Feeling of Burden, Psychological Distress, and Anxiety among Primary Caregivers of Children with Home Enteral Nutrition

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Objective To examine the relationship between several psychological factors and the feeling of burden experienced by caregivers of children with home enteral nutrition. Methods Fifty-six mothers of pediatric patients with chronic diseases requiring long-term home enteral nutrition were recruited. They were asked to respond to specific questionnaires about their anxiety symptoms (State-Trait Anxiety Inventory), psychological distress (SCL-90-R) and feeling of burden (Zarit-scale). Results Caregivers’ feeling of burden was found to be statistically associated to psychological distress ($r = .516, p < .001$) and trait anxiety ($r = .376, p = .005$). No significant differences were found between the type of diagnosis and caregiver burden. Regression analysis indicated psychological distress has a partial mediational effect in the relationship between trait anxiety and caregivers’ burden. Conclusions Psychological distress and anxiety show a positive correlation with caregivers’ feeling of burden, and may disrupt family well-being. Early identification of high-risk situations is essential in order to plan specific psychosocial aid efficiently.

Key words anxiety; children; developmental disabilities; parent stress; psychological testing.

Introduction

Home enteral nutrition (HEN) is an increasingly used nutritional support system that enables patients with medically stable chronic illnesses and their families to return home, thereby improving socialization and “normalization-adaptation” of their way of life (Gómez-Lópe et al., in press). However, the food-related and medical problems leading to HEN, and HEN itself, may pose increased responsibility and pressure on the primary caregiver, who is usually the mother (Sullivan et al., 2004). This excessive responsibility can have an influence on physical and psychological health status (Tucker, Butler, Loyuk, Demond, & Surrency, 2009) and tends to curb social, cultural, and professional opportunities (Grootenhuis & Bronner, 2009). Eventually, this leads to a diminished quality of life (Davis et al., 2010).

Psychological consequences depend on three main factors: (1) external factors, such as home care, family social support, and economic resources (Heyman et al., 2004), medical services coordination, doctor–patient relationship, knowledge of the disease, route by which HEN is administered, and ease to obtain equipment/materials (Evans, Holden, & MacDonald, 2006); (2) patient-dependent factors, like illness severity, poor short-term prognosis, patient–caregiver relationship, psychological status, ability to communicate with the family, aggressiveness, difficulty in handling due to weight or deformities, etc. (Avitsland et al.,...
2006; Phelps, McCammon, Wuensch, & Golden, 2009); and (3) caregiver-dependent factors, such as basic lifestyle, anxiety, fear of leaving the child with another caregiver, preparation to perform technical tasks, work, grief for not having a healthy child, etc. (Tucker et al., 2009).

Caregivers who need technology at home, especially in order to provide HEN, have a particularly high risk of emotional disorder (Wang & Barnard, 2008), especially when their children depend on more than one technique, such as oxygen therapy, mechanical ventilation or peritoneal dialysis (Vanderhoof & Young, 2008). This group of pediatric patients requires almost continuous care and supervision. Thus, the primary caregiver must acquire nursing skills, learn to use devices that their children require, and make numerous visits to the hospital. They often require assistance from third parties regarding the related economic cost, have to modify their job, give it up or reduce their working hours (Moreno et al., 1998). Commonly reported psychological disorders of caregivers include fear surrounding the child’s death and concern about the child’s future (Murphy, Christian, Caplin & Young, 2007), a permanent state of alert (listening out for alarms, fear of HEN disconnecting, lack of control over related technology, anger, guilt, frustration, and sorrow), all of which often have clinical consequences like sleeplessness and anxiety, social and marital problems, or trouble with other children (Wang & Barnard, 2004). This situation can make the patient’s family potential “parallel patients” that require special attention.

In addition, the increased emotional and psychological burden of caregivers of children on HEN may adversely affect their children’s nutrition and health, increasing the number of complications and hospital admissions (Enrione, Thomlison, & Rubin, 2005). Likewise, despite efforts to enhance home care, our National Health System depends heavily on outpatient clinic-based care and there are few opportunities for home care. Thus, the responsibility and pressure on the caregiver is high.

Two factors that are closely linked to the feeling of burden experienced by caregivers of children with chronic illnesses are anxiety (Melnyk, Crean, Feinstein, Fairbanks, & Alpert-Gillis, 2007) and psychological distress (PD) (Black, Holditch-Davis, & Miles, 2009). Assuming that both trait anxiety (defined as the relatively stable tendency of a person to perceive situations as threatening or sense of excessive uneasiness) and PD (an unpleasant emotional state of psychological or social nature that affects the individual’s ability to cope with a particular set of circumstances) (Gadalla, 2009) may account for part of the differences in the feeling of burden (defined as a the negative impact on certain everyday tasks associated with care-giving) experienced by some caregivers, the aim of this study was to explore the influence of trait anxiety and PD on how caregivers of children on HEN perceive the feeling of burden in order to determine the relevance of this problem and establish adequate measures of treatment and prevention. Specifically, we sought to evaluate the possible relationship between the caregiver’s feeling of burden and the following variables: (1) child’s underlying disease, (2) primary caregiver’s socio-demographic variables (maternal age, familial socioeconomic status [SES], etc.), (3) state anxiety (anxiety as a transitory or acute emotional condition that can vary over time and fluctuate in intensity) and trait anxiety, (4) PD, and (5) how PD mediates (at least partially) in the relationship between trait anxiety and a feeling of burden.

Method
Design and Procedure
A prospective observational study was carried out between September 2008 and September 2009 at the Pediatric Gastroenterology and Nutrition Units of four public tertiary hospitals. The sample comprised voluntary parents or caregivers of pediatric patients in whom gastrostomy or nasogastric tube feeding had been indicated. The study protocol was approved by the ethics committee of each hospital in accordance with the Declaration of Helsinki of 1964, revised in Edinburgh in 2000. Written parental informed consent was obtained.

Participants
The group of participants comprised 56 primary caregivers of pediatric patients with chronic diseases that required prolonged HEN. Table I summarizes the patient’s characteristics, as well as those of their primary caregiver, and familiar SES. The latter has been calculated using Hollingshead SES scale (Hollingshead, 1975). The main diagnoses for which HEN and co-morbidities were prescribed were listed in Table II. There were 30 patients with one single underlying disease, mainly neurological (n = 16, 28.6%) or cardio-respiratory (n = 6, 10.7%). The remaining 26 patients presented co-morbidity. Only six patients (10.7%) had a history of prematurity. Regarding enteral access, four patients had nasogastric tube and the rest were gastrostomy-fed.

Measurements
Demographic Survey
The following data was obtained with respect to family demographic characteristics: maternal age, parental educational level, and occupational field. These last two factors
were introduced in the Hollingshead Occupational Scale (Hollingshead, 1975) to obtain the familial SES. Parental educational level was divided into seven categories, ranging from no educational studies to high education. Parental occupational field was divided into eight categories ranging from unemployed housewife to high business manager. The Hollingshead formula (Hollingshead, 1975) is the following:

\[
\text{FSS} = \frac{O: \text{father}/C25 + (E: \text{father} \times 3)}{2} - \frac{O: \text{mother} \times 5 + (E: \text{mother} \times 3)}{2}
\]

where FSS is the familial SES; O the occupational field; E the educational level.

Caregiver Burden Inventory (Zarit)
The Zarit scale (Zarit, Orr, & Zarit, 1985; Hanzawa, Tanaka, Inadomi, Urata, & Ohta, 2008), which was designed to assess the feeling of burden experienced by caregivers of patients with a high degree of dependence, was used. This scale was chosen for being a widely used tool to evaluate the intensity of the caregiver’s feeling of burden (Boyer, Drame, Morrone, & Novella, 2006). It consists of 22 items that assess the negative impact on certain everyday tasks associated with caregiving, effects on the caregiver, expectancy and beliefs on the caregiver’s capacity, and relationship between caregiver and patient. The caregiver was given a Likert-type scale of five frequency values ranging from 0 (not present) to 4 (always present). The scores obtained on every item were added, and the degree of burden of the caregiver was given by the total sum. This result ranged from 0 to 88 points. Generally, it is considered that there is no burden when the score is ≤46, mild burden exists between 47 and 55 points, and high burden if ≥56. Psychometric properties were satisfactory with Cronbach’s alpha of .91 and good test–retest reliability of .91. In this study, cut-offs were not established; instead, correlation between these scores and the other variables were analyzed.

Symptom Checklist 90 Revised (SCL-90-R)
The SCL-90-R (Derogatis, 1994; Gillen, Tennen, Affleck, & Steinpreis, 1998) was used to measure participants’ PD. The inventory includes 90 symptoms that assess the degree of discomfort on a Likert-type five-point scale, from “1” (no symptom) to “5” (full presence of symptom). The scale provides nine symptomatic groups. Analysis was based on the “General Severity Index”, which provides a reliable and valid measurement of PD combining information about the number of symptoms the person presents and the perceived intensity of PD. Test–retest reliability was between .78 and .90, with Cronbach’s alpha between .81 and .90.

State-Trait Anxiety Inventory
The State-Trait Anxiety Inventory (Spielberger, Gorsuch, & Luschene, 2002) is an inventory designed to evaluate two independent concepts of anxiety: state anxiety as a transitory or acute emotional condition that can vary overtime and fluctuate in intensity, and trait anxiety as a relatively stable tendency to perceive situations as a threatening. The score on the items of state varies between 0 and 3, establishing operational criteria according to intensity. The scale is widely accepted and extensively used in clinical research. The test–retest reliability was above .86, with Cronbach’s alpha between .84 and .93.
Data Analysis

Data was analyzed using Statistical Package for the Social Sciences® for Windows (version 16.0). The independent variables for the study were the type of diagnosis, the primary caregiver’s socio-demographic variables (maternal age and familial SES), PD, state anxiety, and trait anxiety. Caregiver burden was the dependent variable. Correlations between the variables under study and linear regression equations were calculated to assess whether increased caregiver burden was related to socio-demographic and psychological variables of the caregiver. For the comparison between the type of diagnosis and caregiver burden, the non-parametric Kruskal–Wallis test was used. Jonckheere–Terpstra test was used to test statistical trends and to estimate the effect of sample size. Significance was fixed at the value .05.

Results

The statistical results for each of the studied variables are summarized in Table III. Maternal age ($r = .165$, $p = .228$) and familial SES ($r = .240$, $p = .081$) were not significantly related to caregiver burden and were excluded from a subsequent more in-depth analysis. Caregiver burden was associated with trait anxiety ($r = .376$, $p = .005$) but not with state anxiety ($r = .087$, $p = .533$); consequently, the latter was also excluded. Furthermore, caregiver burden was found to be associated with PD ($r = .516$, $p < .001$). Regarding the type of diagnosis, no significant differences were found with caregiver burden (Kruskal–Wallis Test = 8.819, $p = .116$, Std. J–T Statistic = −1.033, $r$ Jonckheere = −.0138) and hence this variable was also disregarded for subsequent analysis.

Given the correlations between PD, trait anxiety, and caregiver burden, the potential mediating effect of PD on the relationship between trait anxiety and caregiver burden was analyzed. Various linear regression analyses were performed to check the four mediation conditions established by Baron and Kenny (1986) and restatement of Kenny, Kashy, and Bolger (1998). Table IV summarizes the results of the regression analyses.

To test mediation, four regression equations were used: first, between the predictor and the criterion variable; secondly, between the predictor and mediator variables; thirdly, between the mediator and criterion variable; and...
fourthly, with all three variables. It was assumed that mediation occurred when the following conditions were met: the predictor (trait anxiety) exerted an effect on the criterion variable (caregiver burden) in the first equation; the predictor (trait anxiety) influenced the mediating variable (PD) in the second equation; the mediating variable (PD) influenced the criterion variable (caregiver burden) in the third equation; and by introducing the mediator variable (PD) with the predictor (trait anxiety) to explain the criterion variable (caregiver burden), the predictor drops to a non-significant coefficient, in the fourth equation; in other words, mediation occurred when the predictor did not significantly influence the criterion variable in the equation on including the mediator variable.

Considering these requirements, we conducted four linear regression analyses, making sure they met the three conditions required to discuss mediation according to Baron and Kenny.

The first regression analysis showed that trait anxiety significantly affected caregiver burden ($\beta = .376, p = .005$). The second regression analysis indicated that trait anxiety significantly influenced PD ($\beta = .605, p = .001$) and in the third analysis, PD significantly accounted for caregiver burden ($\beta = .516, p < .001$), and trait anxiety was reduced to a non-significant coefficient in the fourth equation. Regarding caregiver burden, the percentage of variance accounted for by the PD variable reached 25% compared to 12.5% of the trait anxiety variable. The significance of trait anxiety (as a predictor of caregiver burden) ($\beta = .376, p = .005$) disappeared when PD was included in the regression equation ($\beta = .100, p = .504$). The bootstrap procedure was implemented to check the mediational effects throughout the estimation and evaluation of the direct and indirect effects (see Preacher & Hayes, 2008; Holmbeck, 2002, for reviews). The model’s indirect effects were tested using the bias-corrected bootstrap confidence limits. Significance was assessed by whether or not the 95% confidence limits contained zero. This approach takes the non-normality of the multiplicative distribution into account (resulting in asymmetric confidence limits) and has been shown to provide the most accurate confidence limits and greatest statistical power when compared with other existing approaches for detecting mediation (Shourt & Bolger, 2002; MacKinnon, Lockwood, & Williams, 2004; Holmbeck, 1997). Using 1000 resamples, the indirect effects of trait anxiety on caregiver burden through proposed mediators (indirect estimate $= 0.2108$; 95% confidence interval $= 0.0866 - 0.3728$) were significant ($F_{(2, 54)} = 9.752, p = .0003$).

Altogether, these findings support the hypothesis of the partial mediational effect of PD on the relationship between trait anxiety and caregiver burden. Figure 1 depicts the unstandardized $\beta$ coefficient, in terms of the predictive potential of each variable with respect to the adjacent one.

**Discussion**

The results of this study indicate that trait anxiety and PD affect the perception of burden experienced by the primary caregiver (usually the mother) of children on HEN. As we hypothesized, linear regression analysis revealed a partial mediation of the PD between trait anxiety and perceived stress. In particular, trait anxiety indirectly influences burden through its effect on PD.

That is, our results indicate that maternal trait anxiety negatively affects PD levels, and in turn, caregiver PD levels are negatively associated with the caregivers’ perception of the time and effort required to care for their children. This supports and complements previous studies indicating that the perception of stress predicts well-being among mothers of chronically ill children (Pedersen, Parson, & Dewey, 2004; Skok, Harvey, & Reddihough, 2006) and caregiver stress may directly or indirectly affect a wide variety of health indicators: physical, emotional, etc. (Brehaut et al., 2004; Melnyk et al., 2004).

In relation to other factors that may influence caregiver burden, this study found no significant association between the type of diagnosis and caregiver burden, which indicates partial independence between these variables. In other words, a serious diagnosis may not adversely affect the sense of burden. We should note that, in our study, the type of diagnosis variable was based solely on medical criteria (as there was no access to IQ scores or behavioral problems), which may not be sufficiently sensitive to distinguish the ensuing effects on caregiver burden. Other
studies have assessed this issue, finding that the number and complexity of children’s problems influence caregiver health more than the severity of the disease (Raina et al., 2005; Brehaut et al., 2009). However, studies of children with chronic diseases, such as cancer, in which diagnosis correlates closely with prognosis, evidently, the disease is associated with high caregiver anxiety levels (Iobst et al., 2009; Klassen et al., 2007).

No significant relationship was found between maternal age, SES, and caregiver burden. Family SES may be a source of stress for the primary caregiver of children on HEN; however, although one might expect that the greater the family resources the lower caregiver burden, our study was unable to confirm this. Possibly the sample size detracts from differences between groups. Moreover, in this respect, there are highly variable results in other studies of caregivers of chronically ill children (Wanamaker & Glenwick, 1998). Some studies indicate a relationship between socioeconomic and psychological variables (Canning, Harris, & Kelleher, 1996; White-Koning et al., 2007) while others find no relationship (Heyman et al., 2004).

This has been the first study to confirm the hypothesis that PD mediates (at least partially) the relationship between trait anxiety and caregiver burden. The research highlights the important role played by the affective factors of mothers of children on HEN. Many of the tasks that must be performed by the caregiver are emotionally charged and this could potentially jeopardize the caregiver’s mental health and consequently affect child care. Notwithstanding, this point needs to be verified in further studies (Brehaut et al., 2009). It is therefore essential that the professionals supervising these children bear in mind the primary caregiver’s affective factors, their ability to cope with caring for children with complex needs and individual factors bearing on stress (Dobie & Mellor, 2008). Health professionals may adopt different strategies, such as: identifying the most relevant facts for the family (Waters, Maher, Salmon, Reddinhought, & Boyd, 2004; Morrow, Quinzel, Loughlin, & Graig, 2008); simplifying NED administration (e.g., early placement of PEG may decrease primary caregiver stress, because food, water, and medications can be given more safely and easily [Sullivan et al., 2004; Avitsland et al., 2006]); supplying the family information in a broad range of formats; getting them actively involved in medical decisions and helping them gain access to support and resources (Franklin & Rodger, 2003) to reduce stress. Finally, it is important for researchers and clinicians to be able to identify when anxiety levels and PD are of greater intensity and frequency than usual to try to mitigate them or take a specialized approach.

Limitations

The results of this study should be interpreted with caution for a number of reasons. First, the transversal nature of this study limits the ability to draw conclusions of a causational or directional nature. Second, the statistical analysis is restricted to such small samples. Type I error should be considered when interpreting the relationship between the type of diagnosis, SES and caregiver burden. Third, the conclusions reached by this study cannot be extended to the general population because the results are based on individual experiences of the caregivers of children with complex difficulties and HEN.

Despite these limitations, our data contribute to emphasizing the importance of trait anxiety and PD in caregivers (Arnaud et al., 2008) and the high psychological stress is a vulnerability factor that magnifies the burden perceived by the caregiver.

Future research should include mental health problems of parents and carers of children on HEN and any other variables that may contribute to how well children and parents adjust.

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