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Support for Parents of Children with Anorexia: What Parents Want

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Available online: 03 Jan 2008

To cite this article: Anne Honey, Desiree Boughtwood, Simon Clarke, Christine Halse, Michael Kohn & Sloane Madden (2007): Support for Parents of Children with Anorexia: What Parents Want, Eating Disorders, 16:1, 40-51

To link to this article: http://dx.doi.org/10.1080/10640260701773447

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Support for Parents of Children with Anorexia: What Parents Want

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Parents’ encounters with health professionals can influence their ability to cope with having a daughter with anorexia nervosa. Using qualitative analysis of in-depth interviews with 24 parents, we examine the question “What support do parents of teenage girls with anorexia want from clinicians?” The analysis shows that parents wanted clinicians to include them in treatment, support and guide them in their daughters’ care, and demonstrate positive attitudes toward them. The implications for clinicians are discussed, including being sensitive to parents’ vulnerability, ensuring congruence between clinicians’ and parents’ expectations about treatment, and strengthening formal channels of communication.

INTRODUCTION

This paper addresses the question “What support do parents of teenage girls with anorexia nervosa want from clinicians?”

There is increasing recognition that parents can be valuable resources for helping their teenage daughters to recover from anorexia nervosa (hereafter...
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“anorexia”) (Eisler, Le Grange, & Asen, 2003; Lock, Le Grange, Agras, & Dare, 2001). Firstly, because many people with anorexia deny that a problem exists and strenuously resist treatment (American Psychiatric Association, 2000), parents must often encourage or force their children to accept professional treatment (Cottee-Lane, Pistrang, & Bryant-Waugh, 2004; Tierney, 2005). Secondly, parents’ emotional and behavioral responses to anorexia are believed to influence treatment outcomes (Bell, 2003; Colahan & Senior, 1995; Nielsen & Bara-Carril, 2003).

Caring for a daughter with anorexia is a complex and demanding role (Honey & Halse, 2005, 2006) and one that can cause parents to experience high levels of stress, distress and burden (Treasure et al., 2001). The few studies to examine the perceptions of parents of children with anorexia suggest that clinicians can have a substantial impact on their experiences and coping abilities.

Clinicians can also have a strong positive influence on parents’ experiences. Compared to negative experiences, positive parental reports of services have tended to be more vaguely defined and less widely published. This may be because negative events are more heavily weighted in judgement formation and produce more complex cognitive representations and more extreme attributions than positive events (Taylor, 1991, cited in King, Cathers, King, & Rosenbaum, 2001, p. 114–115). Despite this, it is apparent that having the support of clinicians who parents considered understanding, sympathetic, helpful and competent is an immense relief for parents and eases the burden they experience (Gilbert, Shaw, & Notar, 2000; Macdonald, 1993; McMaster et al., 2004; Sharkey-Orgnero, 1999). In fact, such clinicians were so greatly appreciated by parents that they sometimes came “close to being deified” (Tierney, 2005, p. 375).

While parents have often raised issues about service providers when asked about their experiences of having a child with anorexia, few studies
have specifically reported parents’ perspectives on and experiences with professional treatment (Newton, 2001). Those studies that have examined this issue have reported parents’ opinions about a particular service (Kopec-Schrader et al., 1993) or described their experiences thematically (McMaster et al., 2004; Tierney, 2005). We extend this previous research by systematically analyzing the features or characteristics of parents’ interactions with clinicians that make them either positive or negative experiences for parents. We present this analysis as an answer to the question “What support do parents of teenage girls with anorexia want from clinicians?” We discuss how clinicians can use this information to make their services and approaches more helpful to parents of adolescents with anorexia.

**METHOD**

**Participants**

Twenty-four parents of adolescent girls (aged 14–20) who were currently receiving medical treatment for anorexia nervosa participated in the study. A convenience sample of parents whose daughters were attending the adolescent units of two public teaching hospitals and one private paediatric practice were asked to participate and those who agreed were interviewed. To minimize the skewing of the sample toward people with a positive relationship with the treatment facility and the suppression of negative stories, parents were interviewed by an independent researcher and were assured that their individual, identifiable comments did not need to be shared with their clinicians. Overall, the researchers rated 20 out of the 24 participants, from their interviews, as being generally satisfied with their daughter’s current clinical team, while two were dissatisfied overall and two were ambivalent or noncommittal. Most parents, however, discussed their experiences with a number of different services and clinicians, sometimes over several years, and reported both positive and negative experiences. It is always possible that people who participate in research represent a different group than those who choose not to participate. However in this study only 3 parents (from 2 families) who were invited to participate declined, minimizing the chances that participants represented a vocal minority.

The 16 mothers and 8 fathers from 17 families who participated in the study all lived with the daughter with anorexia. All but two parents were born in Australia or the United Kingdom and spoke English at home. The remaining participants spoke English fluently and did not require an interpreter. The educational level of participants was high: 15 of the 24 parents had a university education and 4 had post-graduate qualifications. Girls ages ranged from 14–20 years with a mean of 16.2 years. They had been receiving treatment for anorexia for between six weeks and seven years, with five girls diagnosed within the last twelve months, seven girls diagnosed
between one and four years previously, and five girls diagnosed more than four years ago. Many girls had been seen by a number of different clinicians. Parents in four families saw their daughters as well on the way to recovery, while the remaining 13 families saw their daughters’ eating problems as ongoing. This variation meant that we were able to tap into the perspectives of parents with a wide range of experience with clinicians in order to map a breadth of perspectives.

Procedures

In-depth interviews were conducted using a recursive model in which the interviews are unstructured and conversational in style (Minichiello, Aroni, Timewell, & Alexander, 1990). The interviewer explained that she was interested in parents’ experiences of having a daughter with anorexia and initiated discussion about a number of broad issues, including their daughters’ clinical treatment. Parents were encouraged to discuss specific issues that they brought up and considered important. This approach enabled a broad sample of specific incidents that were important to parents to be examined in detail. Interviews were recorded on audiotape and transcribed verbatim using the Jefferson transcription model (Bucholtz, 2000), which includes notations to indicate speech features such as changes in emphasis, speed and volume.

Parents’ narratives involving clinicians were not viewed as definitive truths but as narratives “constructed around a core of facts or life events” that also encompass “individuality and creativity in selection, addition to, emphasis on, and interpretation of these ‘remembered facts’” (Lieblich, Tuval-Mashiach, & Zilber, 1998, p. 8). No attempt was made to elicit a comprehensive list of all their treatment experiences. This analysis, therefore, is not intended to provide an evaluation of any individual service or of eating disorders services more generally. Rather, parents’ narratives are used to shed light on the characteristics of encounters with eating disorders clinicians that determine whether parents experience them in positive or negative ways.

Data analysis consisted of four steps. First, a content analysis (Neuendorf, 2002) was performed to identify all instances where parents discussed clinicians who were treating their daughter for anorexia. These included doctors, nurses, psychologists, counsellors, and dieticians. Parents in this study did not describe systematically different expectations of different categories of clinicians, as it was individuals’ characteristics and actions that were important.

Second, each individual instance was examined for the presence of external or internal linguistic “evaluation devices,” which are used to indicate positive and negative evaluations of incidents and clinicians (Cortazzi, 1993; Labov, 1972). External evaluation devices are used when interviewees interrupt their narratives to tell the listener what the point is. Five types of
external evaluation device were recognized (Cortazzi, 1993) and are illustrated here with sample quotes from our interviews. In the first type, participants interrupt their story or discussion to explicitly state their evaluation (“I think the treatment she got in [the hospital] was wonderful”). Second, participants describe evaluative thoughts they attribute to themselves in retrospect (“I figured I connected to her”). Third, participants quote themselves addressing others about the situation (“I said it’s all very well, you sitting there in your comfy little seat, and dishing out words of how to initiate World War 3”). Fourth, an interpretive remark is attributed to somebody else (“He said it’s not bloody rocket science, is it?”). Lastly, participants relate evaluative actions (“I howled over that”). An internal evaluation device is used within the narrative (Labov, 1972). For example, intensifiers are when one clause is strengthened, for example by gesture, vocal delivery, or repetition. Comparators are when the interviewee “moves away from the line of narrative events to consider unrealised possibilities and compare them with events that did occur” (p. 387) (“If the care had been tougher then, and probably more hands on, more people around her, then maybe it would have stopped her”).

The third step in data analysis was to examine each evaluated incident to ascertain what features were associated with the positive and negative evaluations. The trustworthiness of the interpretation was enhanced by the conversational style of the interview, which enabled the interviewer to check her understandings with participants throughout the interview. In addition, the data were examined and discussed in detail by three members of the research team to gain consensus as to interpretation.

In the fourth step, the features identified as contributing to positive evaluations were compared, both within and between interviews, for conceptual similarities and differences and grouped into themes (Glaser, 1978), as were the features associated with negative evaluations. Positive and negative themes were compared and integrated to develop an overall framework to describe the support that parents wanted from health professionals.

**FINDINGS**

Parents in our study reported that their first priority was improvement in their daughter’s physical and psychological well being. However parents also understood that anorexia was extremely difficult to treat, and expressed positive feelings about professionals and services that they saw as thorough/comprehensive, competent and caring toward girls regardless of the outcome. But parents also wanted more than just good professional treatment for their daughters. Many of parents’ most positive and negative evaluations of clinicians, services and practices related to whether they acknowledged and supported or ignored and undermined parents’ own
role as their daughter’s primary carer and their efforts to help their daughter. It is this aspect of parents’ experiences with clinicians that is the focus of the current paper.

There were three main ways in which parents wanted professionals and services to support them in their role as their daughters’ primary carers: including them in treatment; supporting and guiding them in their care of their daughters; and demonstrating positive attitudes toward them. These are detailed below with quotes from participants presented to illustrate particular issues.

Including Parents in Treatment

Parents wanted to be included in the clinical care of their daughters. While there was some variation in the amount of involvement they desired, parents who felt they had been excluded from their daughters’ treatment resented it.

Parents wanted clinicians to keep them informed about their daughters’ treatment and progress as well as what to expect next. While parents acknowledged the legal complications of age-based medical confidentiality, many felt that the incomplete and sometimes unreliable reports of their daughters significantly undermined their role of taking care of their daughters.

Last time [my daughter] went into [the hospital] no one spoke to us. And I find that really difficult because we are the carers of her. I’m the one who gets her to her appointments, makes sure she takes her medicine. We provide her with the support that no one else is kind of giving her at that time.

Parents also wanted clinicians to listen to their input and take it into consideration. They did not want their contributions to be discouraged, distrusted or ignored. A number of parents also valued the opportunity to provide information to clinicians frankly, without their daughter always being present. Parents felt that they had a long-standing and intimate knowledge of their daughters which was not directly available to clinicians but which was important for their daughters’ treatment.

You know your child and you’re the one with them all the time.

Parents appreciated the option of having input into treatment decisions. While they often deferred to professionals’ judgement and willingly followed their recommendations, they negatively evaluated instances where major decisions were made without consulting them or against their expressed wishes. Similarly, they did not wish to be given orders or treated
in an authoritarian manner and when they needed to relinquish control to clinicians parents still wanted to be respected as the child’s primary carer.

He’s been really open. He’s willing to try anything...he sits down with you. He’s not one of these condescending doctors that think they know it all and that you should just be quiet and, you know, listen to them.

The first thing he said was, ‘you do know if you don’t do what I say, that she can be made Ward of the State’... [crying] I thought, I think I’m going to be sick.

Supporting and Guiding Parents in Their Daughters’ Care

As girls’ primary carers, yet having no professional background or experience with eating disorders, parents felt they needed help and support from clinicians. The sort of help that parents needed and appreciated (if it was available) included: information about anorexia and its impact on the whole family; ideas about why daughters might be behaving in certain ways; advice about strategies to use at home; post-discharge planning and follow up; coping strategies and more positive ways of thinking about the illness; counselling and emotional support; and opportunities to meet and develop supportive networks with other parents.

Parents valued being provided with clear guidelines to follow and regular feedback as it gave them confidence in what they were doing. Sometimes, however, parents felt that clinicians directed them to do things that placed unreasonable demands on them, such as using strategies that courted continuous confrontation and hostility or were against their own values and beliefs.

[Before starting family therapy] we were sort of flying blind. We were sort of using logic... but you’re not sure if you’re doing the right thing. Well, I was a bit sceptical [about family therapy]. But once [we] got into it, yeah, we worked out how to get around the anorexia.

Basically, you’ve got to hassle them to death. So life becomes so unpleasant that they eat. [The clinician] believes then everything will be hunky dory. That [my daughter] will then be a perfectly normal young lady. And I don’t think that.

Advice and guidance were most appreciated when they were tailored to the individual family circumstances, and acknowledged the uniqueness of their situation. Parents appreciated clinicians who took the time to listen to their concerns and provide suggestions, rather than dismissing or trivializing their problems. A number of parents spoke about the importance of clinicians
being available to provide information and advice and to discuss parents’ issues with them as they arose.

The lines of communication were always there . . . all these questions do arise. And when they do arise, you need to be able to get an answer. And the team here was fantastic, you know.

There wasn’t any other feedback other than oh well that’s difficult. And that’s all the doctors would say.

Demonstrating Positive Attitudes toward Parents

Parents often described having strong emotional reactions to the ways in which they believed they were viewed by clinicians. Positive attitudes were apparent through provision of support and inclusion in treatment as described above. Attitudes were also revealed through the manner of clinicians (for example “rude and abrupt” versus “respectful and nice to us”). Parents appreciated professionals, services and practices that revealed positive attitudes toward them such as empathy, respect and concern and treated them as individuals, acknowledging their unique circumstances.

Everyone was really trying hard to make sure we were not sort of crumbling up in a heap too… I mean just the questions they were asking us made us think that they knew that there could be effects on the whole family.

Parents reported being distressed when they felt as if they were being treated like “bad parents,” as if they had caused the illness or were not acting in the daughters’ best interests. Some parents reported interactions with clinicians in which they felt patronized, distrusted and stigmatized.

Both my husband and I found the psychiatrist very condescending. And so again, it was like well, you’ve got the problem; you haven’t been able to solve it. And it was like they just cut you down and you feel like, oh, you’re about that big.

Sometimes it was not only individuals or groups of clinicians but institutionalised practices that suggested parent-blaming attitudes, such as restricted visiting or not allowing parents to spend time alone with their daughters.

They say you’re not to blame but there’s different rules for you than for anybody else in the hospital. Any other child can have their parent visiting, but you can’t.
DISCUSSION

Parents have an important role to play in their adolescent daughters’ recovery from anorexia (Bell, 2003; Colahan & Senior, 1995; Nielsen & Bara-Carril, 2003). One of their roles can be to facilitate and support the care health professionals provide. For this reason, clinicians have a vested interest in helping parents to fulfil their role in the most positive way possible. The best outcomes are likely to be achieved through a cohesive approach where treatment providers and families work together. Many eating disorders clinicians share this viewpoint and from our interviews we can conclude that most parents are of the same mind. Yet relationships between parents and clinicians can be fraught (e.g., McMaster et al., 2004). While this paper addresses the question “What support do parents of teenage girls with anorexia nervosa want from clinicians?” for a variety of reasons it is not always possible to give parents what they want. Time pressures, privacy legislation, patients’ own wishes and a host of other circumstances may impinge on or prevent clinicians from attending to all parents’ needs. Further, not all parents are easy to engage and sometimes a clinician may find that their best efforts in supporting parents are dismissed or misinterpreted. Yet our findings suggest a number of areas for clinicians to consider in their attempts to positively influence parents’ experiences and ability to support their daughters. While it must be remembered that this is a small-scale study conducted in one location, the findings fit well with the international literature summarized in the introduction to this paper, suggesting that they may have a broader relevance for clinicians.

Parents are strongly affected by the attitudes that clinicians display toward them. When parents first present to treatment with their daughters for management of anorexia nervosa they often do so in a state of extreme stress with acute anxiety about their daughter’s well being and feelings of failure and guilt with regard to their role as parents. Many are also aware of parent-blaming theories of anorexia (Eisler, 1995). For these reasons early parent-professional interactions may be complex and difficult. Clinicians may need to devote particular attention to reassuring parents that they are not blamed, that their current distress and turmoil are to be expected, and that, as primary carers, they are an important resource for their daughter and her treatment team.

In our study the first priority of families was their daughter’s physical and psychological well-being. While these priorities are also shared by clinicians working in eating disorders, expectations about these outcomes are often different. Clinicians regard anorexia as a 5 to 7 year illness where change occurs slowly and distress is an expected part of the change process (Steinhausen, 2002). Many parents initially expect rapid improvement with treatment. Their daughter’s psychological distress is a central concern and its amelioration is often seen as both urgent and necessary for their daughter’s
recovery. These differences in perception between parents and clinicians can lead to confusion and miscommunication particularly when both sides believe they are working toward the same goal. Treatment practices for children and adolescents with anorexia that focus on safe eating even when this distresses the sufferer (Lock & Le Grange, 2005) can be experienced as particularly difficult by parents. It is vitally important for clinicians to identify and explicitly address any dissonance between their expectations and understandings and those of parents. In particular, where parents are being asked to behave in ways that generate distress for their daughters, for example by insisting that girls eat foods they might find frightening, clinicians should ensure that parents clearly understand and are in agreement with the rationale behind this. Parents are likely to need ongoing support to cope with this. Clinicians should not be reluctant to refer families to an alternate treatment team or approach should their long-term treatment approach be irreconcilably incompatible with the family’s culture or beliefs.

For parents, being included in treatment not only meant being asked for their permission for treatment to take place but sharing information between themselves and the clinicians. Direct interaction between parent and clinician is vital, not least of all because relying on patients for information can be unreliable and confusing for parents even when the daughter is willing to relay information. Regularly scheduled meetings between parents and various members of the clinical team are one way to address this issue. Patients can be asked prior to the meetings what they are happy for the team to discuss with their parents and the importance of parental inclusion can be explained to them. Where confidentiality provisions along with girls’ preferences prevent information from being given to parents, these issues should be carefully explained to parents so that they do not think that clinicians distrust or disregard them. Clinicians should ensure that parents have access to adequate support and guidance for the difficult job of looking after a daughter with anorexia, whether that means providing the support or referring parents elsewhere.

In previous studies parents have reported a range of very different experiences with service providers. Many of these experiences are emotionally charged and influential to parents’ coping abilities. We have built on these prior studies by providing a systematic analysis of parents’ descriptions of and responses to a wide range of different encounters with clinicians. In doing so, we have identified the major features of parents’ interactions with clinicians that influence whether parents perceive these interactions as constructive and supportive or unhelpful and even damaging. This knowledge paves the way for further research into parent-clinician interactions and relationships, an important area that has been largely neglected in eating disorders research to date. Clinicians who work with girls who have anorexia and their parents recognize that the task of looking after a sick child is physically and mentally taxing, with little respite. This study adds weight to the assertion that clinicians
have the ability to influence parents’ experiences for better or for worse. By taking parents’ perspectives, as presented in this paper, into account clinicians will be better situated to build productive and positive relationships with parents for the benefit of all concerned.

REFERENCES


What Parents Want


