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Variation in the spillover effects of illness on parents, spouses and children of the chronically ill

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Abstract

Background—Given the broad scope of the spillover effects of illness, it is important to characterize the variability in these outcomes in order to identify relationship types in which secondary impacts of illness are particularly important to include in health economic evaluations.

Purpose—To examine heterogeneity in spillover effects of chronic conditions on family members by type of familial relationship with patient.

Methods—Adults (≥ 18 years) and adolescents (13–17 years) who had a parent, spouse or child in their household with a chronic condition (including Alzheimer's disease/dementia, arthritis, cancer and depression) were recruited from a U.S. national panel to participate in an on-line survey. Respondents were asked to rate the spillover effect of their family member's illness on their own health on a 0–100 scale, with lower scores indicating greater spillover. Regression analysis was used to evaluate the association between rating scale scores and relationship with ill family member (ill parent, child, or spouse) for each illness separately, controlling for caregiving responsibility and the health status of the ill family member.

Results—1267 adults and 102 adolescents met inclusion criteria. In adjusted analyses, having a sick child was significantly ($p < 0.05$) associated with lower rating scale scores compared to having a spouse with the same condition (cancer: -24.2; depression -9.7). Having a non-elderly or elderly adult parent with a condition, compared to a spouse, was significantly associated with lower rating

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Kara Lamarand: Ms. Lamarand coordinated data collection, reviewed and revised the manuscript, and approved the final manuscript as submitted.

Lisa A. Prosser: Dr. Prosser contributed to the conceptualization and design of the study, reviewed and revised the manuscript, and approved the final manuscript as submitted.

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scale scores for arthritis (-3.8) and depression (-5.3), but not for Alzheimer's disease/dementia or cancer.

Conclusions—The impact of illness on family members, measured with a rating scale, varies by relationship type for certain illnesses. Having a child with cancer, a parent with arthritis, or either with depression, is significantly associated with greater spillover, compared to having a spouse with one of these conditions.

Introduction

There is a growing interest in measuring the secondary impact of illness on caregivers and family members, and incorporating these broader effects into health economic evaluations. Previous research has indicated that such spillover effects of illness are measurable, but may be small in magnitude and vary by condition and population affected [1]. These inferences are based on limited research, but there is increasing attention being paid to this issue [1-20]. Given the broad scope of spillover effects, it is important to characterize the variability in these outcomes in order to identify and prioritize cases in which secondary impacts of illness are particularly important to include in health economic evaluations. This involves highlighting situations in which resource-intense measurement of spillover with health utility weights may be warranted based on the size of the effects.

One important source of variability in the magnitude of spillover effects may be family relationship type [6]. Previous research has shown that illness may impact family members differently, depending on the nature of their relationship with the ill individual [6, 21], but evidence on the subject is limited. To date, most studies on spillover have looked at the impact of illness on caregivers in general [2, 3, 10-13, 17, 18, 22] or on specific relationship types, including spouses [7] and parents [9, 14, 16, 19], using a variety of measurement tools. While these studies are useful, their disparate methods limit the ability to examine heterogeneity in the degree of spillover across different relationship types.

The objective of this analysis was to estimate the magnitude of health-related quality of life (HRQOL) spillover, measured with a rating scale, in individuals with a child, parent or spouse with one of four chronic conditions, Alzheimer's disease/dementia, arthritis, cancer and depression. We sought to examine the variation in rating scale scores by relationship type across illnesses.

Methods

Sample

Parents, spouses and children of persons with Alzheimer's disease/dementia, arthritis, cancer or depression were selected from a nationally representative survey research panel of adults (≥ 18 years) and adolescents (13-17 years) for this study. The ongoing panel is managed by GfK Custom Research, LLC; new panel members are currently recruited from a published address-based sample frame that covers approximately 97% of U.S. households [23]. Members of non-internet households who choose to join the panel are provided with internet access and a laptop computer. Households who use their own computer and internet service receive small monthly stipends commensurate with their participation [24]. Demographic

information collected for all new panel members includes sex, age, ages of their household members, race/ethnicity, household income, marital status and education level.

A screener/eligibility survey was sent to 14,157 members of the survey panel (12,907 adults and 1250 adolescents) between December 2011 and February 2012. Adults were screened to determine whether they lived with a spouse or parent with Alzheimer's disease/dementia, arthritis, cancer or depression, or a child with cancer, cerebral palsy or depression. Adolescents were screened to determine whether they lived with parent with arthritis, cancer or depression. Completed eligibility surveys were received from 63.5% of adults (n=8190) and 33.4% of adolescents (n=417). Of those, 1472 adults and 108 children met the eligibility criteria. Eighty-eight percent of eligible respondents completed a 20 minute survey on the impact that their family member's illness had on their own physical and emotional HRQOL.

As part of this survey, we asked respondents to think about how they felt themselves, physically and emotionally, as a family member of a person with Alzheimer's disease/dementia, arthritis, cancer, cerebral palsy or depression, and to rate how they felt on a scale from 0-100 (Spillover rating scale; Figure 1). Lower rating scale scores indicated greater spillover. We also asked them to report if they had been a caregiver for their family member in the past year and to rate their ill family member's health status on a 5 level ordinal scale (excellent, very good, good, fair, poor). Twenty respondents who had a child with cerebral palsy were eliminated from our analysis due to the small size of this group, leaving a final sample size of 1369 adults and adolescents who lived with an ill family member with Alzheimer's disease/dementia, arthritis, cancer, or depression. This study was approved by human subjects review boards at the Harvard School of Public Health and the University of Michigan.

Statistical analyses

We calculated descriptive statistics for rating scale scores for each illness, by relationship type. Descriptive statistics included means, medians, 5th and 95th percentiles. Confidence intervals around mean scores were estimated using non-parametric bootstrapping with replacement procedures [25]. We used the K-sample equality-of-medians non-parametric test to evaluate whether median scores differed by relationship type, within each illness [25].

We used ordinary least squares (OLS) regression to model the independent association between the type of relationship the respondent had with their ill family member and the respondent's rating scale score. For each of the four illnesses separately, models used rating scale scores as the dependent variables. The main independent variables were relationship type; having an ill parent or an ill child, both compared to having an ill spouse. Primary analyses controlled for the health status of the ill family member, and whether the respondent was a caregiver of their ill family member (Appendix A).

Prior to selecting our final model, more comprehensive models were tested that included additional demographic variables: respondent's age, education, sex, marital status, race/ethnicity, and household income. Variables were included in the final model if they showed an association with rating scale scores in more than one illness (family member health) or had previously been established to have an important independent association with spillover

effects (caregiving responsibility) [2, 3]. Alternate models were considered. OLS models performed better than negative binomial models according to the Akaike information criterion [26].

Confidence intervals around model parameters were estimated with non-parametric bootstrapping procedures [25]. The relationship between observed and predicted scores for each model was evaluated using the adjusted R-squared statistic.

Results

Sample

The mean age of our sample was 49 years. Eight percent of respondents were under the age of 18, and 36% were over the age of 60 (Table 1). The majority of respondents (75.9%) were white, non-Hispanic, and were married or living with a partner (70.6%). Fifty percent were female, 49.3% had greater than a high school education, and 43.0% earned over \$60,000 per year. Seven percent of respondents had a child who was ill, 57.2% had an ill spouse, and 36.2% had an ill parent. Forty five percent of respondents had a family member with arthritis, 36.6% with depression, 12.1% with cancer, and 6.3% with Alzheimer's disease/dementia.

Descriptive statistics

Median rating scale scores differed significantly by relationship type for all illnesses except Alzheimer's disease/dementia. For arthritis, cancer and depression, respondents who had an ill parent consistently reported greater spillover compared to those who had an ill spouse, as did those who had an ill child with cancer and depression (Table 2). Respondents who had a parent with arthritis reported a median rating scale score of 60.0, compared to a median score of 69.0 for those who reported a spouse with arthritis ($p=0.010$ for difference in medians by relationship type). Respondents who had a child or parent with cancer reported median rating scale scores of 25.5 and 50.0, respectively, compared to a median score of 54.0 for those who reported that they had an ill spouse ($p=0.016$ for difference). Those who had a child or parent with depression reported median rating scale scores of 49.5 and 50.0, compared to 60.0 for those with an ill spouse ($p=0.001$ for difference). Mean scores were similar to medians.

Regression analyses

After adjusting for the respondent's caregiving role and the ill family member's health status, differences observed in unadjusted analyses remained. In adjusted analyses, having a parent with arthritis was significantly associated with a 3.8 (95% CI: 0.7-7.2) lower rating scale score compared with having a spouse with arthritis and having a parent with depression was associated with a 5.3 (95% CI: 1.1-9.6) lower score compared with having a spouse with depression. There was no significant difference in rating scale scores associated with the parent relationship type for Alzheimer's disease/dementia or cancer compared with spouse. Having a child with cancer was significantly associated with a 24.2 (95% CI: 8.4-36.5) lower rating scale score compared with having a spouse with cancer, and having a child with depression was associated with a 9.7 (95% CI: 3.8-15.0) lower score compared with having

a spouse with depression, controlling for the respondent's caregiving role and the ill family member's health status (Figure 2; Appendix B: Table A1).

The health of the ill family member was also associated with respondent rating scale scores. Having an ill family member in poor or fair health was associated with greater spillover. Having a family member in very good health was associated with less spillover (Appendix B: Table A1). There was no significant association between rating scale scores and caregiving responsibility. In more comprehensive model specifications, there was no consistent relationship across illnesses between rating scale scores and respondent demographic characteristics. (Appendix B: Tables A2- A3). Adjusted R-squared values for the final regression models ranged from 0.04-0.12 (Appendix B: Table A1).

Discussion

The findings from this study demonstrate that the physical and emotional impact of illness on family member HRQOL does vary by the nature of their relationship with the ill individual for certain chronic illnesses. We found that having a child with cancer or depression is significantly associated with greater spillover, as measured with a rating scale, compared to having a spouse with one of these conditions. Having a parent with arthritis or depression is also associated with a greater spillover compared to a spouse.

In examining the broader impact of illness beyond that of the patient alone, previous studies have mainly focused on caregivers. Fewer studies have assessed the impact of illness on family members in general [1]. Both populations are important to study, as previous research has shown that the spillover effects of illness may arise through both a “caregiving effect” and a “family effect” [2, 3]. The caregiving effect refers to the impact another's illness has on a person who is directly involved in their care, while the family effect is the impact another's illness has on someone that shares an emotional bond with that person. Our research supports previous work that suggests that the family effect may be a stronger determinant of spillover than the caregiver effect and that this family effect is related to the health status of the ill individual, with sicker individuals having a greater impact on the wellbeing of family members [3].

Our study takes this work a step further by indicating that the secondary impact of illness within a family also varies by the nature of one's relationship with the ill individual. This work has important implications. Researchers agree that the broad effects of illness should be incorporated into economic evaluations [4, 8, 27]. However, it has also been acknowledged that the size of spillover effects may vary, and that there is a need to more systematically evaluate these effects in different contexts [5]. Given the resources needed to measure spillover effects as detriments in health utility, our results will help researchers begin to prioritize where this measurement should focus. Clinicians may also use this information to better recognize the secondary impacts of illness in certain family members, and recommend additional support services to those persons.

We chose to evaluate the variation in the spillover impact of illness using a rating scale because of evidence that these spillover effects may be small in magnitude. Compared to

other methods of health valuation, such as the time trade off or standard gamble, the rating scale has shown to be more sensitive to small detriments in health [28]. Our goal in this study was to quantify these losses, and not to provide utility values of spillover for use in economic evaluation. Previous studies have shown that health state valuations derived using rating scale methods are not consistent with valuations derived using utility elicitation methods, particularly the standard gamble [29]. Future research should prioritize the estimation of spillover utility values for cases in which we found the secondary impact of illness in family to be most pronounced, and identify the best methods for incorporating these effects into cost-effectiveness analyses. It is important to note, however, that differences of any magnitude may be considered important in the context of cost-effectiveness analyses, since results depend not on the absolute change in utility alone, but rather on the ratio of these differences to the cost of an intervention.

Compared to family members having an ill spouse or parent, it appears that having a sick child may be associated with a greater secondary impact of illness. We found that across all relationships and illness categories we studied, having a child with cancer is associated with the greatest spillover. In a separate study that conducted qualitative interviews of a subsample of survey respondents, parents' psychological distress was seemingly rooted in their concern for their child's present and future well-being and health outcomes. Parents of ill children reported that their child's illness was more all consuming compared to those of an ill spouse or parent due to the dependent nature of the parent-child relationship [30]. The greater magnitude of spillover associated with a child's illness may also be explained in part by research demonstrating that people place a higher value on gains in child health compared to adult health [31, 32].

The conclusions that can be drawn from this work are limited by the fact that we only evaluated spillover in four illnesses. Future studies should expand on these analyses to demonstrate how the patterns we have observed extend to other illnesses. Other limitations in this work should also be noted. There is currently no consensus on the best method for capturing the spillover effect of illness. We used a rating scale to measure spillover effects, but different methods may have produced different results. Our rating scale was bounded on one end by "best health you can imagine" and on the other end as "being dead" and although it was our intention to only capture the decrement in the respondent's health due to their family member's illness, it is possible that respondents also considered the impact of their own independent health ailments when answering the rating scale question. Future research should focus on identifying the best methods for capturing spillover effects. In addition, while our study samples were drawn from a national research panel, these samples were not meant to be nationally representative of adults and adolescents living with an ill family member. In addition, due to the cross sectional nature of our survey, we cannot infer causality from our results and small sample sizes may have prohibited us from detecting true differences where they do exist. Ordinary least squares regression models were used to evaluate the changes in rating scale scores, but linear models may be problematic for modeling rating scale data because of the bounded nature of these data. However, previous research has shown that these models may produce unbiased mean estimates despite these limitations [33, 34]. As OLS violations bias the standard error of estimates and not the mean

estimates themselves, we were able to mitigate these biases by calculating bootstrapped confidence intervals which do not rely on any assumptions of normality.

Spillover rating scale scores were collected from samples of adults and adolescents that currently had a family member with a specific type of illness. In prior health valuation work, it has been shown that persons with an illness generally rate their current health state higher than do healthy individuals hypothetically valuing that health state [35]. It is not known whether this process of adaptation has a similar impact on spillover health valuations, and future work should address this question.

Conclusions

We find that the impact of illness on family members, measured with a rating scale, varies by relationship type for certain illnesses. Based on the limited diseases we studied, having an ill child generally seems to be associated with greater spillover than having an ill parent, which is sometimes but not always associated with greater spillover than having an ill spouse. Future work should explore the generalizability of our results to other illnesses. The impact of illness on additional family members, such as siblings, should also be explored.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Key points for decision makers

- Having a family member with a chronic condition has spillover effects on one's own health-related quality of life.
- The magnitude of this spillover effect varies both by condition and relationship with the ill family member and appears to be greatest in parents of ill children.

Figure 1. Example of a spillover rating scale question for a respondent whose spouse has depression

Figure 2.

Adjusted changes in rating scale scores for respondents with an ill child or parent, compared to an ill spouse, by condition. Estimates are adjusted for family member health and respondent caregiving responsibility. Bars represent bootstrapped 95% confidence intervals.

Table 1
Respondent characteristics

	n = 1369 % (n)
Age, years	
60+	36.0% (493)
45-59	27.5% (376)
-44	14.6% (200)
-29	14.5% (198)
<18	7.5% (102)
Race/ethnicity	
White, non-Hispanic	75.9% (1039)
Black, non-Hispanic	6.4% (87)
Hispanic	10.2% (140)
Other non-Hispanic	7.5% (103)
Sex	
Female	50.0% (685)
Education	
Bachelor's degree or higher	22.5% (308)
Some college	26.8% (367)
High school	31.7% (434)
Less than high school (adolescents and adults)	19.0% (260)
Marital status	
Married or living with partner	70.6% (966)
Never married	21.6% (295)
Divorced/Separated	6.1% (83)
Widowed	1.8% (25)
Household income	
<\$30k	27.0% (370)
\$30k-\$59,999k	30.0% (410)
dollar;60k-\$99,999k	24.0% (329)
\$100k	19.0% (260)
Any caregiving responsibility for ill family member	
Yes	48.1% (659)
Relationship of ill family member	
Child of respondent	6.6% (90)
Spouse of respondent	57.2% (783)
Parent of respondent	36.2% (496)
Family member illness	
Alzheimer's	6.3% (86)
Arthritis	45.0% (616)
Cancer	12.1% (166)
Depression	36.6% (501)

n = 1369 % (n)	
Family member health¹	
Poor	7.4% (101)
Fair	25.3% (346)
Good	41.9% (573)
Very good	21.6% (296)
Excellent	3.7% (51)

¹ As rated by the respondent

Table 2
Unadjusted rating scale scores by illness and relationship with ill family member

Survey version	n	Mean	95% CI ²		Median	5 th /95 th percentile		p-value ³
Alzheimer's								
III Spouse	26	40.9	32.4	49.3	40.5	0.0	70.0	0.64
III Parent	60	50.0	43.4	56.1	50.0	10.5	88.0	
Arthritis								
III Spouse	388	65.4	63.4	67.2	69.0	30.0	92.0	0.010
III Parent	228	61.1	58.0	63.8	60.0	29.0	94.0	
Cancer								
III Child	8	25.9	18.0	34.3	25.5	10.0	40.0	0.016
III Spouse	101	54.1	48.7	58.7	54.0	7.0	90.0	
III Parent	57	46.9	41.0	52.9	50.0	1.0	85.0	
Depression								
III Child	82	49.9	45.5	54.2	49.5	20.0	86.0	0.001
III Spouse	268	58.1	55.7	60.5	60.0	23.0	90.0	
III Parent	151	52.6	49.2	56.2	50.0	20.0	90.0	

² All confidence intervals are bootstrapped, using the full sample with replacement; 500 iterations.

³ P-value for difference in median rating scale score by family relationship type using the K-sample equality-of-medians test.