting health and wellness for families of children with obesity. The early engagement work created a culture that prioritizes family involvement. This cultural contribution is important, given that changing the mind-set of health-care workers has been identified as a key barrier to making patient-centered innovations (26). With additional funding, the team plans to utilize and study the impact of fulsome EBCD methodology, to codesign effective health-care

services. This will involve holding comprehensive codesign sessions with patients, families, staff, and leadership, working together to make programmatic changes. In the future, KidFit plans to implement a family advisory panel to ensure ongoing partnership in creating patient-centered and effective programming.

Based on this experience, the research team suggests that other pediatric weight management programs might consider adopting similar approaches to family engagement and program development. With appropriate leadership support and resources, this pragmatic approach, which uses patient feedback to drive improvements, could be applied to a variety of clinical settings including primary care, multicomponent chronic disease management programs, and acute care settings. Future studies could more comprehensively examine the impact and cost-effectiveness of family engagement on clinical outcomes.

Declaration of Conflicting Interests

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Elizabeth Mansfield is a research scientist at the Institute for Better Health at Trillium Health Partners in Mississauga, Ontario. She is a medical sociologist and qualitative researcher with expertise in program evaluation and implementation science. Her current work brings a population health and intersectionality lens to health services research to support evidence informed policies and practices addressing the diversity of community based patient and family caregiver experiences.

Deepy Sur is a trauma informed clinical social worker with a specialization in mental health and sexual assault. In addition, Deepy is an assistant clinical professor in the Family medicine teaching unit at McMaster University.

Ian Zenlea is a paediatric endocrinologist at Trillium Health Partners where he leads the KidFit Health and Wellness Clinic, which was launched in September 2015. He is currently conducting research on the treatment of childhood obesity as well as public health promotion of family health and wellness. Dr. Zenlea holds an academic appointment as an Assistant Clinical Professor in the Department of Paediatrics at University of Toronto.