

# The Effect of Chronic Illness on the Psychological Health of Family Members

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## Abstract

**Background:** Chronic illness in a family member can cause emotional distress throughout the family, and may impair the family's ability to support the patient.

**Objectives:** We compare the familial impact of mental illness to other common chronic conditions. We examine the impact of a person's chronic illness on the psychological health of all persons in his or her family and identify both individual and family-level risk factors associated with psychological spillovers.

**Methods:** Our analysis is based on data from the 1996 Medical Expenditure Panel Survey (MEPS) that, because of its sample design, can be used to model both individual and family health status. Psychological distress is measured using responses to the general mental health question for each family member. The chronic conditions considered include cancer, diabetes, stroke-related disorders, arthritis, asthma, and mental illness (including dementia). We estimate the relationships of interest using a semi-parametric method, the discrete random effects probit model.

**Results:** Brain-related conditions, including mental illness, impose the most significant risk to the psychological well-being of family members. The effects of the other chronic conditions studied, while not as significant, are notable in that their negative impacts on the psychological health of family members are sometimes larger than their direct psychological impacts on the patient. Economic distress not only directly increases the chance that an individual will experience emotional distress, but it appears it also reduces the family's ability as a whole to cope psychologically with chronic illness.

**Discussion:** Our analysis suffers from problems common to all cross-sectional designs, although the impact of selection bias appeared to be small in sensitivity analysis. While health conditions were based on unverified self-reports, condition categories were broadly defined to reduce the required precision of such reports.

**Implications for Health Care Provision and Use:** Because psychological distress is fairly contagious in families confronted with chronic illness, effective treatment strategies may need to be targeted to all members of the primary patient's family. Providers should be particularly vigilant for intra-family effects when their

patients come from families that lack the financial resources that might protect against the stress of caring for a family member with a chronic illness.

**Implications for Health Policies:** Results suggest that, of the chronic conditions considered, priority for respite care and supportive services should be given to families in which a member has a brain-related disorder, particularly in families with limited financial resources and inadequate insurance coverage.

**Implications for Further Research:** The use of the discrete random effects probit model identified important interpersonal health effects that could not have been detected with standard analytical methods. The potential clinical relevance of the resulting findings underlies the need for additional data collection efforts that, like the MEPS, consider individuals in a family context.

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## Introduction

Chronic illness in a family member can create situational crises that can lead to emotional distress throughout the family. If family members become too distressed, their ability to provide care in the home may be compromised. Recent emphasis on community-based care, due to managed care mandates, trends towards deinstitutionalization, or therapeutic innovations that allow care to be provided in ambulatory settings, increases the demands on patients and their families to manage and treat their illnesses at home. Research regarding possible spillover health effects in families is needed to develop and prioritize respite care and other supportive services. Future health policy also needs to be sensitive to shifts in family composition over time. Trends towards smaller families and changing population demographics may increase the burden a serious medical condition imposes on other family members. An understanding of how family characteristics affect family burden is needed to anticipate the health care implications of these population changes.

Several studies have established the psychological toll suffered by families when a member has a serious mental illness.<sup>1-6</sup> These family members are at increased risk for depression,<sup>1</sup> anxiety,<sup>2</sup> and use of mental health care.<sup>3</sup>

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Similarly, family members of stroke survivors often experience poor psychological well-being,<sup>7</sup> and often show signs of emotional distress<sup>8,9</sup> as well as depression.<sup>10,11</sup> Cancer has been shown to have a significant impact on the mental well-being of family members,<sup>12-14</sup> with family members often experiencing distress and anxiety on a level comparable with or in excess of that experienced by patients themselves.<sup>15,16</sup> There is also some evidence that arthritis, asthma and diabetes may have negative impacts on the psychological health of the family.<sup>17-20</sup>

Only a limited number of studies have compared the psychological effects of different chronic conditions on the health of family members, often with contradictory findings. For instance, chronic conditions that involve cognitive deficits have sometimes been found to impose greater burdens than those that do not,<sup>21</sup> although this is not always the case.<sup>22</sup> Some characteristics of chronic conditions may impact the emotional burden experienced by family members, including the expected disease trajectory<sup>23,24</sup> and the degree of uncertainty associated with the illness.<sup>25,26</sup> While it would seem obvious that illness severity also should be predictive of family member stress, empirical evidence does not generally support this assumption.<sup>9,27</sup> Indeed, Baumgarten et al.<sup>26</sup> found that distress was negatively correlated with severity of illness, although such results may reflect possible selection bias if patients are placed in institutional care when their families cannot cope with their care-giving needs. Thus, while a number of chronic conditions have been found to impact the psychological well-being of families, there is little information about which of these conditions has the most significant impact. Such information is needed to determine how scarce supportive care resources can be allocated most effectively.

Personal characteristics may affect an individual's susceptibility to the stresses associated with chronic illness in a family member. Women are consistently found to be at higher risk of emotional distress than men,<sup>28</sup> with the finding replicated across studies of cancer,<sup>29</sup> cardiovascular disease,<sup>30</sup> mental illness,<sup>31</sup> and dementia or Alzheimer's disease.<sup>32</sup> Similarly, the elderly have been found to be at greater risk of emotional distress than younger family members in studies of cancer<sup>33</sup> and dementia.<sup>26</sup> While the nature of the relationship between the patient and the family member has been found to be an important predictor of family member distress, the direction of the effect appears to be conditional on the nature of the chronic condition. Adult children tend to be at greater risk when the condition entails cognitive impairment, whereas spouses tend to be at greater risk when the condition imposes other impairments.<sup>26,30,31</sup>

Characteristics of the family itself may contribute to the vulnerability of its members to the psychological distress associated with chronic illness. The financial and social resources available to the family partly determine its ability to cope with the material and other needs of a member with a chronic illness. Limited financial means have been found to be a significant risk factor for stress in a number of settings,<sup>34-36</sup> and there is some evidence that family size is related to the risk of psychological distress.<sup>37,38</sup> Two reasons that the ability of the family to sustain itself has not received

more attention are data availability and analytic limitations. Most family analyses involve primary data collection and data are typically collected from only one, principal care-giver. Standard analytic methods assume independence between observations such that possible correlations of health within families are ignored.

In this paper, we compare both the direct and indirect spillover impacts of different chronic illnesses on the psychological health of the entire family. The analysis is undertaken to determine which chronic conditions are associated with the greatest risk to the psychological well-being of family members with ill relations, and to determine which individual and family characteristics exacerbate such risks. In the next section, we describe the data and methods used in our analysis. Then we present the results of this analysis and identify which individuals and families tend to be at high risk of experiencing psychological distress when a family member suffers from a chronic illness. We conclude with the research and policy implications of our findings.

## Methods

### Data Analytic Procedures

Given the dichotomous nature of our dependent variable, the relationship between psychological distress and chronic illness in families could be estimated consistently using standard probit analysis. Such an approach ignores the possible interdependence of psychological distress across different members of the same family. Instead, we use a random effects probit (REP) model to estimate the relationship of interest. Such a model is appropriate when the data are clustered (e.g., by family membership) and observations on individuals cannot be assumed to be independent. Random effects models assume individual observations that belong to a specific group share a common intercept, i.e.,

$$y_{ij}^* = x_{ij}\beta + z_j\gamma + \nu_{ij} \quad (1)$$

where

$$\nu_{ij} = \mu_j + \varepsilon_{ij} \quad (2)$$

for  $j = 1, 2, \dots, J$  families and  $i = 1, 2, \dots, N_j$  individuals in each family  $j$ , for a total of  $\sum_j N_j = N$  observations. The sign of the latent variable,  $y_{ij}^*$ , determines the value of the observed binary dependent variable, i.e.,

$$y_{ij} = 1 \text{ if } y_{ij}^* > 0; 0 \text{ otherwise.}$$

The  $x_{ij}$  are the observed characteristics of specific individuals and the  $z_j$  are the observed characteristics of specific families that influence  $y^*$ , where  $\beta$  and  $\gamma$  are the coefficients associated with individual-level and family-level covariates, respectively. The  $\varepsilon_{ij}$  are assumed to be normally distributed  $IN(0, \sigma_\varepsilon^2)$  and orthogonal to the vector of group-specific error terms,  $\mu_j$ .

We use a semi-parametric method to estimate the REP model that approximates the true density of the random intercept term using a discrete density, i.e., the distribution of  $\mu$ ,  $f(\mu)$ , is assumed to be discrete, where  $\mu$  has  $S$  points of support with values  $\mu_1, \mu_2, \dots, \mu_S$  and associated probabilities  $\pi_1, \pi_2, \dots, \pi_S$ . This approach eliminates the need for computationally intensive numerical integration, and, under suitable regularity conditions, it can serve as an approximation of any probability density, normal or otherwise. While the individual error is scaled to have unit variance, the variance of the group-specific effect is given by

$$\text{Var}(\mu) = \sum_{s=1}^S \pi_s \mu_s^2. \quad (3)$$

Furthermore, the orthogonality assumption implies the correlation between any two members of the same family is a constant given by

$$\rho = \frac{\sigma_\mu^2}{\sigma_\mu^2 + \sigma_\varepsilon^2}. \quad (4)$$

While it has been demonstrated that the discrete REP provides a reasonable approximation of a continuous density,<sup>39</sup> the model offers obvious additional benefits if the data are actually drawn from a finite number of distinct classes. In such cases, each point of support and associated probability describes a latent class. The posterior probability that a particular group (i.e., family) belongs to a particular class (i.e., risk type) can be calculated from the model estimates.

We estimate the discrete REP model in SAS/IML by maximum likelihood using the Broyden-Fletcher-Goldfarb-Shanno quasi-Newton constrained maximization algorithm. Because the appropriate number of points of support cannot be determined a priori, we re-estimate the model assuming various support points and choose the most appropriate number on the basis of empirical performance.<sup>40</sup>

## Data

The data for this analysis are taken from the 1996 Medical Expenditure Panel Survey (MEPS).<sup>41</sup> The MEPS collects nationally representative, health-related data for the civilian, non-institutionalized U.S. population. Because of its sample design, the data can be used to model both individual and family health status. The definition of family is critical to our analysis. The MEPS defines a family as persons who are related by blood, marriage or adoption, as well as foster children and unmarried persons living together as a family unit. Dynamic considerations complicate the definition of family units.<sup>42</sup> Family composition can change over the period data are collected if family members die, are born, or otherwise join or leave the family. One solution is to define family membership at a single point in time. For example, Carlson *et al*<sup>43</sup> have recommended that families be defined at the beginning of the study period to ensure samples are representative of the population from which they were drawn. A second strategy is to limit analysis to families

whose composition remains unchanged throughout the period being studied. We adopt this latter strategy to ensure our results are not influenced by the health of persons who have left the family at some point during the year and, thereafter, may be less concerned about, and less relevant to, the condition of the remaining family members. We also evaluate the robustness of our results by performing a sensitivity analysis on the sample of all families defined at the start of the observation period.

Our final data set consists of 5,699 multi-person families whose composition remained constant throughout the calendar year (i.e., were “stable”) and for whom valid data are available for all members. We record chronic conditions for all family members, but restrict our analysis of the emotional impact of these conditions to the 11,868 adult members of these families (i.e., individuals 18 years and older). Children, because of possible differences in emotional development or ability to understand or be informed of chronic illness, may react quite differently to stressors than adults. Our sample sizes do not permit separate analyses of adults and children to test the extent to which this may be true, and we believe it is appropriate to avoid possible aggregation bias by excluding children’s reactions from our analysis. In addition, some of the variables that might affect the relationship between psychological well-being and chronic family illness in the adult population (e.g., marital status) are not well-defined for children.

## Variables

### Dependent Variable

Psychological stress is difficult to measure. Some studies have employed mental health care use as a proxy of psychological health,<sup>44</sup> although such measures are affected by differences in health care access and insurance coverage. Alternatively, psychological distress can be measured directly using survey methods. We follow this approach and use questions from the MEPS that measure the general mental health of each family member on a five-point scale. We use the response from the final round for the 1996 calendar year to ensure that our measure of psychological health captures all possible reactions to the chronic conditions that have arisen throughout the year. For analytic purposes, we dichotomize this variable into ‘low’ and ‘high’ psychological distress (‘low’ indicates the mental health of the person is reported as ‘good’ or better; ‘high’ indicates the mental health of the person is reported as ‘fair’ or worse).

### Chronic Conditions

Chronic health conditions are identified from the Condition Enumeration section of the MEPS. Information provided by the respondent about specific physical and mental conditions afflicting family members is translated into ICD-9 codes by professional coders, and then grouped into 260 condition categories. We group all mental illnesses, including

dementia, into a single category. We do not use more specific mental illness categories because of concerns with small sample sizes as well as the precision of diagnostic information in the MEPS. We use three criteria to identify the comparison conditions in our analysis. First, the condition has to be one of the priority conditions identified by the Agency for Healthcare Research and Quality.<sup>41</sup> Second, the condition has to be observed with sufficient frequency to support analysis. We limit our analysis to those conditions for which at least 100 cases are reported in the MEPS data. While this is a somewhat arbitrary criterion, our findings are robust to other benchmarks (e.g., observed prevalence greater than one percent). Third, we restrict our comparisons to those conditions for which evidence of significant family spillover effects in a U.S. health care context can be found in the literature. These conditions were identified by a Medline search using the subject headings 'caregiver' (with a subheading of 'psychology') or 'family health' over the past ten years (1992 to October 2001). Abstracts of English language journal articles were reviewed to identify U. S. -based studies in which specific health conditions were found to have impacts on other family members' psychological health. Based on these criteria, we include a total of six conditions in our analysis: cancer (condition codes 011-044), diabetes (049-050), cerebrovascular/stroke disorders (109-112), arthritis (201-204), asthma (128), and mental illness (066-074). We further identify health conditions as either afflicting the individual whose psychological health is being assessed (e.g., CANCER) or another member of the family to which that individual belongs (condition labels prefixed by an 'F\_', e.g., F\_CANCER), unless the other family member is a child of the head of household (in which case the condition labels are prefixed by a 'K\_', e.g., K\_CANCER). We distinguish between conditions afflicting adults and children because we found differences in how families react to illnesses affecting adults and children.

The six conditions considered in this analysis vary in the degree to which they include cognitive deficits, are life-threatening, and involve uncertainty regarding progression of the disease, factors that, in the literature, have been found to influence the emotional strain associated with a chronic illness. While considerable variation exists within these illness categories, we do not attempt to control for possible differences in illness severity (e.g., by including information on activity limitations).<sup>44</sup> The inclusion of functional limitation variables would control not only for differences in severity within categories, but also for differences between categories, thereby invalidating cross-condition comparisons.

### *Individual Risk Factors*

We include information on individual age, gender, race, ethnicity, education and marital status to control for the possible direct impact of an individual's socio-demographic status on his or her reported psychological health. To detect possible non-linear relationships between psychological health and age, a squared age term is also included. We include information on family income from all sources,

family size, and location to control for differences in family-level financial and social stressors that may also directly impact an individual's psychological health. Precise definitions and summary statistics of all variables are provided in **Table 1**.

### *Family Risk Factors*

An advantage of the discrete REP model is its potential ability to distinguish between types of groups, in this case, families at differing risk of experiencing psychological distress. We assign a family to a higher risk group if its calculated posterior probability of belonging to the higher risk group is greater than the calculated posterior probability of belonging to any lower risk group. Although the prior probabilities are constants, the posterior probabilities may depend on family characteristics. The posterior analysis provides additional information about the relationships between family characteristics and family risks that cannot be inferred directly from the coefficients of the discrete REP model. In particular, the analysis of family-level risk profiles provides an opportunity to identify factors associated with intra-family spill-over effects.

We undertake an exploratory analysis to investigate why some families may be at higher risk of emotional distress in response to chronic illness than would be suggested by the individual characteristics of its constituent members considered in isolation. We compare the distribution of family characteristics between the high and low risk groups to identify which may potentially serve as risk factors for families confronted with chronic illness. We focus on variables that capture the social and financial support families have to face such crises. We include total family income and features of the family's insurance coverage that may defray the costs of illness, as well as family size and gender composition to capture possible differences in social ties between types of families. We also consider the effects of location of residence because rural families may be at high risk of unmet needs if support services, particularly respite care, are more readily available in urban environments.<sup>45</sup>

## **Results**

The Consistent Akaike Information Criteria (CAIC) and the Bayesian Information Criteria (BIC), presented in **Table 2**, indicate the model with two points of support is superior to either the model with one point of support (the standard probit model) or the model with three points of support. The results of the model with two-points of support are presented in **Table 3** (with the standard probit results provided for comparison). Individuals who are female, married, better educated, and have higher incomes are significantly ( $p < 0.05$ ) less likely to report poor psychological health than males, singles, less educated or poorer persons. Individuals from larger families are significantly ( $p < 0.05$ ) more likely to experience psychological distress than those in smaller families. In contrast, age, residence, race and ethnicity do

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Table 1. Definitions and Summary Statistics of Variables

Variable	Definition	Mean	SD
<b>Dependent Variables</b>			
Psychological Distress	1 if person's mental health was reported as poor or fair; 0 if reported as good, very good or excellent	0.057	0.232
High Risk	1 if family was assigned to high risk group on basis of posterior probabilities; 0 otherwise	0.053	0.224
<b>Independent Variables (individual level, N=11,868)</b>			
Age	age of individual in years, divided by 10	4.32	1.60
Female	1 if the person is female; 0 otherwise	0.531	0.499
African American	1 if the person is non-Hispanic and African American; 0 otherwise	0.116	0.321
Hispanic	1 if the person is Hispanic; 0 otherwise	0.193	0.395
Education	number of years of formal schooling	12.33	3.12
Marital status	1 if person is married; 0 otherwise	0.693	0.461
Cancer	1 if person was reported as having a cancer-related condition (MEPS condition codes 011-044); 0 otherwise	0.044	0.206
Diabetes	1 if person was reported as having diabetes (MEPS condition codes 049-050); 0 otherwise	0.050	0.218
Mental Illness	1 if person was reported as having a mental illness (MEPS condition codes 066-074); 0 otherwise	0.106	0.308
Cerebrovascular	1 if person was reported as having a cerebrovascular or stroke-related condition (MEPS condition codes 109-112); 0 otherwise	0.008	0.090
Arthritis	1 if person was reported as having arthritis (MEPS condition codes 201-204); 0 otherwise	0.105	0.307
Asthma	1 if person was reported as having asthma (MEPS condition code 128); 0 otherwise	0.033	0.180
<b>Independent Variables (family level, J=5669)</b>			
Income	total family income from all sources, expressed in thousands	50.93	38.33
Urban	1 if family resides in an MSA; 0 otherwise	0.784	0.411
Family Size	number of persons in family, including children	3.417	1.50
F_cancer	1 if non-child family member had Cancer=1; 0 otherwise	0.090	0.286
F_diabetes	1 if non-child family member had Diabetes=1; 0 otherwise	0.108	0.311
F_mental illness	1 if non-child family member had Mental Illness=1; 0 otherwise	0.222	0.416
F_cerebrovascular	1 if non-child family member had Cerebrovascular/Stroke=1; 0 otherwise	0.019	0.136
F_arthritis	1 if non-child family member had Arthritis=1; 0 otherwise	0.214	0.410
F_asthma	1 if non-child family member had Asthma=1; 0 otherwise	0.106	0.307
K_cancer	1 if child family member had Cancer=1; 0 otherwise	0.007	0.083
K_diabetes	1 if child family member had Diabetes=1; 0 otherwise	0.007	0.082
K_mental illness	1 if child family member had Mental Illness=1; 0 otherwise	0.069	0.253
K_arthritis	1 if child family member had Arthritis=1; 0 otherwise	0.022	0.146
K_asthma	1 if child family member had Asthma=1; 0 otherwise	0.053	0.223

Note: there are no observed cases of cerebrovascular disease among children in the sample.

Table 2. Model Selection Statistics and Predicted Probabilities

	Model Selection Criteria							
	Stable Families				All Families			
	CAIC		BIC		CAIC		BIC	
D-REP(1)	4407.04		4379.04		4482.24		4454.24	
D-REP(2)	4255.05*		4225.05*		4330.91*		4300.91*	
D-REP(3)	4263.36		4231.36		4340.46		4308.46	

  

	Predicted Probabilities							
	Stable Families				All Families			
	2-point model		3-point model		2-point model		3-point model	
	$\pi$	$Pr(y = 1)$	$\pi$	$Pr(y = 1)$	$\pi$	$Pr(y = 1)$	$\pi$	$Pr(y = 1)$
Class 1	0.150	0.240	0.072	0.330	0.145	0.245	0.077	0.324
Class 2	0.859	0.023	0.52	0.056	0.855	0.024	0.579	0.054
Class 3	–	–	0.36	0.001	–	–	0.344	0.001

Note: D-REP(S) denotes the discrete random effects probit model with S points of support in the discrete density; \* indicates most preferred model by test criterion.

Table 3. Discrete Random Effects Probit Results (2 points of support, with standard probit results for comparison)

Dependent variable: Psychological Distress	Stable Families (N=11,868)				All Families (N=11,981)			
	Standard probit		D-REP(2)		Standard probit		D-REP(2)	
	Coef.	$\Delta Pr$	Coef.	$\Delta Pr$	Coef.	$\Delta Pr$	Coef.	$\Delta Pr$
Urban	0.006 (0.11)	0.05	0.000 (0.00)	0.00	0.009 (0.18)	0.09	0.005 (0.07)	0.03
Age	0.005 (0.07)	0.04	-0.030 (-0.30)	-0.20	-0.009 (-0.13)	-0.09	-0.050 (-0.52)	-0.33
Age <sup>2</sup>	0.005 (0.77)	0.05	0.011 (1.08)	0.07	0.008 (1.08)	0.07	0.014 (1.44)	0.09
Female	-0.119** (-2.70)	-1.09	-0.168** (-3.08)	-1.11	-0.123** (-2.82)	-1.14	-0.173** (-3.21)	-1.16
Hispanic	-0.132** (-2.10)	-1.21	-0.149 (-1.55)	-0.99	-0.135** (-2.17)	-1.26	-0.154 (-1.62)	-1.03
African American	0.050 (0.75)	0.46	0.079 (0.78)	0.52	0.038 (0.58)	0.36	0.055 (0.55)	0.37
Marital Status	-0.228** (-4.55)	-2.10	-0.278** (-3.61)	-1.84	-0.229** (-4.62)	-2.13	-0.279** (-3.71)	-1.87
Education	-0.064** (-8.75)	-0.59	-0.085** (-7.46)	-0.56	-0.063** (-8.70)	-0.59	-0.082** (-7.41)	-0.55
Income	-0.007** (-7.68)	-0.06	-0.009** (-6.73)	-0.06	-0.007** (-7.76)	-0.06	-0.009** (-6.91)	-0.06
Family Size	0.055** (3.59)	0.51	0.062** (2.16)	0.41	0.060** (3.92)	0.56	0.068** (2.41)	0.45
Cancer	-0.024 (-0.19)	-0.22	-0.030 (-0.18)	-0.20	0.000 (0.00)	0.00	0.007 (0.04)	0.05
Diabetes	0.292** (2.84)	2.69	0.433** (3.27)	2.86	0.276** (2.71)	2.57	0.402** (3.08)	2.69



→ Table 3. Discrete Random Effects Probit Results (2 points of support, with standard probit results for comparison)

Dependent variable: Psychological Distress	Stable Families (N=11,868)				All Families (N=11,981)			
	Standard probit		D-REP(2)		Standard probit		D-REP(2)	
Mental Illness	0.886** (11.76)	8.16	1.186** (10.25)	7.83	0.900** (12.00)	8.37	1.19** (10.52)	8.00
Cerebrovascular	0.474** (2.22)	4.37	0.618** (2.35)	4.08	0.525** (2.49)	4.89	0.669** (2.56)	4.49
Arthritis	0.054 (0.68)	0.50	0.062 (0.59)	0.41	0.045 (0.56)	0.42	0.043 (0.42)	0.29
Asthma	0.135 (1.10)	1.24	0.198 (1.34)	1.31	0.146 (1.20)	1.36	0.219 (1.50)	1.47
F_cancer	0.120 (1.23)	1.11	0.184 (1.29)	1.22	0.100 (1.03)	0.93	0.150 (1.07)	1.01
F_diabetes	0.120 (1.48)	1.11	0.127 (1.06)	0.84	0.120 (1.49)	1.11	0.128 (1.10)	0.86
F_mental illness	0.179** (2.41)	1.65	0.279** (2.65)	1.84	0.168** (2.26)	1.56	0.267** (2.59)	1.79
F_cerebrovascular	0.331** (2.05)	3.05	0.514** (2.19)	3.39	0.317** (1.97)	2.95	0.496** (2.14)	3.33
F_arthritis	0.122* (1.90)	1.12	0.155* (1.67)	1.03	0.119* (1.88)	1.11	0.161* (1.77)	1.08
F_asthma	0.194* (1.87)	1.79	0.272* (1.73)	1.79	0.191* (1.86)	1.78	0.261* (1.69)	1.75
K_cancer	0.294 (1.43)	2.71	0.376 (1.09)	2.48	0.294 (1.42)	2.74	0.390 (1.13)	2.62
K_diabetes	0.545** (2.93)	5.02	0.642 (1.50)	4.24	0.547** (2.94)	5.09	0.653 (1.57)	4.38
K_mental illness	0.237** (3.05)	2.18	0.328** (2.76)	2.15	0.241** (3.13)	2.24	0.334** (2.89)	2.24
K_arthritis	-0.044 (-0.32)	-0.41	-0.065 (-0.32)	-0.43	-0.052 (-0.38)	-0.48	-0.091 (-0.46)	-0.61
K_asthma	0.037 (0.31)	0.34	0.037 (0.21)	0.24	0.045 (0.39)	0.42	0.053 (0.31)	0.36
Constant	-1.09** (5.57)	-10.1	-1.313** (-4.22)	-8.67	-1.10** (-5.64)	-10.2	-1.31** (-4.38)	-8.79

Discrete Random Effects Density

$\mu_1$	1.554** (13.21)	1.56** (12.93)
$\pi_1$	0.150** (2.88)	0.145** (2.90)
$\sigma_\mu^2$	0.426	0.411
$\rho$	0.299	0.291
LL	-2068.5	-2106.0
	-1982.9	-2020.7

Note: t-statistics in parentheses; \*\* - significance at the 5% level; \* - significance at 10% level;  $\Delta$ Pr is percentage increase in the probability of experiencing psychological distress from a unit change in the independent variable; D-REP(2) is the discrete random effects probit model with 2 points of support.

Table 4. Exploratory Analysis of Family Risk Factors

Family Characteristic	Stable Families		All Families	
	High risk (N=353)	Low risk (N=5316)	High risk (N=342)	Low risk (N=5380)
<i>Financial Support Variables</i>				
Total family income (mean)	\$36,722	\$48,737	\$36,885	\$48,548
Insurance (proportions)				
Medicare Coverage of				
Person with chronic illness	0.22	0.12	0.21	0.12
Any family member	0.31	0.18	0.30	0.18
Medicaid Coverage of				
Person with chronic illness	0.14	0.05	0.14	0.05
Any family member	0.27	0.11	0.27	0.11
Other public coverage of				
Person with chronic illness	0.01	0.01	0.01	0.01
Any family member	0.02	0.01	0.02	0.01
Private insurance coverage of				
Person with chronic illness	0.43	0.31	0.41	0.31
Any family member	0.64	0.76	0.62	0.75
No insurance coverage of				
Person with chronic illness	0.14	0.07	0.14	0.07
Any family member	0.31	0.26	0.33	0.26
<i>Social Support Variables</i>				
Family size (mean)	3.38	3.28	3.45	3.28
Composition (proportion female)				
All family members	0.55	0.55	0.55	0.55
Persons with chronic illness	0.81	0.71	0.78	0.72
Urban residence (proportion)	0.77	0.78	0.76	0.78

not, in and of themselves, have a significant impact on psychological well-being.

Chronic conditions are associated with poorer psychological health, particularly if a person is afflicted with a mental illness, diabetes, or cerebrovascular disease. Somewhat surprisingly, cancer, arthritis and asthma do not have a statistically significant effect on own mental well-being. Having a family member with a chronic condition is also associated with compromised psychological health. Mental illness, regardless of the type of family relation afflicted, is significantly ( $p < 0.05$ ) associated with a higher risk of psychological ill-health among other family members. When they afflict non-child members of the family, cerebrovascular disease and, to a lesser degree, arthritis and asthma, are also associated with significantly ( $p < 0.10$ ) worse psychological health among family members. We hypothesize that these conditions may impair role performance in adults in a way that disrupts the family more substantially than when these conditions afflict a child.

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The limited impact of cancer on individual and family emotional health is surprising. Given some cancers are often terminal conditions, our results may be distorted by the omission of families in which a family member may have died. To determine if this concern is valid, we re-estimate the model after adding those families whose composition changed in 1996 (including those in which a death occurred) to our original sample (also reported in **Table 3**). The results, particularly with respect to the impact of cancer, are not affected by the inclusion of these observations. An alternative explanation is that our cancer construct includes a large number of treatable cancer cases (e.g., 'other non-epithelial cancer of the skin' constitute a fifth of all reported cancers) that may lack the severity and chronicity of the other conditions considered in this analysis.

The degree of intra-family correlation in risk of psychological distress (0.299) indicates that psychological ill-health is somewhat contagious within families. To better understand such spill-over effects and how they vary across

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families, we analyze the posterior probabilities calculated from the estimates of the discrete REP model. Our results suggest that families can be divided into two groups: those at high risk of experiencing psychological distress (predicted prevalence of 24 percent) and those whose risk is only a tenth as great. Results of the exploratory analysis are presented in **Table 4**. Because risk class is based on model estimates, standard t-tests would not produce appropriate inferential information to assess the statistical significance of comparisons of mean values. Thus, we present only descriptive statistics in **Table 4**. The average income of the high-risk families in our sample is, as expected, lower than the average income of low-risk families. Similarly, high-risk families in our sample are more likely to have someone in the family who lacks health insurance, particularly the family member with the chronic condition, than low-risk families. Results with respect to type of insurance coverage are mixed, although a higher proportion of high-risk families than low-risk families in our sample have someone in the family who is covered by public insurance. Differences in social support variables between the two family risk groups are less apparent. Family size, location of residence and the overall gender composition of families are very similar between low- and high-risk families, although persons in our sample with chronic illness are more likely to be female in high-risk families than in low-risk families.

## Discussion

We used a random effects probit model to estimate the relationship between chronic conditions and family psychological well-being. Our analysis offers several advantages over earlier studies. Our data are drawn from a large, representative sample of the U.S. population that allows us to compare the impact of a number of chronic conditions. Also, the structure of these data allows us to use statistical techniques that evaluate the psychological health effects of these conditions on the entire family.

Our findings suggest brain-related conditions impose the most significant psychological burden on both patients and other family members. Based on estimated coefficients, the presence of a family member with a mental illness or cerebrovascular condition increases the likelihood that another family member experiences psychological distress by a factor of one-third to one-half (based on an increase from base-line risk of roughly six percent). The effects of the other four conditions studied, while not as significant, are notable in that their negative impacts on the psychological health of family members are sometimes larger than their direct psychological impacts on the patient. Furthermore, psychological distress is fairly contagious within families. If providers fail to acknowledge the risk of chronic conditions on the psychological health of other family members, they may put their "primary" patients at even greater psychological risk.

Our exploratory analysis of the posterior results suggests economic distress not only directly increases the likelihood that an individual experiences emotional distress (as indicated by the coefficients from the discrete REP

equation), but it also reduces the family's ability as a whole to cope psychologically with chronic illness. Although these latter findings need to be verified in future research, they suggest providers should be particularly vigilant for intra-family effects when their patients come from families that lack the financial resources that might protect against the stress of caring for a family member with a chronic illness. Our results suggest that, of the chronic conditions considered, priority for respite care and supportive services should be given to families in which a member has a brain-related disorder, particularly in families with limited financial resources and inadequate insurance coverage.

The MEPS suffers from problems common to all cross-sectional designs. In such analyses, causation must be assumed when associations are observed, and results may be influenced by selection bias. Of particular concern for this analysis is whether extremely stressed families are at high risk of dissolution, either through divorce or institutionalization. Given our results are robust to both stable and more inclusive definitions of the family, we suspect our findings are not unduly affected by potential cross-sectional bias. Secondly, the health conditions (and emotional distress) reported by MEPS respondents were not verified. While our broad grouping of conditions reduces the required precision of such reports, it can bias results if dissimilar conditions are grouped together. Finally, we have not controlled for the use of mental health care that may mitigate the psychological distress caused by chronic illness. Estimates of the relative impact of different chronic conditions would be distorted if health care professionals recognize and act on the mental health care needs of families arising from some chronic illnesses better than others.

The use of the discrete random effects probit model to analyze these data did identify important interpersonal health effects that could not have been detected with standard analytical methods. The feasibility of the method and the potential clinical relevance of the resulting findings underlie the need for additional data collection efforts that, like the MEPS, consider individuals in a family context.

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## References

1. Lowery K, Mynt P, Aisbett J, Dixon T, O'Brien J, Ballard C. Depression in the carers of dementia sufferers: a comparison of the carers of patients suffering from dementia with Lewy bodies and the carers of patients with Alzheimer's disease. *J Affect Disord* 2000; **59**(1): 61-5.
2. Gonzalez-Salvador, MT, Arango C, Lyketsos CG, Barba AC. The stress and psychological morbidity of the Alzheimer patient caregiver. *Int J Geriatr Psychiatry* 1999; **14**(9): 701-10.
3. George LK, Gwyther LP. Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *Gerontologist* 1986; **26**: 253-9.
4. Kiecolt-Glaser JK, Dura JR, Speicher CE, Trask OJ, Glaser R. Spousal

- caregivers of dementia victims: longitudinal changes in immunity and health. *Psychosom Med* 1991; **53**(4): 345-62.
5. Denihan A, Bruce I, Coakley D, Lawlor BA. Psychiatric morbidity in cohabitants of community-dwelling elderly depressives. *Int J Geriatr Psychiatry* 1998; **13**(10): 691-4.
  6. Song LY, Biegel DE, Milligan SE. Predictors of depressive symptomatology among lower social class caregivers of persons with chronic mental illness. *Community Ment Health J* 1997; **33**(4): 269-86.
  7. Forsberg-Warleby G, Moller A, Blomstrand C. Spouses of first-ever stroke patients: psychological well-being in the first phase after stroke. *Stroke* 2001; **32**(7): 1646-51.
  8. Dennis M, O'Rourke S, Lewis S, Sharpe M, Warlow C. A quantitative study of the emotional outcome of people caring for stroke survivors. *Stroke* 1998; **29**(9): 1867-72.
  9. Anderson CS, Linto J, Stewart-Wynne EG. A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. *Stroke* 1995; **26**(5): 843-9.
  10. Grant JS, Bartolucci AA, Elliot TR, Giger JN. Sociodemographic, physical, and psychosocial characteristics of depressed and non-depressed family caregivers of stroke survivors. *Brain Inj* 2000; **14**(12): 1089-100.
  11. Han B, Haley WE. Family caregiving for patients with stroke. Review and analysis. *Stroke* 1999; **30**(7): 1478-85.
  12. Nijboer C, Tempelaar R, Triemstra M, van der Bos GA, Sanderman R. The role of social and psychologic resources in caregiving of cancer patients. *Cancer* 2001; **91**(5): 1029-39.
  13. Raveis VH, Karus DG, Siegel K. Correlates of depressive symptomatology among adult daughter caregivers of a parent with cancer. *Cancer* 1998; **83**(8): 1652-63.
  14. Kazak AE, Stuber ML, Barakat LP, Meeske K, Guthrie D, Meadows AT. Predicting posttraumatic stress symptoms in mothers and fathers of survivors of childhood cancers. *J Am Acad Child Adolesc Psychiatry* 1998; **37**(8): 823-31.
  15. Germino BB, Fife BL, Funk GG. Cancer and the partner relationship: what is its meaning? *Semin Oncol Nurs* 1995; **11**(1): 43-50.
  16. Barraclough J. *Cancer and Emotion* Chichester: Wiley, 1994.
  17. das Chagas Medeiros MM, Ferraz MB, Quaresma MR. The effect of rheumatoid arthritis on the quality of life of primary caregivers. *J Rheumatol* 2000; **27**(1): 76-83.
  18. Reisine ST. Arthritis and the family. *Arthritis Care Res* 1995; **8**(4): 265-71.
  19. Frankel K, Wamboldt MZ. Chronic childhood illness and maternal mental health—why should we care? *J Asthma* 1998; **35**(8): 621-30.
  20. Auslander WF, Bubbl J, Rogge M, Santiago JV. Family stress and resources: potential areas of intervention in children recently diagnosed with diabetes. *Health & Social Work* 1993; **18**(2): 101-13.
  21. Clipp EC, George LK. Dementia and cancer: a comparison of spouse caregivers. *Gerontologist* 1993; **33**(4): 534-41.
  22. Cattanaach L, Tebes JK. The nature of elder impairment and its impact on family caregivers= health and psychological functioning. *Gerontologist* 1991; **31**(2): 246-55.
  23. Wright LK, Hickey JV, Buckwalter KC, Hendrix SA, Kelechi T. Emotional and physical health of spouse caregivers of persons with Alzheimer's disease and stroke. *J Adv Nurs* 1999; **30**(3): 552-563.
  24. Reese DR, Gross AM, Smalley DL, Messer SC. Caregivers of Alzheimer's disease and stroke patients: immunological and psychological considerations. *Gerontologist* 1994; **34**(4): 534-40.
  25. Ireys HT, Silver EJ. Perception of the impact of a child's chronic illness: does it predict maternal mental health. *J Dev Behav Pediatr* 1996; **17**(2): 77-83.
  26. Baumgarten M, Battista RN, Infante-Rivard C, Hanley JA, Becker R, Gauthier S. The psychological and physical health of family members caring for an elderly person with dementia. *J Clin Epidemiol* 1992; **45**(1): 61-70.
  27. Canning RD, Harris ES, Kelleher KJ. Factors predicting distress among caregivers to children with chronic medical conditions. *J Pediatr Psychol* 1996; **21**(5): 735-49.
  28. Yee JL, Schulz R. Gender differences in psychiatric morbidity among family caregivers: a review and analysis. *Gerontologist* 2000; **40**(6): 643-4.
  29. Nijboer C, Triemstra M, Tempelaar R, Mulder M, Sanderman R, van den Bos GA. Patterns of caregiver experiences among partners of cancer patients. *Gerontologist* 2000; **40**(6): 738-46.
  30. Young RF, Kahana E. Specifying caregiver outcomes: gender and relationship aspects of caregiving strain. *Gerontologist* 1989; **29**(5): 660-6.
  31. Cuijpers P, Stam H. Burnout among relatives of psychiatric patients attending psychoeducational support groups. *Psychiatr Serv* 2000; **51**(3): 375-9.
  32. Hooker K, Manoogian-O'Dell M, Monahan DJ, Frazier LD, Schifren K. Does type of disease matter? Gender differences among Alzheimer's and Parkinson's disease spouse caregivers. *Gerontologist* 2000; **40**(5): 568-73.
  33. Fengler AP, Goodrich N. Wives of elderly disabled men: the hidden patients. *Gerontologist* 1979; **19**: 175-183.
  34. Ory MG, Hoffman RR, Yee JL, Tenstedt S, Schulz R. Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *Gerontologist* 1999; **39**(2): 177-185.
  35. Schumacher KL, Dodd MJ, Paul SM. The stress process in family caregivers of persons receiving chemotherapy. *Res Nurs Health* 1993; **16**: 395-404.
  36. Rideout EM, Rodin GM, Littlefield CH. Stress, social support, and symptoms of depression in spouses of the medically ill. *Int J Psychiatry Med* 1990; **20**(1): 37-48.
  37. Nijboer C, Triemstra M, Tempelaar R, Sanderman R, van den Bos GA. Determinants of caregiving experiences and mental health of partners of cancer patients. *Cancer* 1999; **86**(4): 577-88.
  38. Jessop DJ, Riessman CK, Stein RE. Chronic childhood illness and maternal mental health. *J Dev Behav Pediatr* 1988; **9**(3): 147-56.
  39. DebP. A discrete random effects probit model with application to the demand for preventive care. *Health Econ* 2001; **10**(5): 371-83.
  40. Cameron AC, Trivedi PK. *Regression Analysis of Count Data* New York: Cambridge University Press, 1998.
  41. Agency for Healthcare Research and Quality. Household Component Full Year Files [AHRQ web site]. 2001. Available at [http://www.meps.ahrq.gov/Data\\_Pub/hc\\_fydata96.htm](http://www.meps.ahrq.gov/Data_Pub/hc_fydata96.htm). Accessed April 23, 2001.
  42. Duncan GJ, Hill MS. Conceptions of longitudinal households, fertile or futile? *J Econ Soc Meas* 1985; **13**: 61-375.
  43. Carlson BL, Cohen SB, Johnson AE. Family unit constructs, dynamics, and analysis in the household component of the NMES. *J Econ Soc Meas* 1994; **20**(3): 215-35.
  44. Altman B M, Cooper PF, Cunningham PJ. The case of disability in the family: impact on health care utilization and expenditures for nondisabled members. *Milbank Q* 1999; **77**(1): 39-75.
  45. Cuellar N, Butts JB. Caregiver distress: what nurses in rural settings can do to help. *Nurs Forum* 1999; **34**(3): 24-30.