Published in final edited form as:

Psychiatr Serv. 2012 November 1; 63(11): 1118–1124. doi:10.1176/appi.ps.201200014.

Adaptation to a Spouse's Disability by Parents of Adult Children With Mental Illness or Developmental Disability

Subharati Ghosh, M.S.W., Ph.D.,
Heller School for Social Policy and Management and the Lurie Institute for Disability Policy, Brandeis University, 415 South St., Waltham, MA 02453

Jan S. Greenberg, M.S.W., Ph.D., and
Waisman Center and School of Social Work, University of Wisconsin–Madison

Marsha Mailick Seltzer, Ph.D.
Waisman Center and School of Social Work, University of Wisconsin–Madison

Abstract

Objective—This study examined the effects on well-being of a spouse's disability among aging parents already serving as caregivers of adult children with severe mental illness or a developmental disability

Methods—The study sample consisted of two groups of participants in the Wisconsin Longitudinal Study of 1957 high school graduates and their randomly selected siblings—those who had a child with a disability (N=227) and a matched comparison group of parents who did not have a child with a disability (N=1,463). The participants were surveyed in 1992–1994 and 2004–2006, and participants with a spouse with a disability in 1992–1994 were excluded from the analysis. The effect of multiple caregiving roles was investigated by using regression analysis.

Results—Parents of adult children with severe mental illness were more likely than either parents of adult children with developmental disabilities or the comparison group to report that their spouse developed a disability in the early retirement years. The experience of caring for a spouse with a disability and the experience of caring for an adult child with disabilities had additive effects in eroding the well-being of older adults. Parents of adult children with severe mental illness in general had the lowest levels of well-being.

Conclusions—As they move into their retirement years, aging parents who care for children with long-term disabilities are likely to experience multiple caregiving responsibilities. Service providers must address the needs of these aging parents and develop interventions to help them cope and plan for their future.

Parenting a child with developmental disabilities or severe mental illness is a lifelong responsibility. Because individuals with these disabilities are living longer (1,2) and as care of mental illness and developmental disabilities has shifted from the institution to the community (3), parental care of adult children with disabilities has extended well into the parent's retirement years.

Parents of adult children with developmental disabilities and severe mental illness face multiple stressors. In addition to the objective burden associated with providing ongoing

---

subharati@gmail.com..

disclosures
The authors report no competing interests.

care and support, there are emotional stresses and strains that persist over the life course (4,5).

There is considerable evidence that the stresses and strains associated with caring for an adult child with a disability take a long-term toll on the well-being of parents, and parents of adult children with severe mental illness report the poorest outcomes (6). Parents of adult children with mental illness have greater levels of caregiver burden (4), poorer health (4,6-8) higher rates of chronic health conditions (9), poorer self-reported health (9), and elevated levels of general medical symptoms (7) than parents whose children do not have disabilities or parents of individuals with developmental disabilities (10). These parents also have to bear the out-of-pocket expenses caused by inadequate insurance coverage of mental health care (11) and systematic defunding of mental health services (12).

In midlife, measures of general medical health, depressive symptoms (7), and psychological well-being (13 tend to be similar between parents of adult children with developmental disabilities and parents of typically developing children. However, as parents enter their retirement years, those caring for children with developmental disabilities are at greater risk than their peers without similar caregiving responsibilities of experiencing health declines (14). The existing research, therefore, suggests that as they age, parents of adult children with developmental disabilities or mental illness are at an increased risk of greater health and mental health limitations than parents of nondisabled children.

Aging parents of adult children with disabilities also face the possibility of taking on caregiving responsibilities for other family members. In particular, married older parents who have an adult child with a disability often have responsibilities not only for their son or daughter but also for a spouse with an age-related disability. Sixty percent of individuals in their midfifties to early sixties, and 80% of individuals in their mid-seventies, have at least one chronic health condition (15). Individuals in their midlife and early retirement years with care needs depend for care on family and friends (16)—typically a spouse (17), given that a vast majority of individuals at this stage of life are married (18).

A substantial body of research indicates that the acquisition of the spousal caregiving role is frequently accompanied by declines in the caregiver’s general medical health, psychological well-being, and happiness (19); increases in depressive symptoms (19-21); and reduced social and leisure activity (20,22). Little is known about whether the negative effects of spousal caregiving on well-being are greater among older parents who already have responsibilities for the care of an adult child with a developmental disability or mental illness.

In this study, we investigated whether individuals who have an adult child with a developmental disability or mental illness and whose spouse develops an age-related disability during the study period had poorer physical, social, psychological, and financial well-being than multiple comparison groups. The comparison groups included parents of adults with a developmental disability or mental illness whose spouse remained healthy during the study period, parents of nondisabled adult children whose spouse developed an age-related disability, and parents of nondisabled adult children whose spouse remained healthy during the study period.

Methods

Research hypotheses

We investigated three hypotheses that were based on the existing body of research on aging parents caring for adults with severe mental illness or developmental disabilities and a parallel body of research on spousal caregiving.

First, aging parents of adults with disabilities will report lower levels of psychological well-being, greater depressive symptoms, poorer general medical health, less social participation, and greater financial strain than similarly aged parents of adult children without disabilities. In addition, parents of adult children with mental illness will show the most negative profile.

Second, respondents whose spouses develop a disability will report poorer psychological and general medical health, lower levels of social participation, and greater financial strain than respondents whose spouses remain healthy.

Third, there will be a significant interaction effect between the two caregiving roles, such that the negative effects of having a spouse develop a disability will be significantly greater among parents of adult children with disabilities than among parents whose adult children are nondisabled.

Data collection

The data were drawn from the Wisconsin Longitudinal Study (WLS), a prospective study of a random sample of 10,317 men and women who graduated from Wisconsin high schools in 1957 (23). Initially, data were collected from the original respondents (“the graduates”) in 1957, 1975, 1992, and 2004. Starting in 1977, a random subsample of siblings of the graduates was added to the study. In 1992–1994 and 2004–2006, the same interview and questionnaire were administered to the sibling and the graduate samples. Informed consent was obtained from all participants, and the study was approved by the institutional review board of the University of Wisconsin–Madison.

We used data from 1992–1994, when the respondents were in their mid-fifties (mean ±SD=52.82±3.78) and 2004–2006, when they were in their early to mid-sixties (63.93±3.78), to investigate the specific aims of this study.

Sample

Caregiving sample—Parents in the WLS who had a child with severe mental illness or developmental disabilities were identified in the 2004–2006 survey. First, each respondent was asked whether they had a child with a developmental disability or a severe mental illness. If the respondent answered affirmatively, the interviewer inquired about the nature of the disability. Parents whose son or daughter had a specific developmental disability (for example, Down syndrome or autism spectrum disorder) or who used terms such as developmental disability, mental retardation, and cognitive disability to describe the child’s disability were included in the developmental disabilities group. Parents who reported that an adult child had been diagnosed by a health professional with schizophrenia, bipolar disorder, or a major clinical depression that required hospitalization or limited the ability of the person to carry on activities of daily living were included in the severe mental illness group.

In addition, only respondents who met the following additional criteria were included in the analysis. First, they were married to the same spouse in 1992–1994 and 2004–2006. Second, the adult child was either the biological or the adopted child of the respondent. Third, the onset of the child's developmental disability or mental illness condition was prior to 1992–1994, and the respondent had had contact with the child by telephone or in person at least once in the past year. Fourth, the respondent did not report having a disability when data were collected in 1992–1994 and 2004–2006. Fifth, the respondent reported that his or her spouse did not have a disability in 1992–1994.

The disability status of the respondent and his or her spouse was determined by a question currently used by the World Health Organization to indicate any long-term physical or mental condition or illness or a disability that limits what one is able to do or that is likely to limit one's activities in the future. Responses were coded 1, yes, or 0, no.

A total of 227 respondents met the study criteria, of whom 107 had a son or a daughter with a developmental disability and 120 had a son or a daughter with a severe mental illness. A majority of the children (87%, N=197) were the biological children of the respondent and almost half were males (47%, N=104). The mean±SD age of the sons or daughters with disabilities was 37.1±6.62 years, and 75% (N=170) had 12 or more years of education.

Comparison sample—A comparison group of respondents who reported not having a child with any form of disability was selected from the WLS by using the same criteria used to select the sample of parents of adult children with disabilities. We excluded respondents who provided caregiving to others besides their spouse (for example, parents or parents-in-law) because none of the respondents with adult children with disabilities reported providing care to a family member other than a spouse. In cases in which two respondents from the same family met the criteria for the comparison group (the original graduate and their sibling), we selected at random one of the respondents from the pair to avoid dependency in the data.

The comparison sample was stratified by gender, age, and whether the respondent was drawn from the graduate or sibling sample to match the proportions in the sample of parents of children with disabilities. A total of 1,463 respondents were selected for the comparison group.

Measures

Parents of adults with disabilities and parents in the comparison group were assessed on the following measures of psychological, physical, social, and financial well-being. Positive psychological well-being was assessed by a modified version of Ryff's (24) scale of psychological well-being, which consists of 19 items that are common to both the 1992–1994 and 2004–2006 surveys. The Cronbach's alpha was .89 in 1992–1994 and .90 in 2004–2006. A composite score was calculated by averaging the 19 items.

The Center for Epidemiologic Studies Depression Scale (CES-D) (25), which was administered in both 1992–1994 and 2004–2006, was used to measure depressive symptoms. The Cronbach's alpha was .76 in 1992–1994 and .77 in 2004–2006. The 20-item scale recorded the number of days during the past week that the respondent experienced each symptom. The responses were recoded into the standard CES-D categories, from 0, indicating rarely (less than one day), to 3, indicating most of the time (five to seven days).

Two measures of general medical health were analyzed. The first measure, administered both in 1992–1994 and 2004–2006, is a count of 18 somatic health symptoms (for example, lack of energy or aching muscles) experienced in the past six months; responses are coded 1, yes, or 0, no. The Cronbach's alpha was .70 in 1992–1994 and .71 in 2004–2006. The second measure, the Health Utilities Index (26), was administered only in 2004–2006. It measures health-related quality of life with respect to eight domains (vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain). Scores range from 1, perfect health, to 0, poorest health.

Social participation was assessed by a measure of participation in 17 organizations, such as charitable organizations and civic groups, which was administered both in 1992–1994 and in 2004–2006. A single item, asked only in 2004–2006, assesses financial difficulty on a 5-point scale, from 1, no financial distress, to 5, extreme financial distress.

Demographic variables included age (a continuous variable measured in years), gender (coded 1, male, or 0, female), years of education (a continuous measure), employment status (coded 1, employed, or 0, not employed), and number of children (a continuous measure). Household income, a continuous variable indicating the combined incomes of the respondent and his or her spouse, was also assessed. A standard log transformation of this variable corrected for skewness in the data.

Analytic strategy

Analysis of variance for continuous variables and cross-tabulations for categorical variables were used to detect significant differences in background characteristics, such as gender, education, and number of children, of the three groups of parents. Logistic regression was used to investigate whether parents of adults with severe mental illness or a developmental disability had a greater likelihood of having a spouse develop a disability compared with parents without an adult child with a disability.

To test our three major hypotheses, we used ordinary least-squares hierarchical regression to examine the main effects of having an adult child with a disability and having a spouse develop a disability and their interaction effect. The regression controlled for background differences and the dependent variables of the 1992–1994 survey except for health-related quality of life and financial difficulty, which were measured only by the 2004–2006 survey. In a preliminary analysis, we examined the effects of the respondent’s gender, years of education, and number of children and of whether the respondent was living with the adult child with disabilities on the outcome measures, given that the groups differed significantly on these variables. Gender and years of education were retained because they were the only background variables that made a significant contribution to the final regression model. Analysis was calculated with IBM SPSS, version 19.

Results

No significant differences were found between the three groups in age, employment, or income in 1992–1994 (Table 1). With respect to parent gender, the percentage of mothers was significantly higher among the parents of adult children with mental illness (63%, N=75) than among the parents of adult children with a developmental disability (42%, N=45) and the comparison group (51%, N=744). Parents of adult children with a developmental disability reported having a greater number of children than comparison group parents (3.99 versus 3.11, respectively). They were also more likely than parents of adults with mental illness or parents in the comparison group to have children living at home. In 2004–2006, approximately 50% (N=53) of adult children with a developmental disability lived with the respondent compared with only 18% (N521) of adult children with mental illness and 11% (N=155) of adult children in the comparison group. Even when adults with disabilities lived away from home, 44% (N=68) of the parents provided assistance with daily tasks such as money management, transportation, and shopping (data not shown).

Respondents with an adult child with severe mental illness had a greater likelihood of a spouse developing a disability than respondents with a child with a developmental disability (odds ratio [OR]=2.56, 95% confidence interval [CI]=1.39–4.65, $p \leq .003$) or healthy children (OR=2.03, CI=1.39–3.30, p,<001). A total of 38% (N=46) of the spouses of respondents with a son or daughter with mental illness developed a disability between the two waves of the study compared with 20% (N=21) of the respondents who had an adult child with a developmental disability and 23% (N=340) of the comparison group. In other words, parents of adults with severe mental illness were almost twice as likely as respondents in the other two groups to have a spouse develop a disability between the two study points.

Our first hypothesis was that parents of adult children with disabilities would display a more negative profile of psychological, social, physical, and financial well-being than comparison group parents, with parents of adults with mental illness being the most affected by caregiving. Table 2 displays the outcome measures for the three groups in 2004–2006. As shown in Table 3, after controlling for parental education and age and 1992–1994 levels of the dependent variable, having an adult child with mental illness was related at a trend level to declining psychological well-being between 1992–1994 and 2004–2006 and was significantly related to increasing levels of depression and health symptoms as well as to poorer health-related quality of life in 2004–2006.

Parents of adult children with a developmental disability reported significantly poorer health-related quality of life than the comparison group. Also, there was a trend for parents of adult children with a developmental disability to report lower levels of psychological well-being than comparison group parents, but the two groups did not differ on depressive symptoms, general medical health, financial strain, or social participation. Therefore, the results supported our expectation that parents of adults with severe mental illness would be more affected by caregiving than parents of adult children with a developmental disability.

Our second hypothesis was that respondents whose spouses developed a disability would experience a greater toll on their well-being than participants whose spouses did not become disabled. As shown in Table 3, having a spouse develop a disability had pervasive effects on the well-being of the respondent. Respondents whose spouses became disabled reported declining levels of psychological well-being, increasing levels of depression, a greater number of health symptoms, poorer health quality of life, and greater financial strain compared with respondents whose spouses remained healthy. Only social participation showed no deleterious effects from having a spouse develop a disability.

We found only modest support for our third hypothesis that the experience of having a spouse become disabled would amplify the negative effects on well-being of having long-term caregiving responsibilities for an adult child with disabilities. Respondents who had a child with mental illness whose spouse became disabled reported greater financial strain than respondents in the comparison group whose spouse became disabled. Also, there was a trend for social participation to decline after a spouse became disabled among respondents with adult children with mental illness or a developmental disability compared with respondents in the comparison group. However, the interaction effect for the other four outcomes examined was not significant.

Discussion

The primary aim of this study was to explore the impact of having a spouse develop a disability on the lives of aging parents who provide care for adult children with disabilities. Our findings indicate that having a spouse become disabled took an additional toll on the well-being of aging parents of adult children with a developmental disability or severe mental illness. However, the findings provide less evidence that the two caregiving roles had an interactive effect.

Consistent with prior research, our findings suggest that parents of adults with serious mental illness had the poorest health and psychological functioning. They had decreasing levels of psychological well-being and general medical health and increasing levels of depression over the study period. Parents of adults with a developmental disability also showed a significant decline in health-related quality of life and a trend-level decline in psychological well-being.

Separate from the disability status of the adult child, having a spouse develop a disability had pervasive effects on the well-being of respondents across a range of outcomes. Respondents whose spouses became disabled experienced declining physical and psychological well-being, increasing levels of depressive symptoms, and greater financial strains.

Respondents who had an adult child with a severe mental illness were almost twice as likely as parents with adult children with a developmental disability or no disability to report that their spouse became disabled between the two waves of data collection. We interpret this finding as further evidence of the wear and tear of long-term caregiving. Research shows that parents of children with severe mental illness experience greater caregiver burden than parents of a child with a developmental disability (4,5). Because of the cyclical nature of mental illness, parents of persons with severe mental illness must live with greater uncertainty (27) than parents of people with a developmental disability, whose functioning is relatively stable (28).

Compared with parents of adults with developmental disabilities, parents of adults with mental illness must cope with more frequent behavior problems that are more difficult to manage (4,29,30). In addition, the mental health system of care tends to be more fragmented and less supportive of the involvement of parents than the developmental disabilities system of care (31), making it more difficult for families of a child with mental illness to access services. Therefore, it is not unexpected that respondents with an adult child with serious mental illness reported declining health and that their spouses were at increased risk for developing a disability as they transitioned from midlife to the early retirement years.

We found only modest evidence that having a spouse become disabled has a greater impact on parents of adult children with disabilities than on parents of adult children without disabilities. Parents of adults with severe mental illness whose spouse became disabled reported greater financial strain than parents in the comparison group whose spouse became disabled. Parents of adults with severe mental illness often bear the cost of care, given that health insurance fails to cover the full cost of many mental health services and treatments (32). For many years, the lack of mental health parity has been a significant financial hardship for many families. There are likely additional out-of-pocket medical expenses when a spouse develops a disability. Therefore, a spouse’s disability may be particularly stressful financially for aging parents of adults with severe mental illness, given that they may have fewer financial resources in reserve during their retirement years.

We also found among aging parents whose spouse develops a disability that there was a trend to report lower levels of social participation among parents of adults with developmental disabilities or severe mental illness. Aging individuals with multiple caregiving responsibilities likely have less discretionary time and may have little choice but to reduce their social activity. However, a growing body of evidence indicates the psychological benefits of remaining socially active during the retirement years (33). Service providers should develop targeted outreach efforts aimed at individuals with multiple caregiving responsibilities to ensure that they do not become socially isolated. As the population of the United States ages, many members of the National Alliance on Mental Illness (NAMI) now face spending their later years caring for both an adult child with mental illness and an ailing spouse. NAMI's Family-to-Family psychoeducation program, which often becomes a source of social support for participants, could be adapted to better serve individuals with multiple caregiving responsibilities by incorporating information on resources for aging caregivers and how to access the resources.

This study had several limitations. First, the sample was drawn from Wisconsin and thus underrepresents the ethnic and racial diversity found in the U.S. population, which reduces the generalizability of the findings. Second, the study lacks comprehensive data on the chronic nature of the spouse's disability, given that no questions about the chronicity or the severity of the illness were asked. Therefore, it is not known how much help the respondent provided to the disabled spouse and whether that information may have had an additional effect on the outcome measures. Third, we also do not know the exact year when the spouse became disabled. Knowing the year of onset could have allowed us to estimate the effect of the duration of caregiving on a caregiver's well-being.

In spite of these limitations, the study had many strengths, including the fact that it featured a random community-based sample not selected because of the disability status of the adult child or aging spouse. Also, the longitudinal nature of the data allowed us to control for prior levels of well-being for most measures.

Conclusions

The study focused on an emerging and growing number of aging caregivers whose retirement years present additional responsibilities for the care of a disabled spouse as well as continuing care of an adult son or daughter with disabilities. Our findings suggest that this group of caregivers is vulnerable because of the additive effects of stress associated with caring for both an adult child with disabilities and a spouse with disabilities. Aging parents of adults with severe mental illness are particularly vulnerable, and the study findings draw attention to the importance of targeting this group and intervening at the time a spouse is beginning to show health declines. Such intervention may help to mitigate the deleterious effects of caregiving for multiple family members on the health and well-being of the primary caregiver.

Acknowledgments

This study was supported by grants R01 AG20558, R01 AG08768, and P01 AG21079 from the National Institute on Aging and by grant P30 HD03352 from the National Institute of Child Health and Human Development.

References

1. Hennekens CH, Hennekens AR, Hollar D, et al. Schizophrenia and increased risks of cardiovascular disease. American Heart Journal. 2005; 150:1115–1121. [PubMed: 16338246]
2. Janicki MP, Dalton AJ, Henderson CM, et al. Mortality and morbidity among older adults with intellectual disability: health services considerations. Disability and Rehabilitation. 1999; 21:284–294. [PubMed: 10381241]
3. Braddock, D.; Parish, SL. The State of the States: Public Policy Toward Disability at the Dawn of the 21st Century. Braddock, D., editor. American Association on Mental Retardation; Washington, DC: 2000.
4. Greenberg JS, Seltzer MM, Greenley JR. Aging parents of adults with disabilities: the gratifications and frustrations of later-life caregiving. Gerontologist. 1993; 33:542–550. [PubMed: 8375685]

5. Seltzer MM, Greenberg JS, Krauss MW. A comparison of coping strategies of aging mothers of adults with mental illness or mental retardation. Psychology and Aging. 1995; 10:64–75. [PubMed: 7779318]
6. Seltzer MM, Greenberg JS, Floyd FJ, et al. Accommodative coping and well-being of midlife parents of children with mental health problems or developmental disabilities. American Journal of Orthopsychiatry. 2004; 74:187–195. [PubMed: 15113247]
7. Seltzer MM, Greenberg JS, Floyd FJ, et al. Life course impacts of parenting a child with a disability. American Journal of Mental Retardation. 2001; 106:265–286. [PubMed: 11389667]
8. Ghosh S, Greenberg JS. Aging fathers of adult children with schizophrenia: the toll of caregiving on their mental and physical health. Psychiatric Services. 2009; 60:982–984. [PubMed: 19564232]
9. Magaña SM, Greenberg JS, Seltzer MM. The health and well-being of black mothers who care for their adult children with schizophrenia. Psychiatric Services. 2004; 55:711–713. [PubMed: 15175473]
10. Greenberg JS, Seltzer MM, Krauss MW, et al. The effect of quality of the relationship between mothers and adult children with schizophrenia, autism, or Down syndrome on maternal well-being: the mediating role of optimism. American Journal of Orthopsychiatry. 2004; 74:14–25. [PubMed: 14769105]
11. Zuvekas SH, Banthin JS, Selden TM. Mental health parity: what are the gaps in coverage? Journal of Mental Health Policy and Economics. 1998; 1:135–146. [PubMed: 11971153]
12. Zuvekas SH. Trends in mental health services use and spending, 1987–1996. Health Affairs. 2001; 20:214–224. [PubMed: 11260946]
13. Lounds JJ, Seltzer MM, Greenberg JS, et al. Transition and change in adolescents and young adults with autism: longitudinal effects on maternal well-being. American Journal of Mental Retardation. 2007; 112:401–417. [PubMed: 17963433]
14. Seltzer MM, Floyd F, Song J, et al. Midlife and aging parents of adults with intellectual and developmental disabilities: impacts of lifelong parenting. American Journal on Intellectual and Developmental Disability. 2011; 116:479–499.
15. Growing Older in America. [Accessed January 1, 2012] The Health and Retirement Survey: A Longitudinal Study of Health, Retirement and Aging. 2002. Available at hrsonline.isr.umich.edu/sitedocs/databook/HRS_Text_WEB_Ch1.pdf
16. LaPlante MP, Harrington C, Kang T. Estimating paid and unpaid hours of personal assistance services in activities of daily living provided to adults living at home. Health Services Research. 2002; 37:397–415. [PubMed: 12036000]
17. Lima JC, Allen SM, Goldscheider F, et al. Spousal caregiving in late midlife versus older ages: implications of work and family obligations. Journal of Gerontology. 2008; 63:S229–S238.
18. Current Population Survey, 2006. US Census Bureau; Washington, DC: 2007. Available at www.census.gov/population/socdemo/hh-fam/cps2006/tabA1-all.xls
19. Burton LC, Zdaniuk B, Schulz R, et al. Transitions in spousal caregiving. Gerontologist. 2003; 43:230–241. [PubMed: 12677080]
20. Kramer BJ, Lambert JD. Caregiving as a life course transition among older husbands: a prospective study. Gerontologist. 1999; 39:658–667. [PubMed: 10650675]
21. Marks NF, Lambert JD, Choi H. Transition to caregiving, gender, and psychological wellbeing: a prospective US national study. Journal of Marriage and the Family. 2002; 64:657–667.
22. Seltzer MM, Li LW. The dynamics of caregiving: transitions during a three-year prospective study. Gerontologist. 2000; 40:165–178. [PubMed: 10820919]
23. Hauser RM, Sewell WH, Logan JA, et al. The Wisconsin Longitudinal Study: Adults as parents and children at age 50. IASSIST Quarterly. 1992; 16:23–38.
24. Ryff CD. Happiness is everything, or is it? Explorations on the meaning of psychological well-being. Journal of Personality and Social Psychology. 1989; 57:1069–1081.
25. Radloff L. The CES-D Scale: a self-report depression scale for research in the general population. Applied Psychological Measurement. 1977; 1:385–401.
26. Horsman J, Furlong W, Feeny D, et al. The Health Utilities Index (HUI): concepts, measurement properties and applications. Health and Quality of Life Outcomes. 2003; 1:1–13. [PubMed: 12605709]

27. Rolland, J. Families, health and illness; in Handbook of Health Social Work. Gehlert, S.; Arthur, T., editors. Wiley; New York: 2006.
28. Marsh, D., editor. Families and Mental Retardation: New Directions in Professional Practice. Praeger; New York: 1992.
29. Marsh, D., editor. Families and Mental Illness: New Directions in Professional Practice. Praeger; New York: 1992.
30. Pruchno RA, Patrick JMH, Burant CJ. Mental health of aging women with children who are chronically disabled: examination of a two-factor model. Journal of Gerontology. 1996; 51B:S284–S296.
31. Winefield HR, Burnett P. Barriers to an alliance between family and professional caregivers in chronic schizophrenia. Journal of Mental Health. 1996; 5:223–232.
32. Jacobs S, Steiner J, Schaefer M, et al. Financing the care of individuals with serious mental illness. Psychiatric Services. 2004; 55:1096–1098. [PubMed: 15492069]
33. Menec VH. The relation between everyday activities and successful aging: a 6 year longitudinal study. Journal of Gerontology. 2003; 58:S74–S82.

Table 1

Demographic characteristics of parents of adult children with severe mental illness or a developmental disability and a comparison group in 2004–2006[a]

	Severe mental illness (N=120)		Developmental disability (N=107)		Comparison group (N=1,463)			
Characteristic	**N**	**%**	**N**	**%**	**N**	**%**	**Test statistic**[b]	**p**
Age (Ms±SD years)	64.27±3.33		64.01±4.63		63.93±3.75		F=.45	.637
Children (M±SD N)[c]	3.46±1.59		3.99±1.89		3.11±1.45		F=19.68	.001
Education (M±SD years)[d]	14.37±2.56		14.07±2.68		13.8±2.39		F=3.49	.031
Income (M±SD) (log transformed)	10.49±1.88		10.55±1.83		10.2±2.19		F=2.19	.113
Have children living at home[c,d]	21	18	53	50	155	11	χ^2=130.77	.001
Employed	49	41	51	48	667	46	χ^2=1.25	.453
Male gender[d,e]	45	38	62	58	719	49	χ^2=9.78	.008
Spouse became disabled between 1992–1994 and 2004–2006	46	38	21	20	340	23	χ^2=4.04	.040

[a] The comparison group consisted of parents of adult children without severe mental illness or a developmental disability.

[b] df=2 and 1,687 for F test, and df=2 for chi square test

[c] Significant differences were found between parents with children with a developmental disability and the comparison group.

[d] Significant differences were found between parents with children with severe mental illness and the comparison group.

[e] Significant differences were found between parents with children with severe mental illness and parents with children with a developmental disability.

Table 2

Well-being of parents with adult children with severe mental illness or a developmental disability and a comparison group in 2004–2006, by disability of spouse[a]

	Severe mental illness			**Developmental disability**			**Comparison group**				
	Disabilty of spouse			**Disability of spouse**			**Disability of spouse**				
Measure	**Yes (N=46)**	**No (N=74)**	**Total (N=120)**	**Yes (N=21)**	**No (N=86)**	**Total (N=107)**	**Yes (N=340)**	**No (N=1,123)**	**Total (N=1,463)**	**Spouse disabled (N=407)**	**Spouse not disabled (N=1,283)**
Psychological well-being[b,c]	4.69	4.80	4.75	4.62	4.79	4.71	4.76	4.86	4.81	4.69	4.82
Depressive symptoms[c,d,e]	8.24	7.41	7.83	8.03	6.29	7.16	6.75	5.81	6.28	7.67	6.50
General medical symptoms[e,f]	6.96	6.73	6.85	5.73	6.22	5.97	6.37	5.72	6.05	6.35	6.22
Health-related quality of life[c,e,g,h]	.77	.85	.81	.81	.82	.82	.84	.88	.86	.81	.85
Financial difficulty[c,e,i]	1.80	1.37	1.59	1.57	1.50	1.54	1.51	1.39	1.45	1.42	1.63
Social participation[c,j]	2.54	3.13	2.84	2.23	2.92	2.58	2.85	2.69	2.77	2.54	2.92

[a] The comparison group consisted of parents of adult children without severe mental illness or a developmental disability. Group means were adjusted for their values in 1992–1994, except for Health-Related Quality of Life and financial difficulty, for which 1992–1994 results were not available. A total of 46 (38%) parents with a child with a severe mental illness, 21 (20%) parents with a child with a developmental disability, 340 (23%) parents in the comparison group, and 407 (24%) of all parents had a disabled spouse.

[b] Measured by the Ryff Psychological Well-Being Scale. Possible scores range from 1 to 6, with higher scores indicating greater positive well-being.

[c] Significant differences were found between parents with or without a disabled spouse.

[d] Measured by the Center for Epidemiologic Studies–Depression Scale. Possible scores range from 0 to 60, with higher scores indicating greater depressive symptoms.

[e] Significant differences were found between parents with children with severe mental illness and the comparison group.

[f] Measured with an index from the Wisconsin Longitudinal Study (WLS). Possible scores range from 0 to 18 with higher scores indicating greater number of general medical symptoms.

[g] Measured by the Health Utilities Index Scale. Possible scores range from 0 to 1, with lower scores indicating poorer health status.

[h] Significant differences were found between parents with children with a developmental disability and the comparison group.

[i] Measured by a single item from the WLS. Possible scores range from 1 to 5, with higher scores indicating greater financial difficulty.

[j] Measured by a scale that includes participation in 17 organizations, such as charities, civic groups, and country clubs. Possible scores range from 0 to 17, with higher scores indicating greater social participation.

Table 3

Effect of having a child with a mental illness or developmental disability and a spouse with a disability on well-being[a]

Measure	Psychological well-being (β)	Depressive symptoms (β)	General medical symptoms (β)	Health-related quality of life (β)	Financial difficulty (β)	Social participation (β)
Model 1						
Level of dependent variable in 1992–1994[b]	52***	.42***	.38***	—	—	.45***
Education in 1992–1994 (years)	11***	−.04	−.04†	12***	−.09***	.07**
Parent’s gender	−.03	−.05*	−.02	−.03	.08**	.01
Child with severe mental illness	−,04†	.07**	.07***	−.07**	.00	.05†
Child with developmental disability	−.04†	.03	.02	−.07**	.03	.02
Spouse disability status	−.07***	.07**	.07***	−.09**	.08*	.04
Model 2						
Child with severe mental illness × disabled spouse					.06*	−.05†
Child with a developmental disability × disabled spouse					−.01	−.04†

[a] Data are reported in standardized beta coefficients. Results for model 1 were significant for psychological well-being (R^2=.30, F=122.43, df=6 and 1,683, p≤.001), depressive symptoms (R^2=.19, F=67.39, df=6 and 1,683, p≤.001), general medical health (R^2=.16, F=54.40, df=6 and 1,683, p≤.001), and health-related quality of life (R^2=.03, F=10.55, df=5 and 1,684, p≤.001). Results for model 2 were significant for financial difficulty (R^2=.02, F=4.96, df=7 and 1,682, p≤.001) and social participation (R^2=.23, F=61.68, df=8 and 1,681, p≤.001).

[b] Data for health-related quality of life and financial difficulty were not collected in 1992–1994.

* p<.05

** p<.01

*** p<.001

† p<.10