



KEY WORDS

*child
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The Impact of Child Disability Type on the Family

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The purpose of this study is to better understand the differential impact of specific diagnoses on outcomes in families with children who have physical disabilities and to suggest ways in which clinicians across disciplines can use that knowledge to develop and implement more individualized, evidence-based programs. Descriptive statistics, correlation, and a univariate analysis of variance (ANOVA) were used to analyze data gathered from a sample of 205 parents or guardians of children with physical disabilities. Findings revealed a modest effect of diagnosis type on five family outcomes. These outcomes included: (1) how parents or guardians rated their child's current health compared to 1 year before the study, (2) the degree to which the child's physical health caused worry, (3) the degree to which the child's emotional well-being or behavior caused worry, (4) the degree to which the child's health or behavior limited types of family activities, and (5) the degree to which the child's health or behavior interrupted family activities. This article presents an interprofessional model of response.

Abundant evidence exists that suggests caring for a child with a chronic illness or disability is stressful. What is less clear, in part due to a very limited number of investigations, is which aspects of raising a child with a disability have the greatest effect on the family. The purpose of this article is to better understand the differential impact of specific diagnoses on family outcomes and to suggest ways in which clinicians across disciplines can use this knowledge to develop and implement more individualized, evidence-based programs to support families.

Family Outcomes in Families of Children with Chronic Health Problems

Many studies have documented the effects of caring for a child with a chronic illness or disability on both individual outcomes such as depression or life satisfaction, and dyadic outcomes such as marital satisfaction or marital stability. Some early studies, such as a comprehensive critique of the literature around marital adjustment to childhood chronic illness, concluded that parents of children with chronic illnesses experienced more marital distress than parents of children without chronic illnesses (Sabbeth & Leventhal, 1984). In another early review examining the effects of having children with special needs on marital relationships, Benson and Gross (1989) found evidence of both positive and negative effects on the marital dyad. Several studies (Abbott & Meredith, 1986; Capelli, McGarth, Daniels, Manion, & Schillinger, 1994; Kazak, 1987) found no differences in marital satisfaction between parents caring for children with chronic health problems and those caring for healthy children. Because these studies involved small, clinical samples, Eddy and Walker (1999)

examined marital satisfaction and stability using a large, nationally representative sample. They found no differences in either variable between parents caring for children with special needs and those with healthy children.

Nonmarital effects on the family unit have been studied less widely. Nevertheless, a few studies have documented family concerns about social isolation and other psychosocial outcomes (Abresch, Seyden, & Wineinger, 1998; Bothwell et al., 2002; Jenney & Campbell, 1997). As with marital outcomes, at least one study found no differences between families of children with chronic health problems and families of healthy children on a variety of family functioning measures. Magill-Evan, Darrah, Pain, Adkins, and Kratochvil (2001) found that families of adolescents and young adults with cerebral palsy demonstrated similar scores on family functioning and life satisfaction as families of adolescents without a disability.

The Relationship of Child Diagnosis to Family Outcomes

Family functioning is complex for families of children with chronic health problems. It is important to explore what factors are most closely related to increased or decreased family functioning so that individualized, targeted interventions can be designed. One question that needs to be addressed is whether (and in what ways) specific types of chronic health problems are related to family functioning. Most published studies focus on families of children with chronic physical illnesses or developmental disabilities. We know less about families of children with physical disabilities such as neuromuscular disease, spinal cord injury, limb deficiency, or spina bifida. Some researchers, such as Pless and Pinkerton (1975), suggest that the fact

of having a chronic condition is more significant to the child, parents, and siblings than the specific character of the disorder. This framework, deemed the *noncategorical model of child chronic conditions* (Stein & Jessop, 1982), is supported in some studies and rejected in others. An early longitudinal study of the association between type of illness or disability and family functioning differentiated families with children with chronic health problems from families of healthy children, but did not differentiate families of chronically ill children from families of developmentally disabled children (Stein & Jessop). More recently, though, Wallander and Varni (1998) found that neither the nature of the child's impairment (whether involving speech, hearing, motor, or cognitive skills), nor its severity, were associated with maternal adjustment.

In certain cases, there is evidence that type and severity of disability are related to parental functioning. For example, in a study of the health and well-being of caregivers of children with cerebral palsy, behavioral issues and the degree of caregiving burden had direct, negative effects on family functioning, and indirect, negative effects on caregiver psychological and physical health (Rainer et al., 2005). Similarly, behavioral issues in children with developmental disabilities seemed to be clear and consistent predictors of high stress levels in caregivers (Friedrich, Cohen, & Wiltturner, 1987; Singer & Farkas, 1989; Woolfson, 2004).

Social Variables and Their Relationship to Family Outcomes

In addition to the possible effects different types of child disability may have on families, several other variables also may affect family outcomes, including race and ethnicity. Very few studies examine the association between race and ethnicity and outcomes in families of children with disabilities. However, in one study researching families with deaf children, ethnicity was not related to parents' stress level (Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002). The authors speculate that this finding may be unique to their study, because overall stress was low and participants were receiving a high level of continuous support.

The influence of income on families of children with disabilities has been studied more often than the influence of ethnicity. Several studies found that gross income was positively related to family health, although increased costs of providing care and financial concerns in general were associated with stress in families (Bothwell et al., 2002; Dobson & Middleton, 1998; Rainer et al., 2005). One study examined the effects of ethnicity and socioeconomic resources on the well-being of mothers of young adults with an intellectual disability (Eisenhower & Blacher, 2006). Findings suggested that higher well-being scores for

Caucasian mothers compared to Latina mothers were entirely accounted for by socioeconomic status.

Research Question

The present study responds to a gap in the literature by examining the differential impact of child diagnosis on the following variables in families of children with chronic physical disabilities: (1) Compared to 1 year ago, how would you rate your child's health now? (2) How much emotional worry or concern does your child's physical health cause you? (3) How much emotional worry or concern does your child's emotional well-being or behavior cause you? (4) Does your child's physical health limit the amount of time you have for your own personal needs? (5) Do your child's emotional needs limit the amount of time you have for your own personal needs? (6) Does your child's health or behavior limit types of activities you are able to do as a family? (7) How often has your child's health or behavior interrupted various everyday family activities? (8) How would you rate your family's ability to get along with one another? Response options were in 4- or 5-point Likert-type formats.

Methods

Sample and Data Collection

This study reports data about parents gathered from a larger study focusing on chronic pain and fatigue in children with physical disabilities (Engel, Petrina, Dudgeon, & McKearnan, 2005). Respondents were from a convenience sample of 205 parents or guardians of children with disabilities (including spinal cord injury, amputation, congenital limb deficiency, cerebral palsy, spina bifida, or neuromuscular disease) who were receiving healthcare services in western Washington. A variety of strategies, including mailings from clinics at a local children's hospital and rehabilitation clinics, public postings, word of mouth, and publicity at a summer camp for children with neuromuscular disease, were used to recruit a diverse study group. Respondents completed a one-time mail survey or telephone interview conducted by a research assistant trained in the study protocol.

Instrumentation

A structured interview (the "Parent Survey") (that was developed for the larger study evaluating chronic pain and fatigue in children with physical disabilities) consisted of several standardized questionnaires related to pain intensity, pain interference, coping strategies, quality of life, healthcare use, and demographic and descriptive information. Preliminary findings from other parts of the study are reported elsewhere (Engel, Petrina, Dudgeon, & McKearnan, 2005). Family outcome variables of

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interest for this article are part of the Child Health Questionnaire Parent Form 28 (CHQ-PF28) (Landgraf, Abetz, & Ware, 1996). The CHQ-PF28 is a generic, norm-referenced instrument that assesses parent reports of a child's physical and psychosocial well-being as well as his or her own well-being. This instrument was developed for youths 5–17 years of age and has been used in large population studies in Australia, Ireland, and the United Kingdom. Content areas measured by the CHQ-PF28 include a child's global health, physical functioning, everyday activities, pain, getting along with family members, general well-being, self-esteem, physical health, and any emotional or time impact on the parent. The CHQ-PF28 summary measure and one multi-item scale showed adequate internal consistency (Cronbach's $\alpha > 0.7$) (Raaij, Botterweck, Landgraf, Hoogeveen, & Essink-Bot, 2005). The parent versions of the Child Health Questionnaire (CHQ-PF 28 and CHQ-PF 50) have documented lower physical function and psychosocial summary scores for youths with cerebral palsy (Liptak et al., 2001). Construct and discriminative validity of the CHQ-28 has been documented with a variety of subpopulations with chronic illnesses and disabilities (Drotar, Schwartz, Palermo, & Burant, 2006; Gorelick, Scribano, Stevens, & Schultz, 2003; Raaij et al., 2005).

Human Subjects Protection

This study was approved by the Children's Hospital and Regional Medical Center's Institutional Review Board (Seattle, WA) and Madigan Army Medical Center's Institutional Review Board (Tacoma, WA). All parents provided written, informed consent to participate in the study.

Data Analysis

SPSS Version 13 (Chicago, IL) was used for data analysis. Frequencies and percentages for participant gender, marital status, and race and ethnicity were calculated, as were age means, ranges, and standard deviations. Income level was reported categorically and analyzed using mode and median. Child mean age and range were included to better describe families. Associations between demographic variables, child diagnosis, and family outcome variables were examined in order to develop multivariate models to answer the research questions. Results were identical for correlations performed using Pearson R and Spearman Rho . Finally, main effects of diagnosis type on family outcomes were examined using a one-way univariate analysis of variance (ANOVA).

Results

Sample Demographics

Two hundred and five parents responded to the study survey. Seventy three percent of the respondents were mothers, 12% were fathers, and 15% identified themselves as other. Only 33% of the respondents claimed to be married, but many families did not respond to the marital status question. Respondent age ranged from 31–59 years, with a mean age of 43 years. Child age ranged from 8–20 years, with a mean age of 12.7 years. Ethnicity varied widely, with 8 African American respondents, 4 American Indian or Alaska Native, 18 Asian, 154 Caucasian, 7 Hispanic, 2 Pacific Islander, and 7 who responded to the question as "other." Level of income varied widely, even though 24% of the sample did not respond to this question. Two and a half percent of the respondents reported yearly family incomes of less than \$10,000 ($n = 5$), and 28% reported incomes greater than \$70,000 ($n = 58$). Modal yearly income level was greater than \$70,000, and median income level was \$40,000–\$50,000.

Correlations

Neither respondent level of education nor ethnic group was correlated with any of the family outcome variables. Although the correlation was low in this study, income had a positive correlation ($R = .18, p = .048$) with the rate at which family members get along with each other, which is consistent with most existing literature (Rainer et al., 2005).

Child diagnosis was significantly related to five family outcome variables: (1) how a parent rated his or her child's health now compared to 1 year ago, (2) the degree to which a child's physical health caused worry, (3) the degree to which a child's emotional well-being caused worry, (4) the degree to which a child's health limited type of family activities, and (5) the degree to which a child's health interrupted family activities. Three variables that were theoretically related to diagnosis (the degree to which a child's physical health limited time for parent's personal needs, the degree to which a child's emotional well-being or behavior limited time for the parent's personal needs, and the degree to which a family gets along) were not significantly related to family outcomes in this study.

Research Question: What Is the Impact of a Specific Diagnosis on Family Outcomes?

Significant relationships existed between the child's type of disability and the following five family outcomes (Tables 1 and 2). For all variables, higher mean scores indicated more negatively perceived outcomes:

Table 1. Means and Standard Deviations by Child Diagnosis

	SCI	AMP	CLD	CP	SB	ND
Child's health now	2.8 (1.2)	3.9 (0.6)	2.0 (0.6)	2.7 (0.8)	3.0 (0.8)	3.2 (0.8)
Health worry	2.2 (1.2)	2.3 (0.5)	1.9 (0.5)	3.0 (1.3)	2.9 (1.2)	2.9 (1.2)
Emotion worry	2.6 (1.3)	3.0 (1.4)	1.7 (0.6)	2.7 (1.3)	3.1 (1.2)	3.0 (1.3)
Limit activities	3.3 (1.0)	4.3 (0.8)	4.2 (0.6)	3.2 (1.3)	3.1 (1.2)	3.0 (1.3)
Interrupt activities	4.1 (1.2)	4.3 (0.5)	4.7 (0.5)	3.6 (1.3)	3.5 (1.0)	3.7 (1.2)

Note. SCI = spinal cord injury, AMP = amputation, CLD = congenital limb deficiency, CP = cerebral palsy, SB = spina bifida, ND = neuromuscular disease.

1. For "How a child's health was rated now compared to 1 year ago," descriptive statistics ranged from a low perception of worsening health for families with a child diagnosed with congenital limb deficiency to a high perception for families of a child with muscular dystrophy.
2. The degree to which a child's physical health caused worry ranged from low for congenital limb deficiency to high for spina bifida.
3. The degree to which a child's emotional well-being or behavior caused worry ranged from low for congenital limb deficiency to high for spina bifida.
4. The degree to which a child's physical health limited types of family activities ranged from low for muscular dystrophy to high for amputation.
5. The degree to which a child's health or behavior interrupted family activities ranged from low for spina bifida to high for congenital limb deficiency.

**Discussion and Application to Practice:
A Model for an Interprofessional
Response**

As expected, parents of children with conditions that may be less medically stable, such as neuromuscular disease, spina bifida, or cerebral palsy, experienced more worry and concern than parents of children with more stable conditions, such as congenital limb deficiency or amputation. Families whose children had more "stable" conditions such as amputation and congenital limb deficiency were more likely to have family activities interrupted or be limited. Because findings varied by child diagnosis for five of eight variables, it seems clear that plans for family advocacy and care need to be somewhat individualized based on diagnosis. In particular, families of children with conditions that may become worse over time, such as muscular dystrophy, indicated their concern about their child's worsening health. These families need a care team that is able to recognize when care needs to intensify. For this reason, a child's healthcare team members need to work together to ensure

Table 2. Analysis of Variance for Child Diagnosis Effects on Family Outcomes

Outcome	df	MS	F	p
Child's health now	5	2.57	3.67	.004**
Physical health worry	5	3.90	2.84	.018*
Emotion/behavior worry	5	3.63	2.29	.049*
Limit activities	5	3.86	2.69	.023*
Interrupt activities	5	3.21	2.50	.033*

Note. MS = mean square; *p < .05, **p < .01.

that a comprehensive pediatric "healthcare home" is available to all families of children with special needs. According to the National Association of Pediatric Nurse Practitioners (2001), the *healthcare home* is a place where children and families receive (among other resources) health promotion, advocacy for parenting, anticipatory guidance, consultation on developmental and behavioral issues, and assistance with connection to community resources.

The healthcare home does not necessarily refer to a geographic place, but rather a team of professionals dedicated to coordinated care for families of children with disabilities. The authors propose a model—the family *home team*—that is able to respond to the individualized family needs identified by this and other studies because of its flexibility in composition and intensity of services. The home team would include usual aspects of care coordination, such as assessment, planning, implementation, evaluation, monitoring, support, education, and advocacy (Lindeke, Leonard, Presler, & Garwick, 2002), but would differ in that the single point of contact would be the home team rather than a single healthcare professional. The team, consisting of a small group of professionals and led by the family, could be in regular communication and interact flexibly to meet ongoing and changing needs. During this study, local families and healthcare team members interested in this concept suggested having weekly telephone or in-person meetings, with additional communication as needed. Team composition would depend on a family's needs, and may change over time. Comprehensive family assessment would be central to identifying appropriate team members and altering the team as

Key Practice Points

1. Family functioning in families of children with chronic health problems is complex.
2. Parents of children with conditions that may be less medically stable, such as neuromuscular disease, spina bifida, or cerebral palsy, experienced more worry and concern than parents of children with more stable conditions, such as congenital limb deficiency or amputation.
3. Families whose children have conditions that are less medically stable need a care team that is able to recognize when care needs intensify and is flexible enough to meet those changing needs.

needed. Instruments such as the CHQ-PF28 could provide guidance in planning care. Although many quality-of-life assessment instruments are cost prohibitive for use in small studies or clinical settings, the CHQ is widely available to clinicians and clinical researchers for a nominal cost (see www.healthact.com/chq.html).

Team organization and operation could be initiated by rehabilitation or school nursing, occupational or physical therapy, social work, or other healthcare team members as is appropriate for each family's individual circumstances. The primary care provider would remain an integral part of the team but would not have to be responsible for service access at all points along the illness trajectory. For example, a family of a child experiencing amputation might depend on close contact with the primary care physician during the initial postoperative period. This same family might turn to physical and occupational therapy for direction during periods of rehabilitation and stability, and then access social services or school nursing if their child experiences rejection by peers or other socioemotional issues.

Families who have ongoing concerns about their child's physical or emotional well-being or are unable to participate in normal family activities may feel isolated. They may be unaware of available resources or how to get connected with such resources. The home team could suggest appropriate counseling resources to help relieve stress or refer children to occupational and physical therapy services to increase activity mastery and reduce limitations and interruptions to family activities. Stewardship of resources would be facilitated by plans that are individually geared to the family so that needs are met but resources are not wasted. This process might include increased access to specialized healthcare providers and therapists for some families, or it could include finding mobility aids, accessing respite services, or connecting with specialized daycare settings.

To ensure the home team intervention is effective, a widespread dissemination of available services is required. It is important for all stakeholders, including families and healthcare professionals, to share information about the home team with others, such as support group members, clinic staff, provider groups, and local social service networks. In addition, a central telephone number and Web site with information about services for families or professionals about how to begin the process would be made available in local telephone books, social service and healthcare agency handouts, and Internet search engines.

Unfortunately, some of the services mentioned here are expensive, and any comprehensive plan of care must include financial advocacy for families. Families of children with disabilities are often isolated and lack access to care—an issue that can be intensified for families with limited incomes. A home team may be able to intervene in these situations. To ensure that care is sensitive and appropriate, families should be placed at the center of the team; care should play to a family's strengths, rather than their deficits, and consider broader issues of policy development and attention to population health. Details of this study's model will be further developed and refined before intervention testing.

Study Limitations

This sample from Seattle, WA, and the surrounding area is not representative of families' experiences on a national or statewide scale, particularly in relationship to socioeconomic status. Although this study included some racial and ethnic diversity, there was little educational or economic variability. Because ethnic and socioeconomic status did not influence family outcomes in this particular sample, the data collected need to be cautiously interpreted. The literature clearly suggests that income and ethnicity can have a greater impact on family functioning than indicated in this study. It will be important to reexamine these issues with larger and more diverse samples.

Conclusion

The results of this study provide some evidence that the type of a child's disability is related to particular family outcomes. Families whose children have conditions that change or worsen over time are affected by worry about their child's physical and emotional health. Families whose children have physical limitations (causing high caregiver burden) acknowledge greater interruptions and limitations in their normal family life. These findings suggest a need to design programs that are sensitive to differing family needs and flexible enough to accommodate change over time.

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