

Screening for Childhood Eating Disorders in Primary Care

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Objective: Early identification is essential to reduce disabling complications of eating disorders that occur during stages of bone growth and organ development. This study sought to examine health-screening practices of pediatricians and adolescent medicine physicians in a metropolitan area of the Pacific Northwest.

Method: 70 pediatric and adolescent medicine practices were contacted, 34 (49%) participated, and 20 (29%) returned health forms. Five pediatricians participated in a follow-up focus group. Data collection and analysis occurred between June 2005 and April 2006.

Results: 71% (N = 24) of participating practices relied on clinical interviews to detect eating disorders. Less than half of analyzed health-screening forms included questions specific to eating disorders. A pediatrician focus group revealed barriers to identification of eating disorders.

Conclusion: Fast-paced appointments and patients who withhold information compromise identification of eating disorders in pediatric and adolescent medicine practices. Barriers to detection highlight the need for enhanced professional and parent education, practical changes in screening tools and processes, and more frequent appointments when risk factors are present.

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Children and adolescents with eating disorders develop acute and chronic medical complications affecting multiple organ systems. Starvation and dehydration lead to medical complications more rapidly in children and adolescents than in adults.¹ Profound and disabling complications are possible when malnutrition occurs during normative periods of bone growth and organ development.² Eating disorders are associated with serious biological, psychological, and social morbidities in this age group and are the third leading cause of chronic illness in adolescent females.³

The treatment team at Kartini Clinic, a regional center for disordered eating in the Pacific Northwest, questioned why many children and adolescents were presenting for first evaluations with symptoms sufficient to warrant hospitalization. The need for hospitalization is an indication of organ compromise, as evidenced by hospital admission criteria. The American Academy of Pediatrics provides guidelines for hospitalization of youth with anorexia nervosa, including weight loss below 75% of that expected for health, bradycardia less than 50 bpm daytime or 45 bpm nighttime, systolic blood pressure below 90 mm Hg, orthostatic changes in pulse or blood pressure, body temperature less than 96°F, and/or cardiac arrhythmias.⁴ Hospitalization associated with bulimia nervosa is based on additional criteria, which include electrolyte imbalance (potassium and/or chloride), syncope, hematemesis, intractable vomiting, and/or esophageal tears.⁴ When an eating disorder is not detected until the child or adolescent requires hospitalization, the medical complications are more likely to produce chronic and disabling effects. For example, bradycardia, syncope, and hypotension are associated with cardiovascular compromise that can jeopardize return to normal cardiac capacity. Weight below 75% expected for health affects bone cell synthesis, increasing the risk for osteopenia, premature osteoporosis, and stunted growth. This degree of nutritional compromise also affects brain protein synthesis, thereby thwarting brain development and functioning and increasing the risk of cerebral atrophy.

In order to discover barriers to early detection of eating disorders in children and adolescents, a survey of pediatric and adolescent medicine screening practices was undertaken by the Kartini Foundation, which has a research mission in affiliation with the Kartini Clinic (both are located in Portland, Ore.). The Northwest Health

Foundation (Portland, Ore.) provided funding for this study. The aim of this study was to examine methods used in primary care to screen for eating disorders and identify opportunities to improve early-stage identification of these disorders. Analysis of survey data contributed to additional questions about obstacles experienced by pediatricians and adolescent medicine physicians in the context of their busy practices. A follow-up focus group was convened to explore perceptions of practice barriers that contribute to delayed identification.

METHOD

Methods for this study included a survey and analysis of printed health questionnaires used by pediatric primary care practices and a follow-up focus group interview with pediatricians. Practice surveys and health questionnaires were analyzed for evidence of questions specific to eating disorders. The variables and coding scheme were established prior to the analysis. Returned surveys and health questionnaires were assigned unique identification numbers, and practice logos were removed so that coders were blind to practice identities. This survey research was reviewed and found exempt from human subjects considerations by the Institutional Review Board of Oregon Health and Science University. Data collection and analysis occurred between June 2005 and April 2006.

Participants and Procedure

The study sample was identified from a list of pediatric and adolescent medicine practices supplied by the Oregon Medical Association. Practices with addresses in the targeted metropolitan area of the Pacific Northwest were selected for contact. An initial telephone contact was made prior to mailing the survey. The initial telephone contact offered information about the study, invited participation, and alerted office staff to watch for materials being sent by mail. Two attempts at telephone contacts were made, and when it was not possible to talk with office staff directly, messages were left on answering machines explaining the research project and inviting a return call to the research team. Packets were subsequently mailed to 70 pediatric and adolescent medicine practices and included a survey, a request for returned health screening forms, and a stamped self-addressed envelope. Packets were returned by 34 practices (49% overall response rate). Of those who returned packets, 14 responded to the survey only, and 20 returned both the survey and copies of their health forms (29% response rate for health forms). Data from returned surveys and health forms were coded and analyzed.

Participating practices were predominantly private clinics serving general pediatric populations (74%, $N = 25$). Other practices included university- and hospital-affiliated clinics (18%, $N = 6$) and a small portion of specialty pediatric clinics (9%, $N = 3$).

Pediatricians who responded to the survey portion of the study were subsequently invited to participate in a focus group interview to explore, in greater depth, the barriers to eating disorder screening in primary care. Seven pediatricians accepted the invitation, but 5 actually participated in the focus group (4 females and 1 male). Open-ended questions were constructed to focus the interview on pediatricians' perceptions of barriers to eating disorder screening in their practices. As ideas were introduced by participants, less structured interviewing encouraged exploration of ideas among participants. An audio recording was made of the 1.5-hour interview, and the audio tape was transcribed into text. Three reviewers independently read the transcript and identified major underlying themes. Themes identified by individual reviewers were pooled and submitted for further analysis to arrive at common themes. Following this process of theme extraction, the principal investigator (J.E.D.) returned to the interview text to develop descriptions of the common themes based on participant comments. Six themes and descriptions are presented in the Results.

Survey Variables and Coding

Eighteen variables were coded on the basis of data identified on returned surveys and health questionnaires from primary care practices. Variables included demographic information about the practice settings, such as practice type, and methods used by practices to gather health information about patients. Twelve variables were specific to eating disorder screening. Eating disorder variables included history of weight loss, body/weight satisfaction, efforts to control weight with diet, food preoccupation, hiding food, skipping meals, discomfort when eating in front of others, eating together as a family, change in exercise, history of vomiting, and missed menstrual periods. Variables were coded in the following manner: if a health questionnaire had any question about the child's efforts to control his or her weight with diet, for example, then the variable was coded as "yes" or 1. If there were no questions related to the child's efforts to control his or her weight with diet, the variable was coded as "no" or zero.

Statistical Analysis

Descriptive statistics were computed and used to describe the sample and the methods of health screening used by primary care practices. Frequencies were used to report proportions of returned surveys and health questionnaires that had items specific to eating disorder screening.

RESULTS

Survey

Of 34 participating practices, 27 (79%) reported using forms or questionnaires to gather health information from

patients and their parents. More practices identified using forms with new patients (25 of 34) than did those using health forms to update records of existing patients (18 of 34). Additionally, 71% (N = 24) gathered information about child or adolescent eating patterns through clinical interviews during office visits. However, when asked how many eating-disordered patients were identified in their practices during the past year, the numbers reported were very small relative to practice size, with most practices reporting only 1 or 2 patients identified during the previous year.

Analysis of the 20 returned health-screening forms identified only 2 questions potentially associated with eating disorders included on 50% of the forms (i.e., questions about vomiting and questions about exercise). Eight returned forms (40%) included questions that elicited information about last menses for girls, history of weight gain or loss, and efforts to control weight with diet. Seven forms (35%) included a question about satisfaction with body weight and size. None of the forms included questions about skipping meals on purpose, discomfort when eating in front of others, hiding food, or eating meals together as a family.

While health forms were used to collect patient information in 79% (N = 27) of participating practices, only half of analyzed forms included any questions specific to eating disorders. Questions about vomiting and exercise were included on 50% (N = 10) of the analyzed forms, but these questions are not specific to eating disorders. The key diagnostic features of anorexia nervosa include refusal to maintain weight greater than or equal to 85% expected for health, intense fear of gaining weight, 3 months of amenorrhea, and preoccupation with weight or shape in self-evaluations.⁵ Two of these diagnostic indicators (menses and weight loss) were screened on 40% (N = 8) of the analyzed health forms, but questions related to other diagnostic criteria specific to eating disorders were rarely or never included. Survey responses indicated that health forms alone did not provide a complete picture of screening practices related to these conditions. The majority of respondents (71%) used clinical interviews to detect signs and symptoms of anorexia or bulimia.

Focus Group

The 5 pediatricians who participated in the focus group interview expressed appreciation for the opportunity to share their concerns about detecting eating disorders in their patients. They described conditions in busy pediatric practices that serve as barriers to early eating disorder identification and enlisted ideas from each other about how to improve their ability to detect these patients and counsel their parents. Six common themes were extracted from the transcribed text of the focus group interview. These findings are considered preliminary in light of the small number of focus group participants.

Theme 1: Uncertainty delays time between recognition of risk and referral. Focus group participants readily identified children and adolescents in their practices who were at risk for eating disorders but had not been referred for evaluations. Recognized risk factors included having a sibling or parent with an eating disorder, having a parent who was excessively focused on his or her child's body mass index or weight, and children or adolescents who displayed obsessive preoccupations regarding their bodies, exercise, or nutrition. Participants expressed reluctance to discuss these risk factors with adolescents and their parents unless their "suspicions" of risk were associated with definitive signs and symptoms. With heritability estimates of 70% for anorexia nervosa and 60% to 62% for bulimia nervosa,^{2,6} there is a reasonable possibility that the adolescent at risk for an eating disorder will also have a parent or family member affected by an eating disorder. Without sufficient physical evidence to back up their concerns, focus group participants voiced reluctance to address the topic of eating disorders for fear of provoking adolescent and parent anxiety and defensiveness.

Theme 2: Practice pace, brief appointments, and acute focus deter exploratory discovery. The typical appointment frequency in a busy pediatric practice is 1 patient every 10 to 20 minutes, with 25 or more children and adolescents seen in a day. Most appointment schedules do not allow time for exploratory interviewing as a method of diagnostic screening. Additionally, pediatric practices are set up to anticipate acute symptoms such as pain, fever, rashes, sore throats, and influenza. Most illnesses are detected by brief, focused physical examinations and laboratory tests. Eating disorders are not among the "top chief complaints" brought to pediatricians and adolescent medicine physicians, and they rarely fall in the anticipated "acute illness" category until late-stage symptoms emerge. Few patients are brought to the pediatrician specifically for an eating disorder until late-stage manifestations prompt alarm in parents. The signs that bring patients in and alert pediatricians to pursue an eating disorder include extreme weight loss, amenorrhea, and syncope. These are late-stage manifestations that are usually preceded by a period of behavioral signs such as restricting the range of acceptable foods, reducing meals and portion sizes, and increasing preoccupation with food preparation, body appearance, and exercise. A difficulty in identifying prepubescent eating disorders is the inability to use amenorrhea as a criterion. Additionally, many adolescents and parents forestall recognition of eating disorders even after bradycardia and amenorrhea are present, deferring to the belief that "athletes develop low pulse rates and female athletes often miss their periods." In order to recognize the progressing course of an eating disorder, health practitioners must uncover and connect signs and symptoms and detect patterns the adolescent may try to conceal.

Table 1. Parent Questions to Help Pediatricians Identify the Need for Focused Eating Disorder Screening^a

1. Have your child's eating habits changed recently?	Yes	No
2. Do you have any concerns about your child's weight?	Yes	No
3. Has your child expressed any concerns about his/her weight?	Yes	No
4. Has the amount of time your child spends exercising changed recently?	Yes	No
5. Does your family eat dinner together at the table at least 4 times a week?		
6. What did your child eat for dinner last night?		

^aA "Yes" answer to any of the first 4 questions should prompt further eating disorder screening, including questions 5 and 6.

Theme 3: Talking interviews take unscheduled time.

Early in their stages of illness, adolescents with emerging eating disorders may visit their pediatricians and primary care physicians for reasons other than disordered thoughts and reactions to food and body image. Identification of early-stage eating disorders necessitates a process of "discovery" that may take longer than a 15-minute appointment slot. This "discovery" process requires pediatricians to investigate beyond the adolescent's presenting complaints with exploratory interviewing. Busy clinic practices rarely have leeway for appointments that run overtime. Some focus group participants preserved blocks of time at the end of the day to accommodate more extensive discussions with complex patients. While an adolescent with a suspected eating disorder might be asked to come back for an extended time slot, focus group participants acknowledged lack of confidence in employing interview techniques that could prompt disclosure of eating disorder thoughts and behaviors. When focus group participants assessed an adolescent to be at risk for an eating disorder, they were more likely to make a referral to a counselor or nutritionist rather than to an eating disorder clinic for evaluation. Some participants believed it was necessary to confirm an eating disorder diagnosis before referring a child or adolescent to a specialty clinic for evaluation. Reluctance to communicate concerns to parents and adolescents about risk factors and waiting until sufficient criteria for diagnosis are present thus contribute to delays in referrals for eating disorder evaluations. Focus group participants requested information about medical diagnoses, such as osteopenia, that could be used to justify referrals for eating disorder evaluations.

Theme 4: Insurance and practice standards confound timely detection. Timely detection of eating disorders is confounded by practice standards and insurance payments that specify well-child visits once every 2 years unless the child or adolescent is acutely symptomatic. Within 3 to 6 months, an adolescent with an eating disorder can progress from no overt physical signs to the need for hospitalization. Thus, an adolescent with an emerging eating disorder could be asymptomatic at 1 visit and seriously compromised by the next.

Theme 5: Societal attitudes subvert attention from thinness to obesity. The current societal focus is on obesity. Health practitioners are admonished for not promoting dieting and exercise. Loss of weight is viewed as a sign of fitness and health improvement and is generally not associated with illness until it is dramatic. Thus, primary care providers and families may initially praise and encourage the adolescent's weight loss and exercise. Even when weight loss becomes excessive, parents are rarely as alarmed as they would be if their child showed signs of other serious disabling diseases. In our society, there is reluctance to view eating disorders as serious heritable diseases with devastating and disabling consequences. When parents become aware of the serious medical consequences of their child's undetected eating disorder, they are often bewildered and angry. In retrospect, parents may blame the primary care physician, whom they entrusted to safeguard their child's health, for missing early signs of these disorders.

Theme 6: Experiential sensitization prompts heightened attention to screening. Focus group participants reported they were more likely to be alert for eating disorders and other symptoms if they had experienced a patient in their practice who became very ill or disabled by an eating disorder. Experience thereby sensitized pediatricians to the need for aggressive targeted screening for early identification of these disorders.

Focus group participants recommended the following improvements in health screening for eating disorders in children and adolescents: (1) develop sensitively framed information packets for pediatric and adolescent medicine practices to distribute to parents of prepubertal children (aged 10 to 12 years) and adolescents (aged 13 to 19 years), identifying early signs of eating disorders and offering tips about what parents can do; (2) expand medical education about eating disorders, including how and when to recommend specialty evaluations for the child or adolescent who presents with risk factors; (3) increase pediatrician and adolescent medicine physician awareness of the availability of specialty clinics in which eating disorder evaluations are routinely conducted; (4) develop brief screening questionnaires for eating disorder risks to be completed by parents when they check their child/adolescent in for routine well-child and medical appointments (Table 1); (5) increase the knowledge and sensitivity of staff responsible for completing pre-physician/practitioner assessments of patient height, weight, and vital signs; (6) schedule return appointments in 3 weeks whenever risks for eating disorders are suspected; and (7) introduce practice changes through a practice "gatekeeper," the person within the practice who is in the best position to shepherd changes through the organization and understands the dynamics of the practice. The practice gatekeeper is likely to differ among practices; sometimes, it may be the office manager or nurse manager, and sometimes, it is a pediatrician in

the practice who has a keen interest in promoting practice improvements related to eating disorders.

DISCUSSION

Analysis of processes of health screening in pediatric primary care provided insights into barriers to early detection of eating disorders in children and adolescents. While 79% of participating practices reported using questionnaires to gather health information from new patients, only half of practices in this sample used health forms to routinely update health information for existing patients. This can be problematic for families who identify their pediatric providers soon after their children are born and continue with the same providers through adolescence. Without the routine use of health questionnaires to elicit specific health information and concerns, pediatricians are limited to clinical interviews as the primary means of detecting childhood-onset eating disorders. The combined factors of busy clinic practices and patients who typically withhold information to avoid detection generate concerns about the reliability of clinical interviews as the primary method of screening for these disorders. Waiting for physical parameters such as bradycardia and syncope to appear on physical examinations can delay identification until organ compromise has occurred. While most pediatricians would readily identify a severely emaciated child or adolescent with an eating disorder, children and adolescents who binge and purge may not display significant weight changes, and those in early stages of restricting anorexia may look healthy during the physical examination but be severely compromised within 3 months, long before their next scheduled well-child appointment. Unless questions specific to anorexia or bulimia are asked during the clinical interview and/or are included on health forms, children and adolescents with these disorders can escape detection.

In retrospect, children and parents often describe the onset of the eating disorder as marked by a change in the child's food choices and attitudes about his or her body. The course of the disorder is often heralded by the child's decision to "start eating healthy" and "get fit," decisions parents and practitioners may encourage. Parents who are sensitive to their children's increasing modesty during school-age and adolescence may not notice the progressive deterioration in their child's appearance or become alarmed until they inadvertently see their child wearing little or no clothing. The busy schedules of many families with school-age children and adolescents result in few opportunities for families to sit down and eat meals together, opportunities that allow parents to notice changes in the child's or adolescent's eating patterns and preferences. Compounding the challenge of relying on parents to bring concerns to pediatric providers is the high rate of heritability associated with these disorders. Children and adolescents at risk for eating disorders have a greater likelihood

of living with a parent or family member who shares their anxieties about eating and body size.

Children and adolescents in early stages of eating disorders are unlikely to ask their parents or health providers about the risks of restricting dietary intake, purging, or compensatory exercise. They are more inclined to hide their eating disorders from adults and to avoid or deflect nonspecific questions. Thus, nonspecific questions during a clinical interview might not alert the health provider to the need for in-depth exploration of a child's eating disorder thoughts and behaviors. For example, responses to general questions about "exercise" or "weight" might divert the health provider's focus to screening for obesity-related problems. Concerns about missed periods might focus the clinical discussion on topics of sexuality or pregnancy.

Results from this study contribute to increased awareness of barriers to early identification of children and adolescents with eating disorders and thereby increase attention to the importance of screening for these disorders in primary care. These findings provide preliminary data for further research with larger samples. Weaknesses of this study include the limited geographic distribution of the survey and the small number of focus group participants. Surveys and focus groups should be extended to include office managers and nurses in pediatric practices, pediatric nurse practitioners, school health professionals, and sports medicine practitioners, who also have opportunities to identify and refer children and adolescents in early stages of eating disorders.

CONCLUSIONS

Fast-paced appointments, anticipation of defensive reactions, infrequency of well-child appointments, and patients who withhold information to avoid detection may compromise screening methods for eating disorders in pediatric and adolescent medicine practices. Barriers to early detection highlight the need for enhanced professional and parent education, practical changes in health screening tools and processes, and more frequent appointments during which risk factors are identified.

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