

Life course Impacts of Parenting a Child with Disability

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Background: The context of caring for a child with developmental disability or severe mental illness

- Parents take on the caregiving role
- It is a life-time commitment, extending well into the caregivers old age
- Siblings provide care only when the parent is physically unable to care for

Long term effects of parenting a child with a disability

- Elevated levels of depression
- Financial strain, work family strain and strained marital relationship
- Loss of social support
- Negative effect on physical health and psychological well-being

The Study

Multiple Caregiving Roles: Adaptation to Spousal Disability by Parents of Adults with Severe Mental Illness or Developmental Disabilities

Study Objective

The primary purpose of the study was to investigate whether aging parents of children with severe mental illness or developmental disabilities are more vulnerable to the negative effects on wellbeing of having a spouse develop a disability than aging parents of adult children without disabilities.

Why study the phenomenon of multiple caregiving?

- Changing demographic structure of our society
- Aging of the population
- High rate of dependence on one's spouse for care and consequences of spousal caregiving
- Aging of individuals with developmental disabilities & severe mental illness
- Shift of care from institution to the community

Theoretical Underpinnings of this study

- The life course perspective- linked lives, transition, timing of events, off-timedness and duration
- The role theory- scarcity or depletion hypothesis

Uniqueness of this study

The use of the Wisconsin Longitudinal Study

- Random community sample
- Use of a comparison group
- Longitudinal nature of the data
- Sampled individuals prior to them taking upon the caregiving role

Research hypothesis

- Aging parents of adults with disabilities will report lower levels of psychological well-being, greater depressive symptoms, poorer physical health, less social participation, and greater financial strain than similarly-aged parents of adult children without disabilities. In addition, we expect that parents of adult children with mental illness will show the most negative profile
- Respondents whose spouse develops a disability will report poorer psychological and physical health, lower levels of social participation, and greater financial strain than those whose spouse remains healthy

Research hypothesis

- There will be a significant interaction effect between the two caregiving roles, such that the negative effects of having a spouse develop a disability are significantly greater for parents of adult children with disabilities than for parents whose adult children are non-disabled

Study Design

Data source

Wisconsin Longitudinal Study (WLS):

- It is a random community sample of 10,317 men and women who graduated from the Wisconsin high schools in 1957, and their randomly selected brothers and sisters
- Data collected in 1957, 1964, 1975-77, 1992-94 (T1) and 2004-06

Sample Selection

Analytic sample- The non-normative parenting sample

Sample Criteria:

- Targeted developmental disability or severe mental illnesses (e.g. down syndrome, mental retardation, Fragile-X, schizophrenia, bi-polar and severe depression etc.), with onset prior to T1 wave of data collection
- The respondent had to be married in T2
- The respondent had to be married to the same person as in T1
- The respondent had to have a living child with a targeted DD or SMI condition

Sample Selection

- The respondent had to be the biological or adopted parent of the child and to have had contact with the child through phone or in person at least once last year
- The respondent did not report having a spouse with a disability at T1. It was also necessary that the disability status was known across both the study waves
- The respondent did not have a disability in any of the waves

Total cases selected: 227

Selection of the comparison sample

Similar selection criteria as the analytic sample

Additional criteria:

- None of the respondent had a child with DD or SMI or any other form of disability
- The respondents did not have a sibling in the WLS who had a child with DD or SMI
- Did not provide caregiving to others, e.g. parents, parents-in-law

Final Steps

Comparison sample was demographically matched to the analytic sample

Randomly stratified by age and gender and whether the respondent was drawn from the graduate or sibling sample

Total cases selected: 1463

Demographic characteristics of the sample

Variables	SMI	DD	COMPARISON
Age	64.27 ± 3.33	64.01± 4.63	63.93 ± 3.73
Number of children	3.46 ± 1.59	3.99 ±1.89	3.11 ± 1.45
Year of education	14.37 ± 2.56	14.07 ± 2.68	13.8 ± 2.39
Income (log transformed)	10.49 ±1.88	10.55 ± 1.83	10.2 ± 2.19
% of children co-residing	18%	50%	11%
% employed	41%	48%	46%
% males	38%	58%	49%
% spouse became disabled between 1992/94 and 2004/06	38%	20%	23%

Analytic strategies

Three primary analytic strategies:

ANOVA and chi-square to test for significant differences in background characteristics

Logistic regression to investigate whether parents of adults with SMI and DD have greater likelihood of having a spouse develop a disability between the two waves

Hierarchical regression to examine the main effects of spouse and child disability on respondent wellbeing, and the interaction effects of the two caregiving roles

Adjusted group means on outcome measures in 2004/06

Measure	Severe mental illness			Developmental disability			Comparison group			Sps disb	Sps not disb
	Sps disb	sps not disb	Total	sps disb	Sps not disb	Total	Sps disb	Sps not disb	Total		
Psychological wellbeing	4.69	4.8	4.75	4.62	4.79	4.71	4.76	4.86	4.81	4.69	4.82
Depressive symptoms	8.24	7.41	7.83	8.03	6.29	7.16	6.75	5.81	6.28	7.67	6.5
Physical Health symptoms	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	.77	.85	.81	.81	.82	.82	.84	.88	.86	.81	.85
Financial difficulty	1.8	1.37	1.59	1.57	1.5	1.54	1.51	1.39	1.45	1.63	1.42
Social participation	2.54	3.13	2.84	2.23	2.92	2.58	2.85	2.69	2.77	2.54	2.92

Effect of having a child with mental illness or developmental disability and a spouse with a disability on adaptive outcomes

	Psych wellbeing (β)	Depress symptoms (β)	Physical health symptom (β)	Health Related Quality of Life (β)	Financial Difficulty (β)	Social Participation (β)
Prior level of dependent variable	.52	.42	.38	-----	-----	.45
Education 1992/94 (in years)	.11	-.04	-.04	.12	-.09	.07
Parent's gender (1=father; 0=mother)	-.03	-.05	-.02	-.03	.08	.01
Target child has Severe Mental Illness	-.04	.07	.07	-.07	.00	.05
Target child has Developmental Disability	-.04	.03	.02	-.07	.03	.02
Spouse disability status (1= spouse disabled; 0= spouse not disabled)	-.07	.07	.07	-.09	.08	.04
Step 2						
Target child severe mental illness × spouse disabled					.06	-.05
Target child developmental disability × spouse disabled					-.01	-.04

Findings

- Respondents with an adult child with SMI had a greater likelihood of having a spouse develop disability between the two study waves than those with a child with DD (odds ratio= 2.56, $p \leq .003$) or those without disabled children (odds ratio= 2.03, $p \leq .000$)
- Having a child with SMI was related to significant:
 - Decline in psychological wellbeing
 - Increase in levels of depressive symptoms
 - Increase in physical health symptoms and poorer health related quality of life, compared to parents in the comparison group

Findings

Having a child with DD was related to significantly:

- Poorer health related quality of life compared to parents in the comparison sample
- Trend of declining levels of psychological wellbeing

Respondents whose spouse became disabled between the waves reported:

- Declining levels of psychological wellbeing
- Increasing levels of depression
- Increase in physical health symptoms and poorer health related quality of life
- Greater financial strain

Findings

- Greater financial strain for respondents parenting children with SMI when their spouse developed a disability
- Greater decline in social participation for respondents parenting children with DD and SMI, compared to respondents in the comparison group, when their spouses developed a disability between the two study waves

Discussion

- Having a spouse become disabled takes an additional toll on the wellbeing of aging parents of children with disabilities
- Most vulnerable are those parenting children with mental illnesses

Possible reasons for poor adaptation:

Experience greater caregiving burden than those parenting individuals with DD

Cyclical nature of SMI, thus greater uncertainty

Cope with more frequent and difficult to manage behaviors

Off-timedness of mental illness and life course issues

Fragmented and less supportive nature of the mental health system, cost of care and lack of insurance coverage

- Those parenting children with DD show a pattern of adaptation

Implications for practice, policy & research

- Social workers and health providers need to identify families who are at risk of experiencing multiple caregiving roles
- Clinicians must screen for mental and physical health status of caregivers
- Help families plan ahead
- Encourage families to strengthen social ties- adapting the family-to-family psycho-education program to better serve families with multiple caregiving responsibilities
- Integrating services to reduce cost of care
- It questions the basic assumption under which most caregiving studies are conducted

Study Limitations

- Respondents were all from the state of Wisconsin, which reduces the generalizability of the findings
- Self-report of child and spouse disability statuses
- Respondents not questioned on the severity of the disability
- Not known how much care is provided to one's spouse

Future of this study

The new wave of WLS which is already in the field

Additional 100 families are expected to be identified with multiple caregiving roles

A greater likelihood of families where respondent, spouse and a child has a disability

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Current work

Survey of Income and Program Participation

- Material hardships and income poverty in households raising multiple children with disabilities
- Material hardships and income poverty in multigenerational households having both a child and an adult with a disability

Sample

Data used: 2004 and 2008 panels of the SIPP

- administered by the US Census Bureau and is representative of the non-institutionalized US civilian population.
- Detailed information on economic situation of the people in the US, specifically their income, labor force participation and program participation
- Includes measures of quality of life used by researchers to assess material hardships experienced by families in the US

Sample

Households with individuals age 0 to 19 with an identifiable parent

Child disability status, adult disability status and question on household material hardship are asked once during a panel (wave 5, 2004 panel & wave 6, 2008 panel)

Identified household with children with disabilities:

1 child with a disability: 3527

2 children with disabilities: 756

≥ 3 children with disabilities: 168

Initial findings

Income poverty in households with multiple children with disabilities:

No children with a disability: 13.73%

One child with a disability: 21.42%

2 children with disabilities: 26.86%

≥ 3 children with disabilities: 34.76%

Controlling for years of education, household income, age of the respondent, race and ethnicity, the odds of being in poverty are always less in households where none of the children have a disability compared to households where one child has a disability (odds ratio = .49, $p \leq .000$) and household where more than one child has a disability (odds ratio = .69, $p \leq .001$)

Initial findings

Material hardships

	0 children	1 child	2 and more children
Unable to pay for gas and electricity	13.56%	23%	30.84%
Unable to pay rent or mortgage	9%	15%	20%
Unable to meet expenses	19.00%	32%	40%
Did not see a doctor when needed	5.59%	13.16%	17.42%
Did not see a dentist when needed	10.50%	17%	21%

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