

CAREGIVER BURDEN AND DEPRESSION IN PARENTS RAISING CHILDREN WITH DISABILITIES/CHRONIC CONDITIONS

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Parents of children with disabilities/chronic conditions frequently experience a higher amount of stress in providing care to these children than parents caring for typically developing children (Ferrario, Zotti, Zaccaria, & Donner, 2001; Lam & Mackenzie, 2002; Mandleco, Olsen, Dyches, & Marshall, 2003; McDougal, 2002; Melnyk et al., 2001; Ow, 2003; Tsai, 2003). In addition, caregivers of chronically ill children face challenges ranging from maintaining a treatment regimen to dealing with social consequences of the illness (Williamson, Walters, & Shaffer, 2002), which may effect their well-being. Indeed, the nature of caring for a child with a disability/chronic condition puts parents at risk for role overload and caregiver burden that is cumulative and may lead to depression (Tsai, 2003).

Even though researchers have studied children with disabilities/chronic conditions and their impact on family well-being for a number of years, early work often relied solely on the mother as an informant. However, more recently, researchers have broadened their studies by using other family members (including fathers) as informants. Therefore, the purpose of this study is use both mothers and fathers as informants and examine their perceptions of caregiver burden and depression when raising children with a disability/chronic condition. Specifically, the study sought to determine: (1) the relationship between and caregiver burden and depression; (2) if differences in caregiver burden and depression exist according to parent gender; and (3) if there is a difference between caregiver burden and depression in parents raising children with different kinds of disabilities/chronic conditions (autism, Down syndrome, other disabilities).

This quantitative descriptive study is an extension of an on going interdisciplinary research project examining family adaptation to disability/chronic conditions. The 132 families who participated in this part of the study were recruited from local support groups for families raising a child with a disability/chronic condition. Most families were two parent, Caucasian, middle class, earned more than \$50,000, and had an average of 3.8 children. The mothers' ages ranged from 26-59 years with a mean age of almost 40; most (62.6%) worked either full or part time, and had completed almost 15 years of education. The fathers' ages ranged from 29-64 with a mean age of 42; the vast majority (97.3%) worked full time, and had completed over 15 years of education. The mean age of the children with disabilities was 9 nine years, and they were categorized as having autism (20.6%), Down syndrome (25.2%), or other disability (54.2%).

After receiving IRB approval, families were mailed a consent letter, instructions, and a questionnaire that each parent was to complete independently. One part of the questionnaire measured depression, and another part measured caregiver burden.

The Center for Epidemiological Studies Depression (CES-D) Scale (Radloff, 1977), developed for use in the general population, measured depression. The CES-D is a reliable and valid instrument with an internal consistency of .85. This instrument includes 21 statements (i.e. I felt I was just as good as other people, I felt hopeful about the future, my sleep was restless) describing typical feelings and allows a person to rate themselves on how often they feel a certain way (1-rarely or none of the time, 2-some of the time, 3-occasionally, 4-most or all of the time).

The caregiver burden instrument, adapted by Robinson (1983) from the Caregiver Strain Index (CSI) measures major factors influencing caregiver burden (i.e. employment, financial, physical, social, and time), and is used to identify caregivers at risk for burden. The original index, measuring objective burden, has an internal consistency alpha level of .86. The adapted instrument used for this study consists of 20 typical everyday events (i.e. feeling that my children are a source of joy to me, feeling that my children teach me wonderful and worthwhile things, feeling physically drained by caring for my children) that parents are asked to rate themselves not only on how frequently they feel that way (1-rarely, 2-sometimes, 3-a lot, 4-constantly), but also on how much of a hassle they feel the event is (1-no hassle, 2-a

little hassle, 3-medium hassle, 4-big hassle) with respect to the amount of work it takes to raise all the children in their family. The frequency of no burden was analyzed by how often the parent reported “rarely” with respect to negative feelings.

After obtaining descriptive statistics on all variables, a *t* test was performed to compare mother’s and father’s depression, frequency of burden, hassle of burden, and frequency of no burden. Pearson correlations were then calculated and regressions performed with family income, number of children, and mother’s/father’s depression as independent variables with the following dependent variables: mother’s/father’s frequency of burden, mother’s/father’s hassle of burden, and mother’s/father’s frequency of no burden. Finally, analyses of variance (ANOVA) were performed to determine the differences between mother’s/father’s depression, frequency of burden, hassle of burden, and frequency of no burden according to the type of family (raising a child with Down syndrome, raising a child with autism, raising a child with a disability).

Mother’s and father’s frequency of burden and hassle of burden were related to depression in the expected direction. Tsai (2003) suggests higher perceived stress in individual’s results in lower role enjoyment, marital satisfaction, and self-esteem/mastery, and poor functioning which may manifest itself as depression, and these families certainly are experiencing stress. In addition, caring for a child with disabilities/chronic conditions is burdensome. However, it is unclear if the depression is the result of caregiver burden or if caregiver burden is the result of depression. Since an individual’s mental health affects all aspects of his/her life, depression can contribute to a parent temporarily viewing his/her tasks and caregiver responsibilities negatively including caring for a child with a disability/chronic condition. (Tsai, 2003).

Mothers rated themselves higher for depression, frequency of burden, frequency of no burden, and hassle of burden than fathers. This may be because the mothers in this study, even though most worked either full or part time, were the primary caregivers of the child with a disability/chronic condition. On the other hand, fathers worked full time and may not have spent as much time caring for the child with the disability as did the mothers. This finding is similar to another research project which discovered fathers felt their child’s condition indirectly affected them because they worked full-time and the mothers provided more of the routine care (Gray, 2003). In addition, a recent meta analysis found mothers have a higher levels of depression and caregiver burden than fathers (Pinquart & Sorensen, 2006).

Parents of children with autism rated themselves higher for mother’s/father’s frequency of burden and father’s hassle of burden than parents of children with Down syndrome or other developmental disabilities. Due to the nature of autism, the findings are not surprising. Since children with autism have more behavior problems and decreased sociability than children with Down syndrome (Sharpley & Bitsika, 1997), or other developmental disability, they may require more care.

Interventions are necessary to help parents choose healthy coping strategies and adjust to raising a child with a disability/chronic condition. Interventions should include teaching effective communication skills and conflict management strategies. Support groups for families raising a child with a disability/chronic condition that allow them to share information, contact each other, and learn more about their child’s condition may also help ease caregiver burden and depression. Besides providing an emotional outlet for parents, support groups can also provide opportunities for building relationships leading to help with caregiving. Since caring for a child with a chronic illness is a profound stressor, parents should evaluate their own coping strategies and support groups, and seek professional help when their own coping systems fail. In addition, providing respite for these families, especially mothers may also help alleviate the stress and associated impact on well being. Health care providers need to answer questions parents have honestly and comprehensively so they fully understand care and procedures. Parents may also increase their individual adaptation skills by interacting socially, increasing role involvement outside the caregiving role, and seeking support when needed (Tsai, 2003).

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