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Posttraumatic stress disorder in mothers of individuals with Anorexia Nervosa

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Abstract

This pilot study aimed to investigate the prevalence of maternal posttraumatic stress (PTSD), anxiety and depressive symptoms and what aspects of having a child with anorexia nervosa (AN) are perceived as traumatic by the mothers. Thirty-one mothers of daughters with AN completed a range of self-report questionnaires and a structured clinical interview. Higher rates of anxiety, depression and PTSD symptoms were found in mothers than in the general UK population. Mothers reported traumatic stressors that can be viewed as life threatening events during the course of AN, such as ‘thinking their daughter was about to die or dead’, ‘seeing or consenting to their daughter being tube-fed’. We also found that mothers rated chronic aspects of their daughter’s AN as very severely distressing, such as ‘worrying about permanent damage to daughter’s health’. Results suggest that services should conduct routine assessments of the mental health of mothers of individuals with eating disorders.

Keywords: posttraumatic stress disorder, anorexia nervosa, mothers, chronic illness, eating disorder

Posttraumatic Stress Symptoms in Mothers of Individuals with Anorexia Nervosa: A pilot study

Introduction

Parents report that having a child with an eating disorder can affect one ‘profoundly and irrevocably’ (MacDonald, 2000, p.12) and describe their experience as unique and shameful (Nielson & Bara-Carril, 2005). Whilst most cases of AN start during adolescence when individuals are living in the parental home (Haigh & Treasure, 2003), family involvement (particularly that of the mother) remains significant even for adults with this disorder. The majority of adult patients with severe AN either live with their family or rely on them heavily for support, and family involvement is therefore greater than is usual for their biological age.(MacDonald, 2000; Treasure, Whitaker, Whitney & Schmidt, 2005).

Factors that have been identified as distressing for parents include witnessing the symptoms of AN themselves, the difficult behaviours frequently displayed by individuals with AN (e.g. devious behaviour to avoid weight gain, irritability and mood swings) (MacDonald, 2000; Treasure, Murphy, Szmukler, Todd, Gavan & Joyce, 2001), and problems experienced with services (e.g. initial concerns not being taken seriously, not receiving information or choice regarding treatment options) (Cottee-Lane, Pistrang & Bryant-Waugh, 2004). Treasure and colleagues’ (2005) model of carer distress proposes that carers of individuals with AN may develop stress, anxiety and depression in response to a variety of pressures. These pressures include dealing with disorder-related problems (e.g. not eating, mood, antisocial behaviours), lack of skills and knowledge, stigma associated with AN, and role strain (due to balancing caring with the needs of others in the family, work and other commitments). Carers often find it hard to address their own needs, due to the demands of the individuals they are caring for (Cohn, 2005; De La Rie, van Furth, de Koning, Noordenbos & Donker, 2005). However, the nature of the psychological distress experienced by parents of children (as minors or adults) with eating disorders has yet to be investigated in detail.

It has been suggested that a posttraumatic stress model can provide a framework in which to conceptualise and treat ongoing distress such as that experienced by carers of those with AN (Kazak, Alderfer, Rourke, Simms, Streisand & Grossman, 2004). According to the DSM-IV-TR (APA, 2000), learning one's child has a life-threatening illness is an event capable of precipitating posttraumatic stress disorder (PTSD). It has been argued that the life threat involved in severe childhood disease and the threat posed to a child's physical integrity by medical procedures are traumatic for their parents (Wintgens, 1997). Indeed, significant levels of posttraumatic symptoms in parents whose children have life-threatening illnesses, such as cancer (e.g. Kazak, Boeving, Aldefer, Hwang & Reilly, 2005; see Bruce (2006) for a review), spinal cord injury (Boyer, Knolls, Kafkalas, Tollen & Schwartz, 2000), or are submitted to high-risk, invasive medical procedures, such as bone marrow transplantation (Manne *et al.*, 2002), organ transplantation (Young *et al.*, 2003), hematopoietic stem cell transplantation (Manne *et al.*, 2004), meningococcal disease (Shears, Nadel, Gledhill & Garralda, 2005), and admission to pediatric care unit (Balluffi *et al.*, 2004) have been reported.

AN is a serious mental health problem that can involve repeated hospital admissions and high levels of comorbidity; it has the highest mortality rate of all psychiatric illnesses (Haigh & Treasure, 2003; Treasure *et al.*, 2001), and the disorder has devastating physical and psychological consequences. In addition to the threat to their children's life associated with AN, parents have to watch their children physically decline, which can be conceptualised as a threat to their child's physical integrity. In qualitative accounts, parents speak of the frustration and desperation they feel 'watching their child starve' (Cottee-Lane *et al.*, 2004, p.174) and of seeing their child ‘deteriorating before (their) eyes’ (Tierney, 2005, p.376). The individual’s behaviour can also be violent and abusive at times (MacDonald, 2000; Treasure *et al.*, 2001). The dramatic change in their daughter’s personality and behaviour can make it hard for parents to recognise their child (Smith, 2004) and one parent describes AN as a ‘monster’ that took over their child (Cottee-Lane, 2004, p.172). Furthermore, parents may witness invasive, aversive medical procedures carried out against the will of the sufferer, e.g. tube-feeding or platelet transfusion.

We propose that the experience of AN in one’s child fits the definition of a traumatic stressor (Criterion A-1, DSM-IV-TR, 2000), and that this may provide a helpful framework in which to assess and potentially treat the distress experienced by parents of individuals with AN. Parents have also frequently reported feelings of helplessness (Whitney & Eisler, 2005) and fear for their child (Cohn, 2005; MacDonald, 2000), which is in line with Criterion A-2 (DSM-IV-TR, 2000). According to Adshead (2000), stressors that cause chronic fear and helplessness are particularly likely to lead to the development of PTSD. This would be particularly relevant for this population, given that the average duration of AN is 6.5 years, the relapse rate is 68%, and 21% of patients with AN develop a chronic course of the disorder (Eddy *et al.*, 2002; Steinhausen, 2002). There is evidence that parental PTSD may occur in relation to the diagnosis of a child with other chronic illnesses, such as type I diabetes mellitus (e.g. Horsch, McManus, Kennedy & Edge, 2007) or asthma (Kean, Kelsay, Wamboldt & Wamboldt, 2006; see Cabizuca, Mendlowicz, Marques-Portella, Coutinho & Figueira, 2009 for a review). Parents’ negative emotions do not necessarily fade with time (Perkins, Winn, Murray, Murphy & Schmidt, 2004) and they may feel increasingly hopeless, inadequate and powerless as time progresses (Highet, Thompson & King, 2005).

This study aimed to investigate the prevalence of maternal posttraumatic stress, anxiety and depressive symptoms and what aspects of having a child with AN are perceived as traumatic by the mothers.

Method

Participants

Mothers whose daughters had AN were recruited via local eating disorder and child and adolescent mental health services (CAMHS) in Oxfordshire, Buckinghamshire and Berkshire, and via B-EAT (formerly known as Eating Disorder Association). To be included, their daughter had to be twelve years old or above and had to have met the criteria for AN within the last six months. In addition, in order to ensure that the mother had been significantly involved in the care of her daughter, the daughter had to have spent at least two nights staying at home with her mother during the three months prior to recruitment. If the daughter had been an inpatient throughout the three months prior to recruitment, the mother had to have visited her at least once per week. Given that this was an interview- and questionnaire-based study, individuals without sufficient English language skills were excluded.

A letter containing the information sheet and a response slip was sent to the identified families with the patient's consent. If the response slip was returned indicating the mother's agreement to participate in the study, an appointment for the interview at the participant's home was arranged. Before the assessment started, mothers signed a consent form. They then participated in a brief interview and completed the questionnaires. Ethical approval was sought from two local research ethics committees and was granted following minor amendments.

Measures

Structured Clinical Interview-DSM-IV-PTSD Module (SCID; First, Spitzer, Gibbon & Williams, 1995)

The SCID-PTSD module is a standardised diagnostic interview consisting of 17 items, which assesses the DSM-IV PTSD criteria. It was used to assess mothers' PTSD symptoms at the time of the interview as well as a retrospective report of the PTSD symptoms that mothers had experienced at least one month after the AN-related traumatic stressor they identified (see below). A partial PTSD diagnosis was defined as meeting the stressor Criterion A and criteria for two of the three symptom clusters (Manne et al., 2004). The first author received training in the use of the SCID and conducted all interviews. When trained clinicians use the SCID, good inter-rater reliability (.85), sensitivity and specificity, and diagnostic accuracy (82%) is usually achieved (Ventura, Liberman, Green, Shaner & Mintz, 1998).

Posttraumatic Diagnostic Scale (PDS; Foa, Cashman, Jaycox & Perry, 1997)

This self-report measure of PTSD symptoms, which is widely used for screening and assessing PTSD in clinical and research settings, was used to assess symptom criteria of PTSD (Foa, 1995; Foa *et al.*, 1997). A symptom was rated as present when the item corresponding with the symptom was rated 1 or greater than 1 (Foa *et al.*, 1997). Participants had to rate how often they experienced PTSD symptoms in relation to the AN-related traumatic stressor in the past month, using a 4-point Likert frequency scale ranging from 0 'not at all or only one time' to 3 'five times per week or almost always'. The symptom diagnosis of PTSD was made if participants reported at least one re-experiencing symptom, three avoidance symptoms and two arousal symptoms. As a measure of symptoms severity, scores can range from 'mild' (≤ 10), 'moderate' (≥ 11-20), 'moderate to severe' (≥ 21-35) to severe (≥ 36). The PDS has good test-retest reliability (α = .74), high internal consistency (α = .92), and has been validated with survivors of a wide range of traumas (Foa *et al.,* 1997). An agreement of 82% between PTSD diagnoses obtained from the PDS and the SCID for DSM-III-R has been found (Spitzer, Williams, Gibbon & First 1990).

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)

Each of the 14 items on this self-report measure of state-anxiety and depression (Zigmond & Snaith, 1983) is scored from 0 to 3, with higher scores indicating greater anxiety or depression. Scores from 8 to 10 on each scale indicate possible clinical disorder and scores between 11 and 21 indicate probable clinical disorder. The HADS may also be used as a measure of severity from 'normal' (0-7), 'mild' (8-10), 'moderate' (11-14) to 'severe' (15-21) symptoms. It has has good face validity, concurrent validity, and construct validity (Moorey *et al.*, 1991).

Distressing Aspects Questionnaire (DAQ)

This scale, which was administered in an interview format, was developed specifically for the present study in order to ascertain how distressed mothers felt by different aspects of their child's AN, and to identify which aspect of their child's AN mothers found most distressing (traumatic stressor). This list of 18 potentially distressing aspects of AN was compiled by a focus group consisting of clinicians from local eating disorder services and carers (see Table 2). Participants were asked to rate how distressing they found each aspect on a scale from 0 (not at all distressing) to 5 (very severely distressing). Participants were also given the opportunity to add any other aspects of their daughters' AN that they had found particularly distressing.

In order to identify the traumatic stressor, participants were then asked to identify the most distressing event/situation they had experienced with respect to their daughter's AN and to rate the subjective severity of this stressor on a Likert Scale (0 = 'not at all', 10 = 'very'). This most distressing experience was subsequently used as the traumatic stressor during the assessment of PTSD symptoms (as measured by SCID and PDS).

Demographic information, including mothers' psychiatric history and medical information about their daughters, was collected as part of the interview.

Data analysis

Descriptive statistics were used for analysis of the data. In cases when the data violated the assumptions of parametric tests, nonparametric tests were used. Chi-square tests were used to analyse associations between type of PTSD diagnosis and psychiatric history, trauma history and past PTSD. To analyse associations between time since AN-related traumatic stressor occurred and PTSD symptoms/diagnosis, as well as associations between type of diagnosis and PDS and HADS scores, Pearson correlations and Mann-Whitney tests were used.

Results

Sample characteristics

Of the 135 mothers contacted, 36 (26.7%) responded indicating that they were interested in participating in the study. Of these, five were excluded because they did not fulfill the inclusion criteria, so a total of 31 participants took part in the study. Participants' mean age was 52 years (SD = 5.86). Most (26, 83.9%) participants were married with at least two children, and all but one were White British. Eight participants (25.8%) worked full- and 16 (51.6%) part-time, 3 (9.7%) were unemployed, 2 (6.5%) retired, 1 (3.2%) was self-employed, and 1 (3.2%) was a student.

The mean age of participants' daughters with AN was 19.81 years (SD = 4.27); time since diagnosis of AN was 36.65 months (SD = 29.98). The mean lowest Body Mass Index (BMI) was 13.71 (SD = 1.70), whilst the BMI at the time of the interview was 16.20 (SD = 2.00). The mean number of hospital admissions related to AN was 1.87 (SD = 2.93). Eight daughters (25.8%) had one additional diagnosis, and 4 (12.9%) had two; these included depression (n = 7, 22.6%) and OCD (n = 3, 9.7%). The Mental Health Act had been used once to enforce treatment for two daughters (6.5%) and twice for one daughter (3.2%). Five mothers (16.1%) had over-ridden their daughter's wishes once to enforce treatment, and two mothers (6.5%) had done so at least twice. During the last three months prior to the interview, 23 (74.2%) daughters had lived with their mother had home, 3 (9.7%) had stayed with their mother more than one month, 4 (12.9%) had stayed for up to one week, and 1 (3.2%) was an inpatient at the time of assessment.

Anorexia Nervosa-related traumatic stressors

The following AN-related traumatic stressors were identified by participants, which were assessed to meet both Criteria A-1 and A-2 using the SCID: waiting to receive urgent professional help or an inpatient bed (n = 7, 22.6%), finding out their daughter had AN or realising the seriousness of AN (n = 4 , 12.9%), being unable to prevent daughter's deterioration (n = 4, 12.9%), daughter running away (or threatening to) following disagreements regarding food (n = 3, 9.7%), thinking their daughter was about to die or was dead (n = 3, 9.7%), daughter's sudden weight loss (n = 2, 6.5%), seeing or consenting to their daughter being tube-fed (n = 2, 6.5%), daughter taking an overdose in relation to their AN (n = 2, 6.5%), dilemma about whether daughter was too physically ill to travel (n = 2, 6.5%), relapse of daughter's AN (n = 1, 3.2%), and daughter blaming mother for AN (n = 1, 3.2%).

Prevalence of posttraumatic stress symptoms and PTSD diagnosis

Table 1 shows the number of participants who fulfilled each of the individual DSM-IV diagnostic criteria for PTSD. Three (9.7%) participants met full and 5 (16.1%) participants met partial DSM-IV criteria for PTSD diagnosis following the AN-related traumatic event. Two (6.5%) participants met full and 6 (19.4%) met partial DSM-IV criteria for PTSD at the time of interview. In order to check inter-rater reliability of SCID scoring, 10% of interviews (n = 3) were rated by a second SCID-trained individual; the reliability was 82.0%, with agreement on 12 out of 15 criteria. The time since the AN-related traumatic stressor occurred did not significantly relate to PTSD diagnosis (Mann-Whitney test, U = 29.500; ns) or PTSD diagnosis at the time of the interview (U = 21.500; ns).

Insert Table 1 about here

On the PDS, participants' mean trauma severity score was 9.42 (SD = 7.56, range = 0-28). The number of participants fulfilling each PTSD criterion according to the PDS is shown in Table 1. Twenty (64.5%) participants currently met criteria for partial and 11 (35.5%) for a symptom diagnosis of PTSD. The time since the AN-related traumatic stressor occurred did not significantly relate to PTSD symptom diagnosis (Mann-Whitney test, U = 107.500; ns) or PDS total score for frequency (Pearson correlation, r = 0.25).

History of trauma, past PTSD, and psychiatric history

Twenty-one participants (67.7%) reported that they had experienced at least one previous traumatic event, including the death of a parent (n = 12, 38.7%), difficulties giving birth or miscarriages (n = 4, 12.9%), the death of a child (n = 3, 9.7%) and their own serious illness (n = 3, 9.7%). With respect to these events, two participants (6.5%) had been diagnosed with PTSD in the past. Nineteen participants (61.3%) reported a psychiatric history, including: depression (n = 10, 32.3%), anxiety (n = 2, 6.5%), PTSD (n = 2, 6.5%) and adjustment difficulties following their daughters' diagnosis (n = 6, 19.4%). Fourteen (45.2%) had received treatment for these, including medication (n = 11, 35.5%) and counseling (n = 3, 9.7%). Six (19.4%) participants were currently on medication. Analyses revealed no associations between PTSD diagnosis since the traumatic stressor occurred and psychiatric history, $X^2(2, N = 31) = .142$, *ns*; trauma history, $X^2(2, N = 31) = .873$, *ns*; or past PTSD, $X^2(2, N = 31) = .807$, *ns*. Furthermore, there were no associations between current PTSD diagnosis and psychiatric history, $X^2(2, N = 31) = .066$, *ns*; trauma history, $X^2(2, N = 31) = .073$, *ns*; or past PTSD, $X^2(2, N = 31) = .626$, *ns*.

Symptoms of depression and anxiety

Twenty (64.5%) participants reported symptoms of depression in the normal range, 6 (19.4%) in the mild, 5 (16.1%) in the moderate range, and none in the severe range. The mean score for current symptoms of depression was 5.90 (SD = 3.58). Eleven (35.5%) scored above 8, indicating clinically significant levels of depression. The mean score for anxiety symptoms was 10.06 (SD = 4.14), with 10 (32.3%) participants falling into the normal category, 8 (25.8%) into the mild category, 9 (29.0%) into the moderate category, and 4 (12.9%) into the severe category. Twenty-one (67.7%) participants scored higher than 8, which indicates that their symptoms were of clinical significance. The mean total score on the Hospital Anxiety and Depression Scale was 15.97 (SD = 6.90). Analyses revealed significant associations between PTSD diagnosis since the AN-related traumatic stressor occurred and HADS anxiety score, $X^2(2, N = 31) = p < .05$, but not HADS depression score, $X^2(2, N = 31) = .755$, *ns*. Furthermore, there were significant associations between current PTSD diagnosis and HADS anxiety score, $X^2(2, N = 31) = p < .05$, but not HADS depression score, $X^2(2, N = 31) = .755$, *ns*.

Distressing aspects of anorexia nervosa

Participants' mean rating for each item of the DAQ are shown in Table 2, along with the distribution of distress ratings for each item. This also includes aspects of their daughter's AN that mothers reported to be distressing in addition to the once listed on the DAQ. The most highly rated item was 'Seeing how thin my daughter was', with a mean score of 3.87 (SD = 0.43). Twenty-eight (90.3%) participants rated this item as very severely distressing. 'Worrying about my daughter being so unwell she needs hospital treatment' and 'worrying about my daughter dying' were the next most highly rated items.

Insert Table 2 about here

Discussion

The majority of mothers reported clinically significant levels of anxiety, and a notable proportion reported depression and posttraumatic stress symptoms. These findings add to previous research, which has found high levels of distress (Treasure *et al.*, 2001) and poor quality of life with respect to mental health (De La Rie *et al.*, 2005) in carers of those with eating disorders. It appears that living with someone with AN may significantly affect the mental health of mothers; however, since this is not a prospective study, causality cannot be inferred.

Using the SCID, 6.5% of mothers met full and 19.4% met partial DSM-IV criteria for current PTSD. Furthermore, 9.7% of participants met full criteria and 16.1% met partial DSM-IV criteria for PTSD diagnosis following the AN-related traumatic event (retrospective reporting). This is higher than the point prevalence rates of 1.5-3% found in other Western populations (NICE, 2005) and slightly higher than the lifetime prevalence rate of 8% found in US populations (APA, 2000). This latter point is notable since point prevalence rates of PTSD can be expected to be lower than lifetime prevalence rates (NICE, 2005), yet the point prevalence in this study is higher than reported lifetime rates in the general population. The point prevalence rates in the current study are comparable to a sample of mothers of children undergoing bone marrow transplantation (Manne *et al.*, 2002). When considering these findings, it should be noted that a high proportion of participants (n = 21, 67.7%) reported having experienced a previous traumatic event. This could perhaps be expected to influence results, given that history of vulnerability has been widely associated with increased trauma symptoms (Brewin, Andrews & Valentine 2000), and most people will experience at least one traumatic event in their lifetime (Kessler, Sonnega & Bromet, 1995). However, no associations between current PTSD and trauma history or past PTSD were found. As has been found in other studies (e.g. Horsch *et al.*, 2007), the prevalence of PTSD symptoms was higher when assessed by the PDS than when assessed by the SCID. Therefore, the formal diagnosis of PTSD was based on the SCID rather than the PDS.

Anxiety symptoms were higher in this population than in mothers of children with Type I diabetes mellitus (Horsch *et al.*, 2007) or children undergoing stem cell transplantation (Manne *et al.*, 2004), with more than half of participants reporting clinically significant levels. Our finding that PTSD diagnosis or symptoms were associated with heightened symptoms of state-anxiety but not depression is in line with previous research on comorbidity. It should be noted that the anxiety and depression in this population is likely to be multifactorial, as a substantial proportion of participants reported previous psychological difficulties, including anxiety (6.6%) and depression (33%).

The strength of this study was to relate participants' trauma symptoms to specific experiences associated with their daughters' AN, rather than 'AN as a whole'; the majority of studies in the traumatic stress literature to date have treated a child's illness as one traumatic stressor. As expected, mothers reported traumatic stressors that can be viewed as life threatening events during the course of AN, such as 'thinking their daughter was about to die or dead', ‘seeing or consenting to their daughter being tube-fed’, and ‘waiting to receive urgent professional help or an inpatient bed’. However, some of these traumatic events were also of interpersonal nature, such as ‘daughter threatening to run away (because of disagreements regarding food) and ‘daughter blaming mother for AN’, which reflect the pressures on caregivers in dealing with eating disorder-related problems that have previously been proposed in a model of carer distress (Treasure *et al.*, 2005). Given the often chronic nature of AN and the high rate of relapse, caregivers are likely to be confronted again with any of these AN-related traumatic stressors in the future, increasing the risk of further traumatisation. Finally, the traumatic stressors identified by participants met A-1 and A-2 criteria confirming that conceptualising mothers’ distress in relation to their child’s AN as ‘posttraumatic stress’ is useful.

We also found that mothers rated chronic aspects of their daughter’s AN as very severely distressing, such as ‘worrying about daughter needing hospital treatment’, ‘worrying about permanent damage to daughter’s health’, ‘feeling unable to encourage daughter to eat’, and ‘worrying about daughter dying’. This may partly explain the elevated levels of anxiety and depression in this population and is in line with distressing aspects reported by previous studies (e.g. MacDonald, 2000; Treasure *et al.*, 2001; Treasure *et al.*, 2005).

We note the limitations of this study. The response rate and the size of the sample were relatively small and there was a lack of participants from ethnic minorities. Requiring participants to opt-in before contacting them (as required by the ethics committee) may have reduced the response rate and also introduced potential biases. Those mothers who did opt-in were already in contact with services or support groups, or had relationships with their daughters that allowed their daughter to pass information on to them. Given the frequent interpersonal difficulties and secrecy associated with AN (Cottee-Lane *et al.*, 2004), many mothers with distressing experiences related to their daughters’ AN will not have been approached. Another weakness is the reliance on retrospective reporting, particularly with regards to past PTSD symptoms. Furthermore, the Distressing Aspects Questionnaire has not been tested with regards to its psychometric properties. Finally, the use of a cross-sectional design does not lend itself to measuring the chronic course of distress in mothers along the time-course of their daughter's illness. However, the use of a structured clinical interview to assess a diagnosis of PTSD is a major strength of this study, particularly given that the inter-rater reliability of the SCID interviews was checked and found to be sufficient.

The results of this study suggest that services should conduct routine assessments of the mental health of mothers of individuals with eating disorders. It confirms the value of offering carer assessments, and linking in with primary care or general mental health services, in order to assess and to attend to the needs of this population. We would propose that clinicians use similar questions to those used in the study to help mothers articulate the most distressing aspects of their daughters' condition, in order to feel supported and validated. Our finding that several mothers reported 'being unable to prevent their daughter's deterioration' as highly distressing, confirms the value of interventions that endeavour to increase the coping and caring skills of mothers (Treasure, Smith & Crane, 2007). It is likely that interventions targeting mothers experiencing severe distress are also likely to have a beneficial impact on their daughters' well-being (Treasure *et al.*, 2001). Although this study focused exclusively on mothers of individuals with AN, it is likely that the mental health of other carers and family members may also be affected, and therefore services should consider this as well.

The fact that waiting for support or hospital admission was identified as the traumatic stressor for more than 20% of mothers, underlines the need for services to ensure that referrals are processed as quickly as possible, and that individuals and their families are offered advice and access to emergency provision while awaiting support. Mothers found the uncertainty of waiting difficult at these times, and described feeling powerless and alone at such times; the adequate provision of advice and information is therefore important to consider alongside the adequate funding of eating disorder services in general. Services might consider training for primary care and general mental health professionals to ensure that referral pathways do not contribute unnecessarily to any delay.

Given the chronicity of AN, longitudinal prospective research would be helpful in order to further investigate mothers' experiences and to examine whether their distress levels vary along the time-course of their daughter's AN. Further research is also needed in order to investigate the resilience of mothers whose daughters have AN. Finally, it would be important to also consider fathers' responses and to investigate whether their children's AN has a comparable impact on both parents.

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Table 1: Numbers of mothers fulfilling each PTSD criterion according to the SCID and PDS at the time of interview or since AN-related traumatic stressor occurred (n = 31)

	SCID (N, %)	PDS (N,%)
Current PTSD symptoms		
Criterion B	10 (32.3)	22 (71.0)
Criterion C	5 (16.1)	16 (51.6)
Criterion D	4 (12.9)	16 (58.1)
Meet criteria for partial PTSD diagnosis	5 (16.1)	20 (64.5)
Meet full criteria for PTSD diagnosis	2 (6.5)	-
PTSD symptoms since traumatic stressor occurred		
Criterion B	15 (48.8)	-
Criterion C	6 (19.4)	-
Criterion D	6 (19.4)	-
Meet criteria for partial PTSD diagnosis	6 (19.4)	-
Meet full criteria for PTSD diagnosis	3 (9.7)	-

Note. SCID = Structured Clinical Interview for DSM-IV; PDS = Posttraumatic Diagnostic Scale; PTSD = posttraumatic stress disorder

Table 2: Number of participants who rated different aspects of their child's AN as severely or very severely distressing (n = 31) and mean ratings for each of those aspects

Distressing aspect of daughter's AN	**Mean rating (SD)**	**Mothers' item ratings, N (%)**
		Severely or very severely distressing
1. Noticing a change and not knowing what was wrong with daughter	2.24 (1.02)	13 (41.9)
2. Finding out daughter had AN	3.33 (0.80)	24 (77.4)
3. Worrying about daughter needing hospital treatment	3.74 (0.51)	30 (96.8)
4. Worrying about permanent damage to daughter's health	3.52 (0.77)	26 (83.9)
5. Worrying about daughter's future	3.26 (0.86)	23 (74.2)
6. Worrying about daughter dying	3.74 (0.78)	29 (93.5)
7. Daughter's difficult behaviour around eating	2.87 (1.09)	20 (64.5)
8. Impact on family relationships	3.19 (0.87)	22 (71.0)
9. Not feeling involved in daughter's treatment	1.93 (1.19)	9 (29.0)
10. Daughter's physical deterioration	3.65 (0.55)	30 (96.8)
11. Feeling unable to encourage daughter to eat	3.30 (0.79)	26 (83.9)
12. Thinness of daughter	3.87 (0.43)	30 (96.8)
13. Feeling unable to help daughter	3.60 (0.68)	27 (87.1)
14. Daughter refusing treatment/ denying unwell	3.44 (0.93)	24 (77.4)
15. Daughter having treatment against her will	2.71 (1.36)	10 (32.3)
16. Feeling daughter had changed/ I had lost relationship with her	3.33 (0.78)	22 (71.0)
17. Worrying that daughter might be losing her mind	2.84 (1.07)	18 (58.1)
18. Making decisions against daughter's wishes	2.58 (1.18)	15 (48.4)
Items added by participants		
Waste/loss of their daughter's potential		7 (22.6)

Difficulties with services, including feeling blamed, let down and unsupported by professionals		5 (16.1)
Daughter’s violence		4 (12.9)
Loss of mother’s social life		4 (12.9)
Feeling hopeless as their daughter failed to respond to a succession of treatments		4 (12.9)
Impact on the other siblings in the family		4 (12.9)
Loss of spontaneity in the family due to daughter’s rigidity		3 (9.7)
Daughter’s negative self view		2 (6.5)
Impact on their daughter’s pre-existing physical health difficulties		2 (6.5)