



Eating Disorders

The Journal of Treatment & Prevention

ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/uedi20>

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To cite this article: Anna C. Ciao, Jocelyn Lebow, Erin VandenLangenberg, Olivia Ohls & Kelly C. Berg (2022) A qualitative examination of adolescent and parent perspectives on early identification and early response to eating disorders, *Eating Disorders*, 30:3, 249-266, DOI: [10.1080/10640266.2020.1805960](https://doi.org/10.1080/10640266.2020.1805960)

To link to this article: <https://doi.org/10.1080/10640266.2020.1805960>



Published online: 31 Oct 2020.



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A qualitative examination of adolescent and parent perspectives on early identification and early response to eating disorders

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ABSTRACT

This qualitative study examined adolescent and caregiver perspectives on identification and early response in emerging eating disorders. Fifteen female-identified adolescents with an eating disorder diagnosis (*M* age = 15.20 years; 93% White; 20% Hispanic) and 12 caregivers (all biological parents: 1 father, 11 mothers; *M* age = 51.56 years) participated in semi-structured interviews about their experience identifying and responding to the eating disorder, eventually seeking treatment. Participants were recruited from three eating disorder treatment centers in the United States. Interview responses were coded by three raters using inductive consensual qualitative methods. Results found that parents were typically the first to notice and confront the eating disorder, and weight loss and thinness usually were the earliest symptoms identified. The most common adolescent response to detection was mixed (e.g., relief and anger), and common parental reactions included seeking professional consultation and creating limitations on disordered behaviors (e.g., encouraging eating). Barriers to earlier detection were highlighted (e.g., parental hesitancy to act on suspicions), suggesting that parents need greater support for swift and confident responding. To combat this, parents recommended increasing knowledge of eating disorder symptoms. Parents and adolescents both recommended parent-led monitoring of eating and exercise behaviors to increase the chance of noticing changes and responding quickly with aggressive and supportive action. These experiences provide a framework for early identification and the role of caregiver response, highlighting the need for assertive yet compassionate efforts to combat emerging eating disorders.

Clinical implications

- Caregivers are well-situated to identify and respond to emerging eating disorders
- Individuals outside of families also can detect symptoms
- Adolescents and caregivers suggest compassionate yet assertive confrontation of symptoms
- A mixed emotional response is common when the eating disorder is identified
- “Missed opportunities” and uncertainty are common barriers to detecting eating disorders in adolescence
- Greater knowledge of eating disorder symptoms and monitoring of individual behaviors could promote earlier identification of symptoms

Early intervention on eating disorder symptoms is an essential step to reducing the overall morbidity and mortality of eating-related illnesses. Earlier intervention has been linked to better outcomes, particularly for child and adolescent eating disorders; young people who receive interventions soon after their eating disorder begins have the greatest odds of achieving recovery (e.g., Le Grange et al., 2012). Among youth, interventions led by parents are the most effective for promoting eating disorder recovery (e.g., Lock et al., 2010), and caregiver-driven interventions that target the early stages of illness (e.g., when serious symptoms first become consistent) may be most effective in disrupting eating disorder symptoms before they become entrenched within the individual and the family system. And yet, caregivers report that early identification and swift action against eating disorders is quite difficult.

For example, research shows that it can take a family an estimated 11–20 months from symptom onset to detect and seek treatment for an adolescent eating disorder (Lebow et al., 2015). Parents describe that it is hard to identify eating disorder symptoms during initial phases of the illness (Cottee-Lane et al., 2004). In the early phases, eating disorder behaviors (e.g., dietary restriction) and cognitions (e.g., body image concerns) are often subtle, idiosyncratic, or may be mistaken for temporary, normative adolescent behaviors. As parents grapple with uncertainty about whether symptoms are extreme enough to warrant treatment (Golden et al., 2003), the eating disorder may become more severe. Given that caregivers are the ideal interventionists once a child or adolescent eating disorder has begun (e.g., Anastasiadou et al., 2014; Lock et al., 2010; Nicholls & Yi, 2012), it is logical to expect that with adequate information and support, they are well-placed to catch earliest eating disorder symptoms.

In particular, some of the patient-level barriers to seeking eating disorder treatment, such as lack of recognition of symptoms, low motivation to change,

and support for finding help (Ali et al., 2017) can likely be overcome by leveraging caregivers to identify symptoms and initiate help-seeking. While the need for this type of community-based “first aid” against eating disorders has been recognized (e.g., Hart et al., 2009), there is a lack of research on caregiver-supported first aid, specifically. It is still mostly unknown exactly how to best overcome hesitations when disorders are first emerging and empower caregivers to take assertive action against symptoms.

One key difficulty lies in determining exactly when to intervene. If eating disorders are conceptualized on a continuum, with high risk symptoms at one end and severe and enduring illness at the other (Treasure et al., 2015), it not clear where early interventions should occur. Existing research tends to either target subthreshold symptoms (i.e., early intervention for “at risk” individuals; e.g., Jacobi et al., 2012; Ohlmer et al., 2013) or “new” cases (i.e., early intervention shortly after the eating disorder has been identified; e.g., Jones et al., 2012; Nicholls & Yi, 2012), which does not guarantee that the eating disorder *is* new, just that it was recently detected. Both of these approaches can disrupt the trajectory of symptom development, and research shows that caregivers can be trained to intervene once disorders are recognized (Jones et al., 2012; Nicholls & Yi, 2012). And yet both perspectives may miss a critical—and potentially lengthy—developmental period of emerging disorders where early intervention could occur: where eating disorder *risk* (e.g., body dissatisfaction) transitions to specific eating disorder *symptoms* (e.g., severe dieting). This transitional period of emerging symptoms may last months or years (Lebow et al., 2015), and training caregivers to catch the earliest symptoms possible and intervene with confidence during this period seems like an ideal target for early intervention efforts.

The current study aimed to address this gap in knowledge: to provide information about the period where eating disorders are first emerging, and to generate ideas about how to support caregiver-led early identification and early response efforts. Interviews solicited adolescent and caregiver perspectives surrounding two research questions: (1) What actions do families take to first identify an eating disorder and stop its progression? and (2) What advice do families have for earlier identification and response to eating disorder symptoms?

Method

Procedure

Recruitment and selection

Adolescents (ages 12–18) and their caregivers were recruited through patient contact lists and with flyers in three psychiatric treatment centers in the United States. All centers offered specialty outpatient treatment for eating

disorders (one also offered intensive and residential treatment). Eligible participants had been diagnosed with an eating disorder through their treatment facility and were either in current outpatient psychotherapy or had recently completed outpatient treatment. Adolescents who were currently in psychotherapy were required to be past the initial stage of treatment (e.g., past aggressive weight restoration in Phase 1 of Family-Based Therapy). Dyadic participation was not required; adolescents were eligible to participate without their caregivers, and vice versa. Parents provided consent for adolescent participation as well as their own; assent was also obtained from all adolescent participants. All participants were compensated with a gift card. All research procedures were approved by on-site Institutional Review Boards.

Interviews

Adolescents and caregivers were interviewed separately in one-hour semi-structured interviews. Five interviewers across the three sites were involved in clinical care and may have had prior contact with participants either as clinical assessors or therapists; three interviewers also were involved in the coding process (described below). Initial interview prompts were shaped by research questions and asked about early eating disorder symptom development as well as identification and early response (e.g., “Did anyone around you know about the eating disorder? What did they do or say?”) and advice for clinicians and caregivers (e.g., “Based on your own experience, what advice do you have for family members who want to encourage their loved ones to get help?”) Optional follow-up question prompts were listed in the interview script and used at the interviewer’s discretion. The full interview scripts are available on the first author’s Open Science Framework website https://osf.io/bj9xp/?view_only=b41ae3ecf68e4ef7bcaad3ab721e31c6. The current study focuses on the responses to the research questions about identification, response, and advice.

Assessment

Following their interviews, adolescents completed the Eating Disorders Examination-Questionnaire (EDE-Q; Fairburn & Beglin, 1994). Eating disorder diagnosis and treatment information (e.g., the number of sessions completed, type of intervention) was pulled from the clinical file and verified by parents at the start of interviews. Parent surveys completed after the interview asked for other clinical information about their child (eating disorder onset and diagnosis date, comorbid mental health diagnoses, and medication history). For adolescents who participated without their parents ($N = 4$), relevant information was pulled from clinical files, which typically was reported by the patient or their caregiver during the intake assessment.

Participants

Interviews were completed with 15 female-identifying adolescents (M age = 15.20 years, SD = 1.81) and 12 caregivers (all biological parents: 1 father, 11 mothers; M age = 51.56 years, SD = 5.81). Four adolescents participated without their parents, and one parent participated without their child; the remaining participants were adolescent-parent dyads (N = 11 dyads). Adolescents identified as primarily White and non-Hispanic (N = 11) with one participant self-identifying as Black and Non-Hispanic and three identifying as White and Hispanic. Ten of the adolescents were diagnosed with Anorexia Nervosa, one with Bulimia Nervosa, three with Other-Specified Feeding or Eating Disorder, and one with Avoidant/Restrictive Food Intake Disorder. About half had completed eating disorder treatment (N = 7; EDE-Q Global M = 0.60, SD = 0.88); the others were in the later stages of treatment (N = 8; EDE-Q Global M = 2.26, SD = 2.11). The adolescent who was the focus of the sole parent interview also had a diagnosis of AN and had completed treatment. On average, at the time of the interviews, around two years had passed since the parent-reported onset of eating disorder symptoms (M = 26 months, SD = 12 months; range = 10–48 months). Over half of adolescents (N = 9) had a comorbid anxiety or depressive disorder diagnosis. [Table 1](#) includes individual participant demographic and clinical information.

Data analysis

Data analysis followed three-coder modified consensual qualitative research procedures established by Hill and colleagues (Hill et al., 2005, 1997). The members of the coding team each had at least three years of experience in eating disorders research and clinical work (range of experience was 3–15 years). At each step, inductive coding was first done individually by three raters and then coder consensus was achieved through discussion of discrepancies until agreement was reached before moving to the next task. Coding was conducted separately for adolescent and parent transcripts in teams of three, with two coders consistent across the coding teams.

First, individual interview transcripts were reviewed and reorganized by responses linked to each primary research question: (1) how the eating disorder was identified and the initial response, and (2) advice for early detection and early response. Next, domains were established via consensus to represent primary topic areas within each research question. Then, each transcript component was assigned to one or more domain, with use of a “miscellaneous” category for sections of transcript that did not fit into an existing domain. Domain assignments were finalized via consensus and the miscellaneous domain was reviewed for any potential re-assignment to an existing domain or the creation of a new domain. Once domain assignments

Table 1. Demographic and clinical characteristics of adolescent and caregiver participants.

Adolescent Age	Race and Ethnicity	Eating Disorder Diagnosis	Adolescent Interview?	Parent Interview?	Parent Age	Illness Duration (months)	Comorbidity	EDE-Q Global	Completed Treatment?
17	White, Hispanic	AN	Yes	–	–	12	None	0.14	No
12	White, Non-Hispanic	AN	Yes	Yes	51	21	None	1.41	No
16	White, Non-Hispanic	AN	Yes	Yes	53	10	None	0.32	No
16	White, Non-Hispanic	AN	Yes	Yes	57	21	None	0.73	Yes
13	White, Non-Hispanic	AN	Yes	Yes	52	16	None	0.00	Yes
14	White, Non-Hispanic	AN	Yes	Yes	40	17	None	0.77	Yes
15	White, Non-Hispanic	AN	–	Yes	49	29	None	–	Yes
15	White, Non-Hispanic	AN	Yes	Yes	47	16	Depression, Anxiety	0.45	No
15	White, Non-Hispanic	OSFED	Yes	–	–	28	Depression, Anxiety	5.41	No
17	White, Non-Hispanic	AN	Yes	Yes	63	42	Depression, Anxiety	1.64	No
15	White, Non-Hispanic	OSFED	Yes	Yes	45	24	Depression, Anxiety	4.23	No
18	White, Non-Hispanic	OSFED	Yes	Yes	52	10	Depression, Anxiety	2.45	Yes
17	White, Hispanic	BN	Yes	Yes	57	21	Anxiety	4.45	No
17	White, Hispanic	AN	Yes	–	–	28	Anxiety	0.18	Yes
16	Black, Non-Hispanic	AN	Yes	–	–	17	Depression	0.05	Yes
12	White, Non-Hispanic	ARFID	Yes	Yes	45	48	Anxiety	0.05	Yes

AN = Anorexia Nervosa; BN = Bulimia Nervosa; OSFED = Other Specified Feeding and Eating Disorder; ARFID = Avoidant Restrictive Food Intake Disorder

were completed, transcripts (now reorganized by domain codes) were reviewed to generate and assign categories and sub-categories, or key ideas across participants within each domain.

To summarize findings, the representativeness of each theme was captured using participant number according to adapted criteria from Hill et al. (1997, 2005), where “general” themes were endorsed by all or most of the cases (> 90%); “typical” themes were endorsed by more than half of the cases (50–89%); “variant” themes were endorsed by fewer than half of the cases (20–49%); and “rare” themes were endorsed by few cases (< 20%).

After the initial coding process was complete, an independent “auditor,” who had no part in the prior coding process or any of the interviews, reviewed all coding decisions using a document of research questions, domains, and categories (and sub-categories, if applicable), with relevant transcript segments included. The auditor challenged unclear or potentially non-representative coding decisions and made suggestions for modifying coding labels. The entire team reviewed and discussed the auditor’s suggestions and agreed on changes, returning to the raw data when necessary. After both adolescent and parent coding was complete, the coding team revisited and revised research questions, domains, and categories until all felt confident that the analysis across participants (and across adolescent and parent coding systems) was a good representation of the data. The data that support the findings of this study are not publicly available due to privacy or ethical restrictions but are available on request from the corresponding author.

Results

Results are presented in response to the two research questions: (1) How was the eating disorder identified? and (2) What advice do you have for early detection and early intervention? Headings and bolded text reflect domains. The results below focus on general themes (endorsed by > 90% of cases) and typical themes (endorsed by 50–89%) in domains and categories across parental and adolescent interviews. “Rare” (endorsed by < 20% of cases) and “variant” themes (endorsed by 10–49%) are occasionally presented to illustrate the range of responses. Full results are presented in [Tables 2](#) and [3](#).

How was the eating disorder identified?

First to notice

Both parents and adolescents typically identified parents (usually mothers) as the **First to Notice** the eating disorder (60% of adolescents, 83% of parents). Interestingly, across the two samples, a variety of other individuals were

Table 2. Themes across how the eating disorder was identified.

Adolescent Responses				Parent Responses			
Domain/Category	n	%	Descriptor	Domain/Category	n	%	Descriptor
Domain 1. First to Notice	15	100%	General	Domain 1. First to Notice	12	100%	General
Category 1. Parent	9	60%	Typical	Category 1. Parents	10	83%	Typical
Category 2. Peer/Friend	7	47%	Variant	Category 2. Teen	4	33%	Variant
Category 3. Other Authority Figure	5	33%	Variant	Category 3. Other Adult	3	25%	Variant
Category 4. Other Family Member	4	27%	Variant				
Domain 2. First to Confront	13	87%	Typical	Domain 2. Others Who Noticed	11	92%	General
Category 1. Parents	13	87%	Typical	Category 1. Family Member	4	33%	Variant
Category 2. Other Authority Figure	4	27%	Variant	Category 2. No one else	4	33%	Variant
Category 3. Physician	3	20%	Variant	Category 3. Other Adult	4	33%	Variant
Category 4. Self	2	13%	Rare	Category 4. Adolescent's Friend	2	17%	Rare
Domain 3. Symptoms Prompting Identification	15	100%	General	Domain 3. Symptoms Prompting Identification	11	92%	General
Category 1. Weight Loss/Thinness	8	53%	Typical	Category 1. Weight Loss/Thinness	8	67%	Typical
Category 2. Extreme Eating and Exercise	7	47%	Variant	Category 2. Extreme Eating and Exercise	7	58%	Typical
Category 3. Unclear or Unspecified	3	20%	Variant	Category 3. Other Physical Symptoms	3	25%	Variant
Category 4. Other Physical Symptoms	2	13%	Rare	Category 4. Miscellaneous	2	17%	Rare
Domain 4. Parent Responses	13	87%	Typical	Domain 4. Parent Responses	11	92%	General
Category 1. Consultation	9	60%	Typical	Category 1. Approaching/addressing child	8	67%	Typical
Category 2. Encouraged Eating	8	53%	Typical	Category 2. Consulting a professional	7	58%	Typical
Category 3. Books/Research	2	13%	Rare	Category 3. Research	5	42%	Variant
Domain 5. Barriers to Action	13	87%	Typical	Domain 5. Barriers to Action	11	92%	General
Category 1. Failure to Act	9	60%	Typical	Category 1. Symptoms overlooked/missed	10	83%	Typical
Category 2. Symptoms Overlooked	7	47%	Variant	Category 2. Lack of Knowledge/Resources	6	50%	Variant
Category 3. Symptoms Minimized	5	33%	Variant	Category 3. Others Noticed but Didn't Say	2	17%	Rare
Category 4. None	4	27%	Variant	Category 4. External Stressors	2	17%	Rare
Domain 6a. Adolescent Response to Confrontation	14	93%	General	Domain 6. Adolescent Response to Confrontation	11	92%	General
Category 1. Mixed	10	67%	Typical	Category 1. Resistance	7	58%	Typical
Category 2. Negative	7	47%	Variant	Category 2. Neutral/Acceptance	3	25%	Variant
Category 3. Denial	6	40%	Variant	Category 3. Positive	2	17%	Rare
Category 4. Positive	5	33%	Variant				
Domain 6b. Others' Response to Identification	5	33%	Variant				
Category 1. Increased Monitoring	3	20%	Variant				
Category 2. Minimize	2	13%	Rare				
Category 3. Discouraged Eating Disorder	2	13%	Rare				

Table 3. Themes across advice for early identification and early intervention.

Adolescent Responses				Parent Responses			
Domain/Category	n	%	Descriptor	Domain/Category	n	%	Descriptor
Domain 1. Notice Changes in Your Child	15	100%	General	Domain 1. Notice Changes in Your Child	10	83%	Typical
Category 1. Notice Eating Related Changes	12	80%	Typical	Category 1. Notice eating-related changes	8	67%	Typical
Category 2. Notice Other Behavior Changes	10	67%	Typical	Category 2. Notice other Behavior Changes	8	67%	Typical
Category 3. Look for Body Dissatisfaction	11	73%	Typical	Category 3. Notice weight loss	4	33%	Variant
Category 4. Look for Physical Changes	4	27%	Variant				
Domain 2. Take action	14	93%	General	Domain 2. Take action	11	92%	General
Category 1. Be Supportive	13	87%	Typical	Category 1. Be Assertive/Push	9	75%	Typical
Category 2. Unsupportive Responses	13	87%	Typical	Category 2. Don't Wait/Be Proactive	7	58%	Typical
Category 3. Don't Wait/Be Proactive	10	67%	Typical	Category 3. Form a Team	5	42%	Variant
Category 4. Be Assertive/Push	10	67%	Typical	Category 4. Stop Eating Disorder Behaviors	4	33%	Variant
Domain 3. Lessons learned	12	80%	Typical	Domain 3. Societal/Prevention Suggestions	11	92%	General
Category 1. Benefits of Early Intervention	8	53%	Typical	Category 1. Address Appearance Comments	5	42%	Variant
Category 2. Focus on Prevention	5	33%	Variant	Category 2. Dangers of health messages	5	42%	Variant
Category 3. Limitations to Early Intervention	5	33%	Variant	Category 3. Education	3	25%	Variant
				Category 4: Talk about it/Start a dialogue	1	8%	Rare
				Category 5. Miscellaneous	1	8%	Rare
				Domain 4. Be Educated About Eating Disorders	9	75%	Typical
				Category 1. Know Signs and Symptoms	6	50%	Variant
				Category 2. Know Risk Factors	5	42%	Variant
				Category 3. Know developmental norms	3	25%	Variant

named as identifying the eating disorder “first” (early in its progression), including friends of the adolescent, other authority figures (e.g., teachers, coaches), and other family members and adults. At times, these “other” individuals were named as identifying the eating disorder when parents did not; but more often, participants described that another person noticed the disorder at the same time as the parent, such that multiple people converged in recognizing and naming the problem around the same point in time. While four parents indicated that their child brought up the eating disorder for the first time (making the adolescent the “first to notice”), this was not reported by any of the adolescents (although the wording of the question also could have prevented adolescents from naming themselves).

Others who noticed

A related domain emerged only within parent interviews: ***Others Who Noticed***, referring to other individuals who identified the eating disorder, although not necessarily at its earliest stages (endorsed by 92% of parents). There was no typical category within this domain; these individuals included family members or relatives, friends of parents, friends or siblings of the adolescent, and coaches.

First to confront

A related domain only in adolescent interviews was ***First to Confront***, with adolescents stating that even though other individuals may have known about the eating disorder, parents (usually mothers or both parents together) were typically the ones who confronted them about changing their behavior (87% reported this).

Symptoms prompting identification

For both parents and adolescents, weight loss and thinness was the most typical ***Symptom Prompting Intervention*** (53% of adolescents, 67% of parents). Parents, but not adolescents, also noted that it was typical to be concerned about extreme eating and exercise habits (58% reported this) such as excessive exercise (e.g., exercise that took priority over socializing with friends) or severe dietary restriction (e.g., skipping meals, avoiding certain food groups).

Parent responses

For both parents and adolescents, a typical first ***Parent Response*** (once the eating disorder was identified) was consultation (mentioned by 60% of adolescents and 58% of parents). Parents described primarily consulting professionals (physicians, therapists), while adolescents reported that the parental consultation was a bit broader (consulting various professionals and non-medical adults). It also was typical for parents to address the eating disorder behaviors directly with the adolescent; 53% of adolescents said their parents

encouraged them to eat more as soon as they found out about the eating disorder, and 67% of parents described one or more child-focused interventions, falling into three variant subcategories: 1) confronting their child, 2) limiting eating disorder behaviors (e.g., forbidding exercise), and 3) monitoring their child.

Barriers to action

Both parents and adolescents articulated **Barriers to Action**, or factors that interfered with the identification or intervention process. Adolescents most typically reported that there was a “failure to act” (60% reported this). For example, one adolescent stated that *“I think people noticed but they kind of just shook it off.”* There was variability across adolescents in terms of who failed to act on their suspicions, including coaches, parents, doctors, and friends. Parents echoed this barrier, with 83% reporting that someone (parents, physicians, or other adults) overlooked or missed the eating disorder symptoms. The number of parents who said their concerns were dismissed by their child’s pediatrician or other health care provider is striking (42% reported this); for example, one parent shared, *“the doctor said . . . her BMI’s going down—yeah but it’s not dangerously low.”*

Adolescent responses

Once the eating disorder was confronted, the typical **Adolescent Response**, from their own perspective, was mixed (67% reported this). For example, one adolescent stated *“I was mad because I was like, ‘why are you guys watching over me? I’m not a little kid anymore.’ But I knew that I couldn’t do it by myself.”* Another adolescent acknowledged that *“I wanted help, and I wanted people to notice more than they did. I didn’t want people to notice but at the same time I would feel sad because I wanted people to care about me.”* From the parental perspective, however, the adolescent response to confrontation was typically perceived as resistant (58% reported this).

What advice do you have for early detection and early intervention?

Notice changes

A recommendation from both adolescents and parents was to “be aware” of your child’s baseline behaviors in order to **Notice Changes**. Parents and adolescents both typically stated that eating-related changes were especially important to notice (suggested by 80% of adolescents and 83% of parents). Adolescents named a variety of specific eating-related changes to look out for, including dietary restriction, preferring to eat alone, negative feelings around food, and eating too “healthy.” Both parents and adolescents also stated that changes in other key areas of behavior (e.g., social, exercise) should be noticed (67% of both adolescents and parents). Adolescents

highlighted that social isolation was typical within their disorder and should be monitored (53%). Despite it being a largely cognitive symptom, 73% of adolescents also indicated that body dissatisfaction could be detected by others. For example, one adolescent shared that *“Hating your body . . . if making verbal comments about how much you dislike it . . . if you’re willing to say that out loud, then it’s definitely a problem you have with yourself.”* Adolescents also referred to less obvious instances of body dissatisfaction, such as hyper-focusing on others’ appearance or making clothing changes to hide the body.

Be educated

Parents also brought up a related domain of **Be Educated** (75% reported this), and although there was no majority consensus on suggestions in this domain, the key takeaway was to increase knowledge of eating disorders (e.g., risk factors, signs and symptoms, developmental norms) to help detect abnormal thoughts, behaviors, and emotions.

Take action

Parents and adolescents agreed that **Taking Action** toward the eating disorder was an essential early intervention step. Typical recommendations fell into categories of being proactive (67% of adolescents, 58% of parents) and being assertive (67% of adolescents, 75% of parents). Being proactive was often discussed as intervening at the earliest point possible to prevent symptoms from progressing; for example, one adolescent said, *“Try to get help even though you don’t want to. It’s best if you do earlier. If not, it’s going to get worse.”* Assertiveness was often framed as directly confronting concerning symptoms. As one adolescent stated, *“Even if you’re not sure, it’s better to say something than wait until it’s really bad.”*

Within the **Take Action** domain it also was typical for adolescents to recommend being supportive (87%); specifically, it was typical to mention the desire for others to be positive (53%) and understanding (53%) about the eating disorder and the adolescent’s well-being. One adolescent spoke of the positive support she wished she had: *“If someone had said something to me personally, and said it in a way that let me know they had cared . . . I don’t know if that would’ve changed the outcome, but it would have at least helped some.”* Another spoke of her desire for validation, stating that it was helpful when people said things like *“It gets better . . . you’re not alone. A lot of people have this . . . and it’s not just a phase, it’s something serious.”*

It also was typical for adolescents to mention unsupportive responses that they now recognized were counterproductive to effective early identification (87% reported this). While no representative subcategory themes emerged, specific topics included encouraging thinness (usually from peers), negativity

about the disorder or minimizing their symptoms (from a variety of individuals) or hyper-focusing on the illness (usually from parents).

Lessons learned

Adolescents and parents both shared “takeaways” or suggestions for researchers and clinicians based on their own experiences. Adolescent responses clustered into a **Lessons Learned** domain, and their responses were quite varied. The only typical response was how earlier intervention would have been beneficial (53% reported this). One adolescent stated:

I think it would have been really, really helpful to have had treatment earlier. I was so stuck doing the exact same things every day and it just became routine and like my entire life. And so then when I tried to find healthy ways to cope later on, it was so weird to get back to living a more normal life . . . it made it so much harder.

Other adolescents mentioned that earlier intervention would have meant a reduced toll on the self, primarily in terms of physical, social, and academic consequences (e.g., missing out on school or social interactions). It also is noteworthy that a variant subset of adolescents (33%) noted some ambivalence about early intervention and its effectiveness; for example, one adolescent noted “*I had to get bad before I got better.*”

Societal/prevention strategies

Parental “takeaways” focused on **Societal/Prevention Suggestions** (92% endorsed this domain). As with adolescents, the responses were varied, with no typical categories emerging. Variant categories ranged from challenging appearance-related comments (42%), education about the dangers of health messaging that can trigger eating disorders (42%), and greater education about eating disorders (25%). A variant response in the **Lessons Learned** domain for adolescents also focused on eating disorder prevention; both parents and adolescents talked about the harm of societal messages surrounding thinness and attractiveness and the need for tools to resist these messages.

Discussion

This qualitative study explored eating disorder detection and the help-seeking experiences of adolescents and their caregivers. Results highlight some important similarities in these lived experiences and emphasize unique ways to empower families in identifying and responding to emerging eating disorders. Ideally, early detection efforts would equip caregivers and other capable individuals to recognize the symptoms of an eating disorder soon after they emerge and before they become entrenched within the individual and the family. Next, they would promote an assertive and supportive response to encourage professional intervention.

A primary finding is that caregivers *are* well-suited to detect and intervene on eating disorder symptoms in their child, although additional tools may be needed to encourage swift and confident responding. Parents usually were the first to notice the eating disorder and the first to confront it, although it is unclear how delayed the family reactions were. Parents and adolescents both identified obstacles to a quicker response against the eating disorder. This included the symptoms being overlooked or missed and parental hesitancy to take action, which is reflected in other research (e.g., Cottee-Lane et al., 2004; Eichhorn, 2008). To combat this, parents in this study urged others to seek out information about eating disorders and their typical symptoms. According to both parents and adolescents, increased awareness of eating disorder symptoms should also be paired with parent-led monitoring of eating and exercise behaviors to increase the chance of noticing changes and responding quickly.

The recommendation to increase knowledge about eating disorder symptoms has been endorsed in other evidence-based guidelines for responding to eating disorders (e.g., Hart et al., 2009). It also connects to the literature on overcoming treatment barriers through education about the severity of the illness (Ali et al., 2017). The responses here highlight how caregivers are in a unique position to have familiarity with both the typical signs and symptoms of eating disorders *and* their child's individual health-related habits. This combined knowledge could increase awareness of concerning changes that do not fall within developmentally normal shifts. The results of this research also suggest that information *about* the hesitancy to act might help to normalize it and encourage earlier action. Both parents and adolescents advocated for more proactive and assertive efforts against emerging eating disorder symptoms, and many adolescents (53%) shared that they wished they had started therapy earlier.

While caregivers are well placed to be first line responders to emerging symptoms, the results of this study encourage more comprehensive education on eating disorders for *all* who are capable of early identification of eating disorders, including health care providers, teachers, and coaches. Adolescents and parents reflected on how other individuals who have a close relationship with the adolescent can create a climate where eating disorder attitudes and behaviors are non-normative and therefore, more easily detected if and when they emerge. The need for greater education is not limited to individuals in close contact with the family. The fact that almost half of parents in this study (42%) reported that their concerns (e.g., with weight loss) were dismissed by their child's health care provider is quite concerning, and suggests that knowledge of eating disorder symptoms and warning signs also could be improved among health care providers. Together, these findings highlight the essential role of "eating disorders literacy" and understanding of developmental and cultural norms in disrupting eating disorder development. While mental health literacy has been identified as a broad solution to improving mental

illness identification (Jorm, 2012), in the case of eating disorders, it may be even more essential as it serves to fight against societal norms that praise thinness, vilify fatness, and embrace diet culture. Broader educational efforts may also need to include specific information about how easily eating disorder symptoms are missed within this cultural context.

It is not surprising that the physical and behavioral symptoms of eating disorders (e.g., weight loss, extreme eating behaviors, and exercise changes) were most consistently mentioned by both adolescents and their parents as the ones that prompted concern. Furthermore, the “easiest” symptoms to notice were weight loss and thinness. This is somewhat concerning from an early detection perspective, since thinness is not a given within the context of all eating disorders, which can occur at any body size. In fact, adolescents with a history of overweight who present with anorexia nervosa at higher body sizes take twice as long to be identified (Lebow et al., 2015), and community members fail to identify or recognize the seriousness of bulimia nervosa in higher weight individuals compared to those in smaller bodies (Galbraith et al., 2019). Given this, educational efforts that directly address this knowledge gap could empower specific agents to detect atypical weight-related changes through adolescence across the weight spectrum. This could include pediatricians and school staff in health-related areas (e.g., school nurses) who are likely to monitor weight changes in their professional roles.

Once the suspicion of an eating disorder is confirmed, parents and adolescents alike suggested strong and swift action against the disorder. Specific recommendations included consultation with professionals who have expertise in eating disorders, adolescent development, or mental health; monitoring concerning behaviors; and parent-driven limitations on disordered behaviors (e.g., encouraging eating, limiting excessive exercise). Adolescents had suggestions for the style of these responses, recommending direct but supportive action that includes validation without blame. This echoes the strategies of both eating disorder first aid (Hart et al., 2009) and broader mental health first aid, advising compassion and support while facilitating intervention (Morgan et al., 2018). The recommendations here take this one step further to encourage parents to facilitate intervention while also directly disrupting symptoms (e.g., through monitoring or limiting them). Interestingly, adolescents were most likely to report that their emotional response to being confronted about their disorder and helped into intervention was mixed (e.g., with anger *and* gratitude), but parents were most likely to only notice the negative side of this response. This discrepancy is important, as it suggests that parents and other professionals should not avoid confrontation for fear of negative emotions. Rather, caregivers who respond to symptoms and clinicians who begin interventions should *expect* to see negative responses, and be aware that they may not see the positive reactions that are present simultaneously, such as relief.

A few limitations to the current study should be noted. The representation of the sample is limited in terms of racial and ethnic diversity, patient gender identity, and eating disorder presentation. The fact that so many adolescents in our sample suffered from Anorexia Nervosa likely impacts some of the key findings, such as thinness being the most recognizable sign of an illness. There also was some discrepancy in our ability to consistently gather clinical characteristics of the sample, given that some adolescents participated without their caregivers, and the relevant clinical information was pulled from their clinical file, rather than caregiver-reported as in the rest of the sample. All participants in this study were engaged in eating disorder psychotherapy at some point in their recent past. This is likely to influence their reflections on the eating disorder and its development, and it also precludes our understanding of symptom trajectories that improve, rather than worsen, over time without intervention. To enhance our understanding of early identification and first response, it will be important for future research to sample individuals whose symptoms have more recently emerged. Along with this, it is important to acknowledge the difficulty of objective retrospective recall of emotionally-laden information; many parents in this study discussed the period of detection and response to the eating disorder as a source of guilt, potentially impacting the information recalled.

Overall, these findings are consistent with clinical knowledge about reducing the impact of eating disorders, including who is best to intervene on symptoms, what types of symptoms are most easily detected, what type of response strategies should be implemented within families, and expected reactions from adolescents with the illness. A strength of this work is that it systematically captures the lived experiences of eating disorder identification and response from both the patient and caregiver perspective. This research provides a framework for early intervention work, highlighting the need for aggressive yet informed efforts to combat emerging eating disorders in adolescents. Future research should support caregivers who have questions about the presence of an eating disorder in their child, who are invested in addressing early symptoms or risk factors in their child, and/or who are uncertain about the appropriateness of when or how to intervene. It is imperative to increase caregiver efficacy around engaging in detection and intervention efforts by increasing knowledge about eating disorder symptoms and encouraging action against early behaviors. Future research also should continue exploring the individual and family's adaptation to the presence of an eating disorder, including psychological and interpersonal shifts that occur as the eating disorder develops and embeds itself into the family system. Accurately detecting early eating disorder symptoms and taking early and aggressive steps toward intervention could significantly reduce the burden of eating disorders on families, professionals, and society.

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