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Article in *American Journal of Public Health* · February 1998

DOI: 10.2105/AJPH.88.1.75 · Source: PubMed

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Perceived Parental Burden and Service Use for Child and Adolescent Psychiatric Disorders

ABSTRACT

Objectives. Pediatric chronic physical illness and adult psychiatric disorders are substantial sources of burden for family caretakers, but little attention has been paid to parental burden resulting from children's or adolescents' psychiatric disorders. This paper describes the predictors of perceived parental burden and its impact on the use of specialty mental health and school services.

Methods. A representative general population sample of 1015 9-, 11-, and 13-year-olds and their parents completed structured psychiatric diagnostic interviews and the Child and Adolescent Burden Assessment.

Results. Weighted estimates indicated that 10.7% of parents in the general population perceived burden resulting from their children's symptomatology. Significant predictors of perceived burden were levels of child symptomatology and impairment and parental mental health problems. Children's depressive and anxiety disorders were associated with less burden than other diagnoses. The effects of child disorder severity on specialty mental health service use appeared to be mediated by the level of burden induced.

Conclusions. Substantial levels of parental burden resulted from child psychiatric disorders and were a major reason for specialist mental health service use. (*Am J Public Health*. 1998;88:75-80)

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Introduction

Platt defined burden as "the presence of problems, difficulties, or adverse events which affect the life (lives) of the psychiatric patient's significant other(s)." 1-p 383 While other definitions of burden have been proposed,^{1,2} all emphasize the effect the patient has upon the family, or the impact that living with the patient has on the family's daily routines and, possibly, health. Most studies have focused on caregivers for adults with severe and persistent mental illness or for the elderly.³⁻⁸ These studies have found that caregivers experience relatively high levels of both objective burden (e.g., providing transportation, assisting the patient with daily tasks) and subjective burden (e.g., reduced caregiver well-being, worry). Furthermore, caregiving frequently adds a set of burdens to an already high level of hardship within the family. Caregiver burden has also sometimes been associated with frequency of patient hospitalizations.⁹⁻¹²

Providing any care for an adult relative is an unexpected event, but parents are expected to be responsible for the care of their minor children. Emotional and financial hassles are part of the normal parenting process. When the additional burdens associated with a child's psychiatric problems are added to these normal hassles, might they be more difficult to bear? Contrariwise, since such hassles are normal, parents of psychologically disturbed children may be primed to take additional difficulties in their stride, with little sense of burden. Parents of children with chronic illness report substantial levels of social, financial, and emotional burden.¹³⁻²⁹ However, similar studies of children with psychiatric disorders do not seem to have been done, although many of the factors associated with increased burden for families of adult patients (such as the patient's living with

family, poverty, single-parenthood and unemployment) are common in the families of children with psychiatric problems.³⁰⁻³⁸

There is a big difference in seeking help for psychiatric disorders for children and for adults in that children rarely refer themselves for treatment. We know from several community studies^{34,39} that only a small proportion of children with psychiatric disorders are receiving treatment at any point, so the presence of a disorder is not sufficient to explain treatment seeking. This paper examines the level of burden experienced by parents on account of their children's problems as a factor in propelling parents to seek help for their children's disorders.

Methods

Subjects and Procedures

The Great Smoky Mountains Study is a longitudinal study of the development of psychiatric disorder and need for mental health services in rural and urban youth. The details of the study design and instruments used can be found in Costello et al.⁴⁰

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This paper was accepted April 16, 1997.

Briefly, a representative sample of 4500 9-, 11-, and 13-year-olds, identified through the Student Information Management System of the public school systems of 11 counties in western North Carolina, was selected through a household equal-probability design. A screening questionnaire was administered to a parent (usually the mother), by telephone or in person. This consisted of 55 questions from the Child Behavior Checklist about the child's behavioral problems, together with some basic demographic and service-use questions. All children scoring above a predetermined cutpoint score of 20 (designed to include about 25% of the population) on the behavioral questions, plus a 1-in-10 random sample of those scoring below the cutpoint, were recruited for the longitudinal study. The response rate was 80%, resulting in an interviewed sample of 1015. Design weights were used for the computation of population prevalence estimates.

Measures

Child and primary caretaker were interviewed separately about the child's psychiatric status and service use on the basis of the third edition of the Child and Adolescent Psychiatric Assessment,⁴¹ which generated DSM-III-R (The Diagnostic and Statistical Manual of Mental Disorders, 3rd ed, rev) diagnoses, and the Child and Adolescent Services Assessment.⁴² Of primary caretakers interviewed, 84% were biological mothers, 6.7% were biological fathers; 8.6% were other females, and 0.6% were other males (all will be referred to in this paper as "parents"). The Child and Adolescent Burden Assessment⁴³ was administered to the parent only. The reference period for each of these instruments was the 3 months prior to the interview.

The Child and Adolescent Burden Assessment. The Child and Adolescent Burden Assessment (CABA) was completed after the diagnostic interview. Parents were asked about 20 potential perceived burdens—that is, problems or difficulties in their own lives that they perceived as being caused or exacerbated by their child's psychiatric symptoms. The following areas were covered: expenses and financial difficulties, problems in relationships with family or social network members, restrictions on activities, and decreased feelings of well-being and competence. Items were scored as 0, 1, 2, or 3 depending on the degree of burden (possible scores ranged from 0 through 59). Rules for assigning these scores are contained in the CABA schedule.

The first step in the administration of the CABA involved an interviewer decision about whether there was any potential for parental burden, since we found that asking questions about psychopathology-related burdens was inappropriate when little or no child symptomatology had been reported or when the parent had already indicated in response to detailed questioning about symptoms that he or she had no significant problems with the child. On the basis of all the information collected in the interview, the interviewer decided whether there was any potential for burden, and if there was, the CABA was administered. All together, 349 CABAs were completed. Of these, 193 indicated the presence of at least one perceived burden, while 156 indicated that perceived burden was absent. In all other cases, perceived burden was regarded as being absent.

Factor analyses have indicated that one major factor predominates in the CABA in both general population and severely disturbed clinical samples, accounting for approximately 30% of the items' variance.⁴⁴ Coefficient alpha for the scale in this sample was .88. Two-week stability of the CABA in a small ($n = 19$) clinical sample was adequate (intraclass correlation coefficient = .60). Construct validity of the CABA is indicated by significant mean differences in CABA scores between groups with varying rates and severity of psychopathology: 0.9 ($SD = 3.3$) in the Great Smoky Mountain Study general population sample; 7.4 ($SD = 7.1$) in a child guidance clinic sample; and 15.7 ($SD = 10.1$) in a group of seriously emotionally disturbed youth at imminent risk for out-of-home placement.⁴⁴

The Child and Adolescent Psychiatric Assessment. The Child and Adolescent Psychiatric Assessment is an interviewer-based interview, that provides a structured questioning scheme enabling interviewers to determine whether symptoms, as defined in an extensive glossary, are present or absent and to code their frequency, duration, and onset.⁴¹ Diagnostic 1-week test-retest reliabilities for child self-reports range from 0.55 for conduct disorder to 1.0 for substance abuse/dependence.⁴⁵ Diagnoses and symptom scores are generated by computerized algorithms. A symptom was counted as being present if it was reported by either the parent or child. Psychosocial impairment secondary to psychiatric symptomatology in 17 areas of functioning was also rated according to a series of definitions and rules specified in the *psychiatric assessment's* glossary and the interview schedule. The intraclass correlation coefficient for level of psychosocial impairment by child

self-report was .77.⁴⁵ In addition, the assessment contained a number of questions about demographic status, past history of parental psychiatric problems, recent life events, and family relationship problems.

The Child and Adolescent Services Assessment. The Child and Adolescent Services Assessment collects parent and child reports on the use of mental health services provided by the specialty mental health sector, schools, child welfare, primary health care, juvenile justice, and informal community sources. Use of a service was coded positively if either the parent or the child reported it. Psychometric analyses showed that test-retest consistency of children's responses to the services assessment was very good for the most intensive services ($\kappa = .82-.92$ for inpatient, out-of-home, and juvenile justice services); adequate for moderate level services ($\kappa = .52-.58$ for outpatient, crisis, and other professional services); and not very good for the least intensive services ($\kappa = .39-.43$ for school and informal services). Parents showed a similar pattern, except that school, informal, and outpatient services were somewhat more reliably reported. Combined parent and child reports from the services assessment correctly identified 90% of children who were receiving services according to a community mental health center's records.

Results

Details of the rate of diagnosis, impairment, and service use have been published elsewhere. The 3-month prevalence of any DSM-III-R Axis I disorder was 20.3% ($SE = 1.7$). Four percent of children had received specialist mental health services during the preceding 3 months, and 12.4% had received services for mental health problems in other than mental health settings.

Rates of Perceived Burden

A total of 10.7% of all parents of 9-, 11-, and 13-year-olds in the population reported at least one perceived burden resulting from child psychiatric symptomatology. The most common individual burdens involved effects on personal well-being, stigma, and restrictions on personal activities (see Messer et al. for details).⁴⁴ Some burden was perceived by 4.5% of parents of children with no diagnosis or psychosocial impairment, compared with 16.8% of those whose children had only a diagnosis, 17.8% of those whose children had only impairment, and 38.8% of those whose children

TABLE 1—Predictors of the Presence of Any Burden Remaining Significant in a Logistic Model in the Whole Population: Great Smoky Mountains Study

	Odds Ratio (95% Confidence Interval)	Standardized Parameter Estimate	SE	P
Total DSM-III-R symptom score	1.15 (1.11, 1.18)	.51	.016	3×10^{-17}
Total functional impairment score	1.23 (1.15, 1.31)	.33	.033	4×10^{-10}
Anxiety or depression diagnosis	.49 (.26, .81)	-.12	.312	.02
Parental history of mental health problems	1.74 (1.18, 2.56)	.14	.198	.005

Note: DSM-III-R = *Diagnostic and Statistical Manual of Mental Disorders, 3rd ed, rev.*

had both a diagnosis and impairment (weighted prevalence estimates).

Degree of Burden

A simple measure of degree of burden is the sum of all 20 self-reported burden item scores in the CABA. For the whole population, the weighted mean total burden score was 0.9 (SD = 3.3; range = 0 through 28).

Those whose children had no diagnosis or impairment had a mean CABA total score of 0.3 (SD = 2.1), compared with 1.4 (SD = 3.3) for those with only a diagnosis, 1.2 (SD = 3.2) for those with impairment only, and 4.4 (SD = 5.2) for those whose children had both a diagnosis and impairment.

Predictors of Burden

We conceptualized four groups of possible causes of burden in addition to the existence of diagnosis or impairment. The first group of causes were demographic factors: rurality of residence; poverty (family income less than \$10 000 per annum); the age of the child; and the child's gender. The second group consisted of stress-and-strain measures generated by the Child and Adolescent Psychiatric Assessment: total negative life events in the preceding 3 months; a parental history of psychopathology; parent-child relationship problems; and a group of "family structure" and community problems, comprising parental unemployment, residence in substandard conditions or a poor neighborhood, large sibship (more than 4), and single-parenting. The third group contained two variables defining severity of the child's psychopathology: the number of symptoms that would count towards a DSM-III-R diagnosis and the total impairment score from the Child and Adolescent Psychiatric Assessment. The final group concerned whether the child had an anxiety or depressive disorder or had a disruptive behavior disorder, and contained all 28 specific diagnostic categories. The question addressed by this final group was

whether any specific diagnoses are associated with a particularly elevated burden when overall level of symptomatology and impairment and overall type of diagnosis are already controlled.

We conducted this analysis in two stages because the error scores in initial trial regressions were not normally distributed. The first stage consisted of best-subset logistic regressions of the presence of any burden, and may be thought of as addressing the question, "What gets parents over the threshold for experiencing burden?" In the second stage, best-subset, ordinary least squares regressions of the predictors on the log of the total burden scores in those who had parental perceived burden (n = 193) were conducted. In this group, the residuals from the regressions adequately approximated a normal distribution. This stage addressed the question, "Once the parent is over the threshold for experiencing burden, what determines the level of burden experienced?"

The final best-fitting models from these two sets of regressions are presented in Tables 1 and 2. The odds ratios, parameter estimates and test statistics refer to simultaneous models in which each effect is estimated with all the other terms in the model controlled for.

It could be argued that the correlations observed here do not represent burden resulting from symptoms (although that is what parents were instructed to report on), but rather that the perception of burden

makes parents more likely to report symptoms or functional impairment in their children. As a check on this possibility, we regressed child-only reports of total symptoms and total impairment level on the probability of the presence of any burden. Both were significantly associated with parental burden (symptoms odds ratio [OR]=1.05; P = .02; impairment OR = 1.23; P = .00007). Then, we regressed these same child-only reports of psychopathology on the level of parental perceived burden for parents with reported burden. This time, only the level of impairment was a significant predictor (impairment F(1,192) = 10.49; P = .001). Given the well-known low correlations between parent and child reports of symptoms and impairments, we concluded from these results that parents really were reporting on burdens attributable to their children's symptomatology.

Burden as a Predictor of Service Use

We looked first at the rates of specialty mental health service use by children of parents with and without parental burden. Figure 1 presents rates of service use for children with and without diagnoses and impairment.

We then explored the impact of burden on the probability of service use, in comparison with the other potential predictor variables described above, using best-subset logistic regression.

TABLE 2—Predictors of the Level of Perceived Parental Burden Remaining Significant in a Regression Model in Those with Perceived Parental Burden in the Great Smoky Mountains Study (n = 193)

	Parameter Estimate	SE	F (3,189)	P
Total DSM-III-R symptom score	.01	.008	8.6	.004
Total functional impairment score	.02	.016	9.2	.002
Tics	.17	.171	4.0	.046

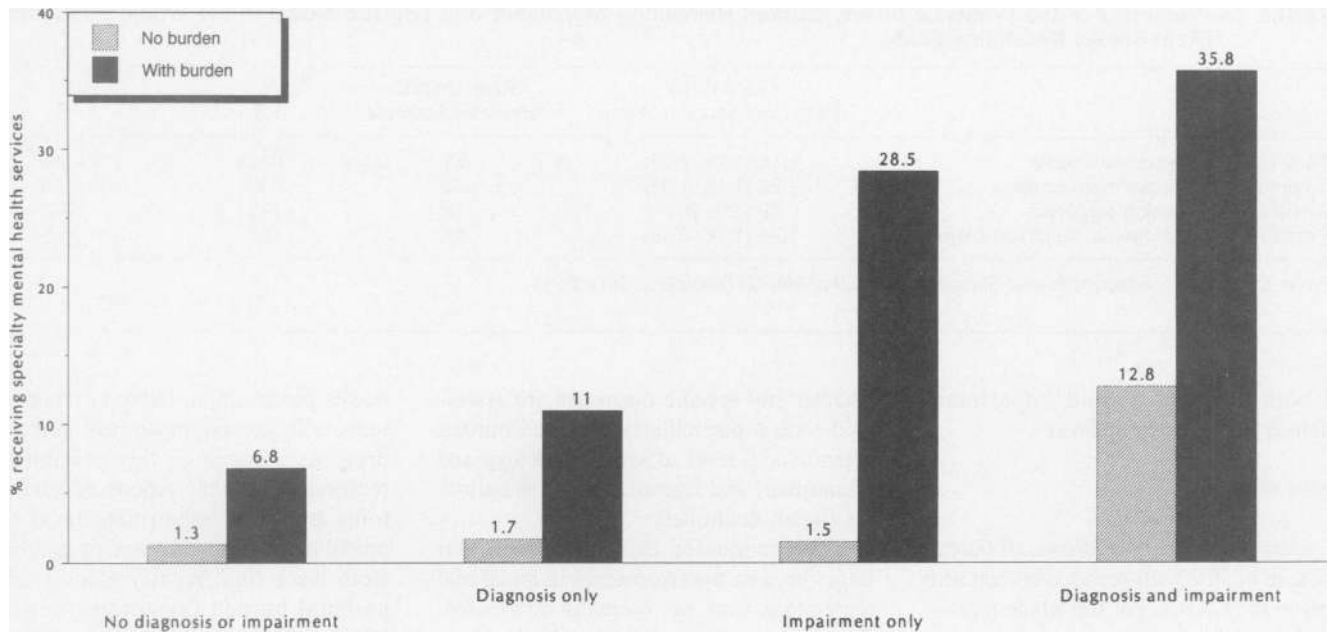


FIGURE 1—Weighted percentage of children receiving professional mental health services by diagnosis, impairment, and parental burden group in the Great Smoky Mountains Study (n = 1015).

Table 3 shows the odds ratios for significant predictors in the final model. Only two significant predictors emerged, by far the strongest of which was parental burden. We also observed that the effect of burden on the probability of service use was a decelerating quadratic function, with little or no additional increase in the probability of service use above a total burden score of 8.

Since children often do not need their parents' help to make contact with school-based services (counselors, psychologists, or special classes), we compared the effects of parental burden and the other potential predictors on the use of school services

(Table 3). This time, a rather different picture emerged, with the child's total symptom score having the largest effect and parental burden having a smaller effect. The presence of depression or anxiety was associated with less school service use than the presence of other disorders.

Discussion

The strongest predictor of the presence of any perceived burden was the child's total symptom score, but the child's level of impairment also made a substantial contri-

bution. Children with depressive or anxiety disorders proved less burdensome than children with other disorders, while parents with preexisting mental health problems perceived more burden than those without. The final model, for level of perceived burden (Table 2), showed that again levels of the child's symptomatology and functional impairment had the most effect on parental perceived burden scores. In addition, the presence of tics was associated with increased perceived burden.

Perhaps the most important result is the very low rate of specialty mental health service use when no perceived burden was

TABLE 3—Predictors Remaining Significant in Logistic Models of Specialist Mental Health Service and School Use in the Great Smoky Mountains Study (n=1015).

	Odds Ratio (95% Confidence Interval)	Standardized Parameter Estimate	SE	P
Specialist mental health service use				
Total DSM-III-R symptom score	1.05 (1.01, 1.08)	.16	.016	.007
Parental burden	1.39 (1.25, 1.55)	.83	.055	2×10^{-9}
Parental burden squared	.99 (.98, .99)	.60	.002	2×10^{-5}
School service use				
Total symptom score	1.08 (1.05, 1.11)	.28	.015	8×10^{-7}
Depression or anxiety	.46 (.24, .89)	-.13	.331	.02
Parental burden	1.17	.40	.046	5×10^{-4}
Parental burden squared	.99 (.99, .99)	-.25	.002	.02

reported. Fewer than 2% of children without a diagnosis, impairment, or burden saw a mental health professional. Similarly, fewer than 2% of children with only a diagnosis or only impairment received specialty mental health services. In each of these situations, the presence of perceived burden was associated with at least a fivefold increase in the rate of service use. When a child had both a diagnosis and impairment, the presence of perceived burden was associated with a threefold increase in the use of specialist mental health service. Thus, at every level of psychopathology, the presence of parental perceived burden was a powerful predictor of the use of specialty mental health service. When parental perceived burden was taken into account, the amount or type of symptomatology shown by a child had relatively little effect on the probability of receiving services, and the level of impairment had no effect. In an earlier paper,⁴⁹ we reported substantial effects of diagnosis and impairment on specialty mental health service use in analyses where burden was not considered. It appears that most of the effects of symptomatology and impairment on service use were mediated by perceived parental burden. We also observed a dose-response relationship between level of parental perceived burden and probability of service use. School services, on the other hand, were more directly sensitive to the number of the child's symptoms than to parental burden although it is possible that had we measured *teacher* burden, it might have proved to be more highly related to school service use.

However, this is only a single study conducted in a largely rural area, so it is important to know whether similar findings occur in other regions (e.g., the inner city) and other service systems. In addition, we investigated only limited dimensions of service use. It is important to know whether burden influences inception into services, maintenance and volume of service use, level of care received, and the costs of services. We also measured only perceived burden in one parent, and it seems likely that the burdens felt by other caregivers are also important.

There is also a question as to whether the CABA is really measuring only the burden of psychiatric disorder in children. We asked parents to report only burdens that they *attributed* to their children's psychopathology, but it is possible that they misattributed some of the normal hassles of parenting to their children's psychopathology. Our finding that symptomatology and impairment that were reported by the child also predicted parental burden suggests that

such misattribution is not the whole story. But even if it were, the fact remains that parents who attributed burden to their children's symptomatology were much more likely to seek specialty mental health services for their children and their children were also more likely to receive school services. Thus, even if the CABA measures misattributions in whole or in part, those misattributions are important for understanding mental health service use.

Although a great deal of work has been done on the effects of parental psychiatric disorders on children and on the links between parent-child relationships and psychopathology,⁵⁰⁻⁵³ little attention has been paid to the impact of children's problems on parental mental disorder. The psychological burdens described by parents as resulting from their children's problems suggest that this issue is worthy of more attention. In addition, some parents reported that their children's problems had substantial negative effects on their family and social relationships; this situation might be expected to increase the risk of future psychological problems.

It would be interesting to know how the perception of burden emerges in reaction to the development of psychiatric disorder, and to what degree and why it fluctuates over time. For instance, do parents adjust to their children's problems over time and experience less burden, or does continuing symptomatology lead to escalating burden? It would also be interesting to know what criteria parents use in deciding to attribute a difficulty of their own to a child's behavior, and why some parents report no burden despite having a severely disturbed child. One also wonders what other ways parents deal with their sense of being burdened. For instance, do they seek help from their social networks? By what mechanism is the perception of burden related to service use, and why do some parents who report high levels of burden still not get help for their children? □

Acknowledgments

This project was supported by grant MH48085 from the National Institute of Mental Health. Additional support was provided through faculty scholar awards from the William T. Grant Foundation to Dr Angold and Dr Costello and a center grant from the Leon Lowenstein Foundation to Dr Angold.

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