



Caregiver burden and illness perceptions in caregivers of medically hospitalized youth with anorexia nervosa



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ABSTRACT

Caregiver burden is common in caregivers of youth with anorexia nervosa (AN) and could impede the successful implementation of family-based therapy (FBT). Thus, it is important to better understand mechanisms by which caregiver burden is developed and maintained. This study aimed to examine the relation between caregiver illness perceptions about AN, symptom severity indicators, and caregiver burden in a sample of medically hospitalized youth with AN. Fifty-one youth with AN ($N = 34$) or Atypical AN (AAN; $N = 17$; mean age = 14.85, $SD = 1.41$; 76% female) and their primary caregivers ($N = 47$ mothers and $N = 4$ fathers) completed self-report questionnaires at hospital admission. Collected data included caregiver and youth illness perceptions about AN, caregiver burden, and youth self-reports of psychological symptoms. Physiological data regarding symptom severity included admitting percent of expected body weight (%EBW) and minimum heart rate during admission. Findings indicated that caregiver beliefs about negative consequences of AN were associated with caregiver burden, independent of youth age, sex, illness duration, and diagnosis. Youth reports of symptom severity, % EBW, and low heart rate were not associated with increased caregiver burden. Findings suggest that the subjective experience of having a youth with AN are a greater determinant of caregiver burden than objective indicators of illness severity. Further, these findings provide support for the FBT clinician to strike a balance between providing information about the potential consequences of AN, while instilling hope for recovery and bolstering parent self-efficacy.

1. Introduction

Anorexia nervosa (AN) is often a chronic condition with the greatest incidence rate among adolescents (Herpertz-Dahlmann, 2009). Family Based Therapy (FBT) has the most empirical support for the treatment of pediatric AN and is associated with faster recovery rates, higher sustained remission rates, and a significant decrease in hospital readmissions and associated treatment costs as compared to individual psychotherapy (Couturier, Kimber, & Szatmari, 2013; Crow & Nyman, 2004; Lock et al., 2010; Lock, Couturier, & Agras, 2008). Theoretically, FBT draws upon the neurobiological underpinnings of AN, emphasizing that brain impairment secondary to starvation impedes the patient's ability to make appropriate health choices, including self-regulation of food intake. In FBT, caregivers are considered the primary treatment resource; they are directed to remove food-related decisions from their youth and to assume responsibility of all eating-related tasks (e.g., meal planning, preparation, supervision) until a healthy weight is restored, regardless of the child's motivation to change. Thus, treatment success is contingent upon caregivers' capabilities in these tasks (Lock & Le

Grange, 2013).

It is well established that the hallmark characteristics of AN, including body image distortion, fear of weight gain, emotional consequences of malnutrition, and the ego-syntonic nature of symptoms, often impede one's motivation to recover (Guarda, 2008; Vitousek, Watson, & Wilson, 1998; Westwood & Kendal, 2012). Thus, caregivers often recognize signs of the illness before affected youth even perceive symptoms to be problematic (Treasure, Gavan, Todd, & Schmidt, 2003). It is common for caregivers to initiate treatment and, in FBT, spearhead the weight restoration process while youth remain highly invested in AN symptoms. Strong resistance and emotional reactivity in youth is common during phase 1 of FBT. Consequently, caregivers may struggle with increased anxiety associated with consistent implementation of FBT interventions (Halmi, 2013; Whitney & Eisler, 2005).

Independent of treatment modality, caregiver burden is consistently illustrated in families of youth with AN (Padierna et al., 2013; Zabala, Macdonald, & Treasure, 2009), even exceeding that experienced by caregivers of individuals with schizophrenia (Treasure et al., 2001). Generally, caregiver burden is associated with poor mental health,

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lower quality of life, and experiencing negative aspects of care more intensely (de la Rie, van Furth, De Knoning, Noordenbos, & Donker, 2005; Martín et al., 2013). Given the paramount role of caregivers in successful FBT implementation, it is imperative to better understand the mechanisms by which caregiver burden is maintained. This will facilitate the development of interventions targeting caregiver burden in AN that in turn, could improve engagement in FBT.

In this study, we sought to examine illness perceptions in caregivers of youth with AN, given findings that negative-held beliefs about AN contribute to caregiver distress (Whitney, Haigh, Weinman, & Treasure, 2007). Generally, one's beliefs about a given illness (i.e., illness perceptions) have been implicated in treatment engagement, coping, and outcomes in both medical and mental health conditions, including cancer, cardiac and pulmonary diseases, diabetes, irritable bowel syndrome, asthma, depression, and psychotic disorders (Ashley, Marti, Jones, Velikova, & Wright, 2015; Bucks et al., 2009; Fortune, Barrowclough, & Lobban, 2004; Leventhal, Phillips, & Burns, 2016; Olszanecka-Glinianowicz & Almgren-Rachtan, 2014; Rutter & Rutter, 2002; Watson et al., 2006; Weinman, Petrie, Sharpe, and Walker, 2000; Wisting et al., 2015). In adults with eating disorders (ED), research indicates that negative illness perceptions are associated with higher levels of depression, anxiety, and more severe and chronic ED symptoms (DeJong, Hillcoat, Perkins, Grover, & Schmidt, 2012).

Despite the central role that caregivers have in facilitating recovery in FBT, little is known about caregiver illness perceptions about AN. Sim and Matthews (2013) found that mothers of youth in outpatient care perceived AN to be less understandable and controllable than mothers of youth with type 1 diabetes. Further, perceived consequences of AN, illness chronicity, and emotional burden secondary to their child's illness was associated with poorer family functioning, maternal anxiety, and depression (Sim & Matthews, 2013; Whitney et al., 2007). Padierna et al. (2013) found that mother's beliefs about the severity of their child's ED symptoms predicted greater caregiver distress, whereas neither child self-reports nor physician clinical ratings of symptom severity impacted caregiver well-being.

In the current study, we examined illness perceptions in the primary caregivers (mothers and fathers) of youth with AN, and the relation between illness perceptions about AN and caregiver burden. Our sample was unique in that youth were acutely ill and medically hospitalized for complications secondary to AN (i.e., bradycardia, postural orthostatic tachycardia syndrome, electrolyte imbalance). Further, youth in our sample were newly diagnosed with AN and had never received mental health treatment for AN. Study aims were threefold. First, we were interested in the relationship between caregiver and youth illness perceptions about AN. Given the ego-syntonic nature of AN and common denial of symptom seriousness in patients with AN (e.g., Westwood & Kendal, 2012), we hypothesized that caregivers would perceive AN more negatively than youth. Because FBT relies on the caregiver's motivation to engage in treatment, highlighting disparate illness beliefs of caregivers and patients with AN could foster caregiver persistence in implementing FBT despite child distress.

Given established evidence that caregiver burden is associated with negative beliefs about AN, particularly perceived consequences, chronicity, and emotional burden (Sim & Matthews, 2013), we examined the relation between these specific illness beliefs and burden in caregivers of medically hospitalized youth with AN. In line with previous findings (Sim & Matthews, 2013), we hypothesized that negative illness perceptions held by caregivers would be associated with burden associated with caring for a youth with AN.

Finally, given previous findings that child self-reports and clinician ratings of symptom severity were not associated with caregiver burden in ED (Padierna et al., 2013), we examined the association between physical indicators (e.g., lowest heart rate during hospitalization, percent expected body weight (%EBW) at admission) and child-reports of symptom severity with caregiver burden.

2. Method

2.1. Participants

Participants included 51 youth (mean age = 14.85, $SD = 1.41$; 76% female) hospitalized at a Midwestern children's hospital for medical complications secondary to AN, and their primary caregivers ($N = 46$ mothers and $N = 5$ fathers). Participants met DSM-5 diagnostic criteria for AN ($N = 34$) or atypical AN (AAN; $N = 17$; American Psychiatric Association, 2013). At admission mean body mass index (BMI) for youth with AN was 16.02 kg/m² ($SD = 1.41$) and mean percent of expected body weight (%EBW; defined by the 50th percentile for current height and age (Kuczmarski et al., 2000)) was 80.14% ($SD = 6.90\%$). In youth with AAN, mean BMI was 18.61 kg/m² ($SD = 1.63$) and mean % EBW was 93.33% ($SD = 5.86\%$). Mean illness duration for all participants was 6.66 months ($SD = 5.10$), mean length of hospital admission was 12.94 days ($SD = 7.35$) and mean minimum heart rate during admission was 37.31 beats per minute ($SD = 6.46$). Study exclusionary criteria included prior treatment history of FBT for AN, psychosis, acute suicidality, non-English speaking youth and/or caregiver, and neurodevelopmental disorders such as autism spectrum disorder, or intellectual disabilities in youth and/or caregiver that would prevent them from being able to read or interpret self-report questionnaires. This study was approved by the institutional review board and informed consent and assent were obtained from caregivers and youth.

2.2. Procedure

Assessment batteries were completed in participants' hospital rooms within 72-hours of admission. Youth and caregivers completed self-reports of illness perceptions about ED (Brief Illness Perceptions Questionnaire; Brief IPQ). Caregivers also completed a questionnaire about caregiver burden in the context of caring for child with ED (Eating Disorder Symptom Impact Scale; EDSIS) and youth completed symptom assessments of ED, depression, and anxiety (Eating Disorders Examination-Questionnaire; EDE-Q; Children's Depression Inventory-2 Short Form; CDI-2-S; Multidimensional Anxiety Scale for Children-Second Edition; MASC-2).

2.3. Measures

2.3.1. Brief Illness Perceptions Questionnaire (Brief IPQ; Broadbent, Petrie, Main, & Weinman, 2006)

The Brief IPQ is a self-report assessment of one's cognitive and affective perceptions about a given illness. It consists of 8-items that represent unique dimensions of illness beliefs. Whereas composite scores can be used on the Brief IPQ, summing items is recommended with caution and may not be valid with certain illnesses. Specifically, because the Brief IPQ is used to assess illness beliefs across diverse conditions, dimensions of illness perceptions are related in different ways based on characteristics of a given illness (Broadbent et al., 2015). Three specific dimensions of illness perceptions were used in our study, including perceived consequences of ED, perceived timeline of the illness (acute-chronic), and emotional impact of ED symptoms, as these domains have been associated with caregiver burden, maternal well-being, and family conflict (Sim & Matthews, 2013). Brief IPQ items are rated on a 0–10 scale, with higher scores representing increasingly negative perceptions. A recent meta-analysis demonstrated that the Brief IPQ has predictive validity for various mental and physical health outcomes (Broadbent et al., 2006). In our study, separate caregiver and youth versions of the Brief IPQ were given. Examples of items on the caregiver form included “How long do you think your child's eating disorder will continue?” (0 = “a very short time” to 10 = “forever”) and “How much does your child's eating disorder affect his/her life?” (0 = “no affect at all” to 10 = “severely affects his/her life”). Example items for youth included “How long do you think your eating disorder

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