Patient Engagement and Attrition in Pediatric Obesity Clinics and Programs: Results and Recommendations

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KEY WORDS

obesity, weight-management programs, patient retention

ABBREVIATION

NACHRI—National Association of Children's Hospitals and Related Institutions

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abstract

Pediatric tertiary care institutions are well positioned to provide multidisciplinary, intensive interventions for pediatric obesity known as stage 3 treatment. One contributor to the difficulty in administering this treatment is the high rate of patient attrition. Little is known about the practices used by pediatric weight-management clinics and groupbased programs to minimize attrition. Hospital members and nonmembers of FOCUS on a Fitter Future were surveyed on the methods used to engage and retain obese children in their clinics and programs. Shortly thereafter, a benchmarking activity that centered on rates of patient nonattendance at initial and follow-up clinic visits was initiated among FOCUS-group-participating hospitals. Clinic- and group-based program results were contrasted. Staff from groupbased programs reported that the majority of patients did not complete even 50% of program follow-up visits. Multiple patient/family- and clinic/program-level barriers to retention were identified. Attention to successful techniques should be paid during planning for new programs and improvement of established ones. *Pediatrics* 2011;128:S59–S64

The prevalence of overweight and obesity has increased significantly among children in all age groups in the last 30 years, according to data from the most recent National Health and Nutrition Examination Survey. Despite evidence that the rates of overweight and obesity might be leveling off,2 severe obesity (children with a BMI at the ≥99th percentile) has increased 300% in the past 30 years; the highest rates are seen in black, Latino, and lowersocioeconomic-status children.3 In 2007, the Expert Committee on the Assessment. Prevention and Treatment of Child and Adolescent Overweight and Obesity recommended that obese children and teenagers who fail to lose a significant amount of weight during primary care—based stage 1 and 2 interventions should be referred to multidisciplinary weight-management programs in pediatric tertiary care centers, known as stage 3 interventions.4 Stage 3 interventions consist of multidisciplinary visits with frequent (up to weekly) visits for 8 or more weeks. Although the recommendations are based on available and mounting evidence of the efficacy of these multidisciplinary, moderate- to high-intensity interventions,5,6 stage 3 childhood obesity treatment is practically challenging to deliver. This difficulty is multilevel; there are patient-, provider-, institutional-, managed care-, and community-level barriers that affect the achievement of successful outcomes. One such barrier is the high rate of patient attrition from stage 3 weight-management clinics and programs⁷⁻⁹ in both the initial treatment and maintenance phases of these programs.10

Minimizing attrition is crucial for individual patient success. Patient retention in treatment is also critical for weight-management programs to be able to demonstrate improved out-

comes, to optimize the use of staff, and for continuing quality improvement. A small but significant literature exists regarding patient-level predictors of attrition. Common predictors of attrition include Medicaid status, black ethnicity, older age, depression, lower self-concept,8 elevated parental BMI, race/ethnicity,9 overall health status, overall quality of care, difficulty with medical insurance coverage, location and timing of program visits, unfulfilled parental expectations, and a child's desire to leave the program.7,11 In the adult literature, women who had more previous weight-loss attempts were more likely to not complete a program.¹² It is possible that caregivers who have made multiple attempts at weight loss might negatively affect their child or adolescent's completion of a pediatric weight-management program. Other possible predictors of attrition include ambivalence around engaging in weight-management treatment, fear of weight bias or stigmatization, cultural incompetence of weight-management providers, and the length of visits. Although experiences of single weight-management programs with patient attrition have been reported, there is a lack of comparison of the methods that multiple clinics and programs use to maximize patient engagement before the first visit and minimize attrition thereafter. In addition, comparison of clinic-based strategies (more likely to be individual patient visits) versus program-based strategies (more likely to be group visits) has not been described.

Therefore, this study's aims were to (1) examine and contrast patient engagement and retention practices among a group of children's hospital—based weight-management clinics and programs through the National Association of Children's Hospitals and Related Institutions (NACHRI) FOCUS on a Fitter Future program, (2) report

FOCUS-group member hospitals' aggregate experience with patient nonattendance at initial and follow-up appointments, and (3) identify common engagement and retention practices among programs with the lowest average nonattendance rates to make recommendations to other pediatric tertiary care facilities with current and future stage 3 programs.

METHODS

The FOCUS-group long-term patient care and family engagement subcommittee met in person and via conference call to design 2 surveys to query colleagues on their practices related to initial and subsequent patient and family engagement at clinic or program visits. Questions regarding the characteristics of these clinics' and programs' initial and maintenance or follow-up period, methods used to minimize attrition during this period, and perceived barriers to patient retention were also included in the surveys. The survey questions were refined, electronically formatted, pilot-tested with several subcommittee members and NACHRI staff, and revised into final form before being sent to FOCUS and non-FOCUS program champions for completion. These program champions were asked to complete separate surveys for weight-management clinics and group-based weightmanagement programs. The survey results were compiled by NACHRI staff and synthesized by the subcommittee co-chairs.

Simultaneously, and in similar fashion to previously convened NACHRI FOCUS groups (eg, pediatric critical care medicine), FOCUS on a Fitter Future member hospitals were asked to identify and develop consensus on a common important patient care topic around which to benchmark their experiences. The topic that received the most consensus among the 15 mem-

ber hospitals was patient engagement at initial clinic visits and patient retention during subsequent clinic visits. NACHRI staff then facilitated a benchmarking project to determine member hospitals' aggregate retrospective and prospective experiences with patient nonattendance at initial and follow-up clinic visits (data from January 2008 through November 2009 are reported).

For this project, FOCUS-group hospitalprogram champions were asked to submit an electronic spreadsheet to NACHRI staff monthly to report the rate of patient nonattendance for initial and follow-up visits. Patient nonattendance was defined as a visit in which the patient and parent/caregiver did not attend and in which the parent/ caregiver did not call before the day of the visit to reschedule. The longterm patient engagement subcommittee co-chairs collaborated with NACHRI staff to determine average initial and follow-up visit nonattendance rates for the reporting period, the number of months in which data were reported, and the average number of clinic visits per month for each FOCUS-group hospital. Survey responses from FOCUS-group member hospitals with average initial and follow-up nonattendance rates lower than the group aggregate average were then examined to search for common characteristics, including common practices designed to minimize patient attrition.

RESULTS

Of the 47 member and nonmember hospitals queried, 24 hospitals responded to the clinic- or group-based program survey, or both (response rate: 51%). Of these hospitals, all 24 completed a survey for weight-management clinics, and 14 hospitals additionally completed a survey for group-based programs.

Patient Engagement and Retention Practices: Clinic and Program Similarities and Differences

Fifty-two percent of the clinics and 43% of the programs were staffed with a specific person to make patient appointments. Some locations also used a centralized scheduling system. The wait for an initial clinic appointment ranged from <1 month to 10 to 12 months, and 58% of the clinics reported an average wait time of [2] months]. Seventy-eight percent of group-based programs reported an average wait time of <2 months. All the clinics and programs involved at least the caregiver with the child, and more than half of them allowed other family members, including siblings, to attend. Eighty-nine percent of the program respondents from programs that allowed siblings reported that the siblings received education about healthy lifestyles when they attended. Seventy-four percent of the clinics and 78% of the programs reported that the frequency of patient visits was biweekly to monthly. Fifty-seven percent of the programs reported seeing patients every 1 to 2 weeks, and 42% reported seeing patients every 3 to 6 weeks.

Hospitals used a variety of methods aimed at maximizing patient and family engagement at initial and follow-up visits. Seventy-nine percent of the clinics and 86% of the programs reminded patients with a telephone call before the patient's initial visit. In addition. many clinics and programs reported using methods such as a staff phone call, printed educational materials, dietitian-only visits, and orientation sessions about the clinic or program to interest patients before the initial visit. Fifty-four percent of the clinics and 79% of the programs gave a reminder before follow-up visits, most often by telephone or with printed educational materials. In addition to staff phone calls, other methods of maintaining patient engagement between clinic and program visits included visits with a personal trainer, fitness club activities, exercise classes, and provision of physical activity and nutrition diaries.

Although 79% of the respondents with group-based weight-management programs reported that their programs had a fixed number of treatment visits. 70% of weight-management clinics had an open-ended policy in which patients were allowed to return for an unlimited number of visits. Most group-based programs allowed patients who had completed the program to reenroll and/or return to the associated clinic. Seventy-one percent of the programs had a defined follow-up or maintenance period; 2 programs (14%) followed patients indefinitely. Incentives or rewards used to enhance patient retention in group-based programs ranged from gift cards to physical activity-promoting games and toys to music downloads. Both clinic and program respondents considered patients ready for discharge if they met their goals and were independently implementing healthy weight strategies.

Clinic and Program Attrition Experiences and Perceived Barriers

For clinic-based programs, the most commonly encountered barriers to patient follow-up were the inability of caregivers to miss work (64%) and transportation difficulties (59%). Other barriers included children having to miss school (55%), the parent or child perceiving no benefit from the visits (36%), and the cost of clinic visits (23%). All 14 weight-management program respondents reported that the parent or child perceived no benefit from the program as a primary barrier. Seven of the 8 (88%) program re-

spondents with a maintenance program stated that the majority of patients did not complete one-half of the maintenance visits. These families were contacted by phone by all programs to determine their reasons for nonattendance.

Benchmarking Patient Attrition and Identifying Successful Practices

The FOCUS-group hospital clinics implemented a benchmarking process to determine patient nonattendance rates for initial and follow-up visits. Monthly data were collected between January 2008 and November 2009. Only clinics that reported a minimum of 6 months of benchmarking data were included in the analysis. The mean reporting period for benchmarking at initial and follow-up visits was 14.6 months (range: 3-23 months) and 14.8 months (range: 4-23 months), respectively. Clinics saw an average of 40.8 new (initial) patients per month and an average of 76.8 follow-up patients per month. The average rate of patient nonattendance at initial clinic visits was 28.3% (range: 5%-69.3%) and 32.1% (range: 10%-75.7%) for follow-up visits.

The 11 clinics with greater-thanaverage initial and follow-up patient visit attendance shared several common patient engagement and retention practices, which included use of a clinic-specific scheduler, use of reminder phone calls, and involvement of the entire family in the treatment program. The clinics with the lowest initial patient-nonattendance rates reported limiting their capacity to see new patients to <5 per week. Conversely, the clinics with the lowest follow-up patient-nonattendance rates reported that they had the capacity to see >20 follow-up patients per week. The majority of clinics with the lowest initial and follow-up nonattendance

rates did not use methods to engage patients before or after the initial visit. For those clinics that did, this contact was provided via telephone, mailed educational materials, an orientation session, and visits with a registered dietitian. Wait times for new patient appointments among these clinics ranged from 1 to 12 months. The majority of clinics saw patients monthly and would see patients for an indefinite time period. Most of the clinics would allow patients who had completed or not completed their treatment program to return to clinic.

DISCUSSION

The results of this study shed additional light on patient engagement and retention practices in children's hospital pediatric weight-management clinics and programs. The clinics and programs surveyed shared a number of common characteristics including family-targeted interventions, a clinic/ program-specific scheduler, short wait times for initial visits, and biweekly to monthly patient visits thereafter. Common barriers to follow-up for both clinics and programs included treatment schedules that were inconvenient because of school and work commitments and difficulties with transportation. These results are similar to those found by others^{7,11,13} and can prompt programmatic changes such as after-hours clinic or program visits, open-enrollment group programs, and improving families' and providers' knowledge about alternative transportation options such as those that might be offered through insurance.

Although clinics and programs differ in their approach to patient follow-up during treatment and after the treatment has ended, they both measure clinical, behavioral, and psychosocial outcomes. Group-based treatment programs struggle especially with pa-

tient attrition; nearly 90% of them reported that the majority of patients complete fewer than half of the follow-up visits. The identified patient/ family-level barriers to both clinic and program follow-up highlight the need for new and continued efforts to successfully engage patients and families. Programs need to develop a systematic approach to addressing insurance coverage before program onset and should consider local insurer reimbursement patterns in determining program structure.

Initial patient-nonattendance rates for these hospital-based weightmanagement clinics averaged 28%, which is similar to rates found in some pediatric specialty clinics. 14,15 This information is important for clinic and hospital leadership to know to set reasonable expectations for clinic expenses and revenues and to plan for staffing needs. It also points to the need for clinic staff to be in contact with referring primary care providers to potentially enlist them in motivating families to attend these initial evaluations. The majority of clinics had an average wait time of <2 months for a new patient appointment, which is comparable to that of other subspecialty clinics surveyed by the NACHRI.¹⁶ Shared patient engagement and reten-

tion practices of FOCUS-group hospitals with lower-than-average patientnonattendance rates included having a clinic-specific appointment scheduler, using reminder telephone calls, seeing patients monthly for an indefinite time period, allowing patients to return to the clinic after the initial treatment period, and involving the entire family in clinic visits. It is interesting to note that most of these clinics/programs had lengthy initial wait times of 5 to 6 months. It is possible that families place a higher value on these initial visits because they were challenging to obtain. Hospitals with the lowest initial patient-nonattendance rates limited their new patients to <5 per week, which might suggest provision of particularly comprehensive initial visits. Hospitals with the lowest patient-nonattendance rates at follow-up reported the capacity to schedule a larger number of patients, which potentially suggests that patients are able to be seen for follow-up frequently.

Given the well-known difficulty in retaining patients in pediatric weightmanagement programs, this study's findings are relevant and intended to be useful to both new and established programs. The geographic distribution of the children's hospitals surveyed was broad, and the responses represent unique clinics and programs of varying lengths and number of years of experience. Because many of the barriers to engagement and retention were shared among clinics and programs, the opportunity exists to devise solutions that can be generalizable to most programs.

There are limitations to this study. The small sample size indicates that its findings might not be indicative of the majority of stage 3 pediatric weightmanagement clinics and programs in

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the United States. Also, the surveys did not capture all patient engagement and retention practices, and they did not address staff or patient perceptions about the reasons for attrition. Finally, because the outcomes of clinics and programs were not assessed, we could not establish an association between lower nonattendance rates and patient success.

CONCLUSIONS AND RECOMMENDATIONS

Children's hospitals with pediatric weight-management programs are making many efforts to engage and retain patients and families. Despite these efforts, the majority of patients in group-based programs are not completing the entire course of treatment. More emphasis needs to be placed on studying best practices in engagement and retention in clinics and programs, including surveying a larger number of clinics and programs with a more comprehensive instrument and potentially using individual structured interviews. In addition, quantitative and qualitative studies that target parents and children enrolled in these programs should be performed. Eliciting barriers as perceived by obese patients and families is necessary to

provide more acceptable treatment programs. For instance, definitions of treatment success in clinics and programs might differ between families and program staff. The engagement and retention of patients and families is a crucial component in current and future stage 3 obesity programs. New programs should assess and address known clinic/ program- and patient/family-related barriers during program development and subsequently institute quality-improvement measures to minimize attrition and improve patient and program outcomes.

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