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How illness affects family members: a qualitative interview survey

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Abstract

Purpose—Spillover effects of illness on family members can be substantial. The purpose of this study was to identify the domains of family members' health and well-being that are affected when a relative has a chronic health condition.

Methods—Semi-structured telephone interviews were conducted in February, 2012 with 49 individuals whose relatives had any of five chronic health conditions (arthritis, cancer, Alzheimer's disease/dementia, cerebral palsy, and depression), purposively sampled to include different relationships with the ill relative (parent, child, spouse). Subjects were queried on whether and how having an ill relative affected their health and well-being; they were also asked about their caregiving responsibilities and the relative's health. Interview data were analyzed using thematic analysis.

Results—Family members in our sample reported experiencing psychological and non-health effects from having an ill relative, and secondarily somatic effects. Effects on emotional health were most commonly reported as psychological spillover; non-health effects frequently included changes in daily activities and provision of caregiving. Spouses of patients reported the broadest range of spillover domains affected and adolescents of ill parents the fewest. Family members reported experiencing effects that were perceived as both positive and negative.

Conclusions—Spillover of illness onto family members encompasses a wide range of domains of health and well-being, extending beyond those included in many existing health-related quality of life measures. Outcomes measurement efforts should be expanded to adequately capture these health and well-being outcomes for analysis, to ensure that the benefits of interventions are accurately estimated and conclusions are valid.

1. Introduction

Having an ill or disabled relative imposes a well-documented burden on family caregivers and non-caregiving family members.^[1,2] These "spillover" effects of illness affect many aspects of family members' lives, from physical and emotional health to quality of life and well-being.^[3–6] Quality of life and well-being are subjectively-assessed constructs that may

include aspects of health, functioning, capabilities, security, spirituality and other domains depending on the context.^[7] This study empirically assessed the range of effects experienced by family members of ill individuals to capture the entirety of disease burden, ranging from focused symptomatology to elements of well-being.

Prior research on family spillover effects of illness has shown that caregivers experience increased mortality risk, with findings often suggesting an association between caregiver strain and negative outcomes.^[8,9] Contradictory evidence, however, suggests positive, even life-extending benefits from caring for an ill relative.^[10] A duality in effect has been described, distinguishing between providing caregiving for an ill relative and caring about that person^[11], that suggests that spillover effects are more nuanced than may have previously been thought.

Documentation of disease-specific effects have generally focused on measurement of caregiver burden (e.g., arthritis^[12], Alzheimer's disease^[13], multiple sclerosis^[14], spina bifida^[15], stroke^[16]). Existing instruments include scales for caregiver-experienced conditions (e.g., sleep disorders^[17]), caregiver strain^[18], "hassle"^[19], and burden^[20], and more general measures such as caregiver quality of life^[21] and health state utility.^[22–24] Though useful in documenting caregiver experiences, these measures focus primarily on caregiving itself and risk excluding the entirety of the family's experience including non-caregiving effects and non-caregiving family members, that are noted to exist but may not be fully recognized.^[1,2,11,25]

To fully understand of the complete burden of disease we must consider the effect of illness on family members as well as the patient. The purpose of this research was to identify the domains of an individual's well-being that are affected when a family member has a chronic health condition, including both family caregivers and members who do not provide caregiving. We further explored the variation in this experience by the type of condition the family member had and the relationship between the two family members. Our goal was to improve medical decision making by improving our understanding of the reach of illness, and through this understanding, to inform measurement of these outcomes for inclusion in decisions.

II. Methods

A. Sample

As part of an internet survey measuring spillover disutility of chronic conditions^[25], semi-structured telephone interviews were conducted in February, 2012 with a subset of survey respondent volunteers. The internet survey was conducted with a US-representative panel of respondents, administered by GfK Knowledge Networks, Inc. Respondents included adults (>18 years) and adolescents (13–17 years) who identified themselves as having a relative with at least one of five conditions: arthritis, Alzheimer's disease/dementia, cancer, cerebral palsy, or depression. Conditions were chosen to include those expected to affect both physical functioning and mental functioning: arthritis and cerebral palsy have a substantial physical component, Alzheimer's disease/dementia and depression have substantial mental components, while cancer includes both to varying degrees. All internet survey respondents were queried at the end of the on-line instrument about participating in a follow-up interview survey. Those who agreed were asked to supply a first name, telephone number and good time to call. A purposive sample was created from the online volunteers, stratified by the relative's condition and relationship with respondent, such as parent with depression, spouse with depression, child with depression, etc. Within each condition/relationship combination category (excluding those unrepresented in the on-line sample: child with arthritis or Alzheimer's disease/dementia, parent and spouse with cerebral palsy), up to 16

volunteers were randomly selected from those who provided a valid telephone number and a “time to call” that fell within the interview period (some volunteers indicated specific days that had passed before interviews began). If 16 volunteers were not available for a specific condition/relationship combination, all in sample were included (all 25 adolescent volunteers were included in interview sample). Sixteen was chosen to provide sufficient volunteers to arrive at a final completed sample of 4 respondents in each relationship/condition combination. Individuals included in the purposive sample were recruited by telephone until the target condition/relationship combination sample size was achieved ($n=4$) or until the volunteer supply for that combination category was exhausted (a substantial number of phone numbers provided were non-functional or were not answered after multiple attempts). Verbal informed consent was obtained from participants prior to the start of the interview, and parental consent was obtained for adolescent participants prior to telephone recruitment. The study was approved by the applicable Human Subjects Committees.

B. Data

Interviews followed a semi-structured guide to query participants on whether and how they were affected by having an ill relative (in addition to process questions about the internet survey instrument). Subjects were asked open-ended questions about “what it is like” to have an ill family member, what “sorts of things [they] think about”, what aspects of their lives were affected and how, whether effects changed over time, and if/how other family members were affected. Prompts were used to explore comments offered, and, if needed to encourage talking, to ask about effects identified in the literature (such as health, daily activities, finances^[1,11,26–28]). The interview guide was refined through pre-testing prior to administration. Interviews were conducted in English by a professional interviewer, audio-recorded, and transcribed for analysis.

Demographic characteristics of each respondent were provided by the survey research firm from previously-collected data from all panel members, including age, race, ethnicity, education, marital status, employment status, household income, region of residence, and household composition. Additional data elements were provided in responses to the online survey from which the volunteer pool for the interviews was derived (including patient health status and respondent caregiver status).

C. Analysis

Transcripts were coded for spillover domains mentioned. An inductive approach was used in the analysis, which was informed by both preexisting themes from the interview guide and themes that emerged from the data themselves.^[29,30] Two investigators (EW and AS) read the transcripts to identify the full range of domains and categories of spillover mentioned by respondents. Each specific domain mentioned by a respondent was recorded at the level of specificity used in the conversation and coded to capture similarities. For example, some respondents described a general effect on their daily activities and offered no further detail even when prompted, which was coded as “general daily activities,” while others reported specific effects within daily activities such as their own motivation to take care of themselves, which was coded as “heightened attention to self-care.” A Microsoft Excel spreadsheet was created with columns for each respondent and rows for the domains; domains were categorized into somatic health, psychological health, non-health areas, and scope/duration of spillover for visual presentation. Following the preliminary coding of a sample of transcripts, validation was performed to ensure consistency of the coding scheme. Inter-coder reliability was assessed and misclassified data were recoded into the more appropriate domain.

Domains of spillover were analyzed across respondents by condition, relationship and caregiving categories, summarized by whether the domain was mentioned by more than half, less than half, or none of respondents in that subcategory. A comparative analysis examined differences in spillover domains and frequency of reports across three dimensions: relationship of respondent to patient, patient's condition, and respondent's caregiver status (for adult respondents only).

III. Results

A. Sample

The internet survey sample totaled 1,389, of whom 543 volunteered to be interviewed (Figure 1). A purposive sample of 99 was selected and telephoned; 57 volunteer respondents were successfully reached, including 46 adults and 11 parents of adolescent volunteers. After refusals and other exclusions, interviews were completed with 41 adults and 8 adolescents. Interviews averaged 26 minutes in length (range: 14 to 44).

Respondents' mean age was 47.1 years (range: 14 to 86; Table 1); adolescent respondents were between 14 and 16 years of age. The majority of respondents were female (57%) and white (82%). A substantial proportion of adult respondents were retired (32%) or not working due to a disability (20%; Table 2). The respondents' relatives had: depression (n=16), arthritis (n=11), cancer (n=10), Alzheimer's disease/dementia (n=8), and cerebral palsy (n=4); for most conditions there were 4 respondents in each of the relationship categories, with the exceptions of cerebral palsy for which there were only adults with children with this condition, Alzheimer's disease/dementia for which there were only spouses and adult children of individuals with this condition, and arthritis for which there were no children with this condition in the sample. Nine respondents had an ill child, 16 had an ill spouse, 16 were adults who had an ill parent and 8 were adolescents who had an ill parent.

The average time since the relative's diagnosis was 7 years, ranging from 2.8 years for those with Alzheimer's disease/dementia to 17 years for children with cerebral palsy (Table 2). Adults with ill children had the longest duration of living with the illness in the family, at a mean of nearly 11 years. None of the respondents reported their relative's health status as excellent: over half were reported as very good or good (65%), 25% as fair and 10% as poor. Over half (59%) of adult respondents reported being the primary caregiver for their ill relative; spouses most commonly reported being the primary caregiver for their ill spouse (69%), while adults with ill parents were only half of the time their primary caregiver. Most respondents (76%) lived in the same household as their ill family member; nearly all adolescents lived with their ill parent (88%).

B. Domains affected by spillover

The reported domains of life affected by having an ill family member with one of these five conditions spanned somatic, psychological and non-health areas, and varied by the individual's relationship with the ill family member, the family member's health condition, and whether the individual was a caregiver for the family member (Tables 3, 4 and 5, respectively). The spectrum of domains reported by respondents was broadest for non-health domains, including caretaking which was reported frequently by all respondents except adolescents with ill parents (Tables 3 and 4), effects on work/job, finances, social activities, church attendance, confinement to home, loss of activities with relative, and self-care (Table 3). With the exception of self-care, all reported non-health effects were perceived as negative by the respondents, as a loss or limitation (self-care was reported as heightened to ensure ability to care for patient or decreased due to demands of caretaking). Psychological

health domains included general emotional health which was consistently mentioned by a majority of respondents across relationships and conditions, general mental health which was less-frequently mentioned, and sub-domains within this realm including stress/anxiety, worry/fear, feeling helpless or lost, sadness/depression, frustration/impatience, and resentment. Effects in these domains were also perceived as negative by respondents. Fewer domains of somatic health were mentioned, and those were less-frequently mentioned within our sample. General physical health was not consistently mentioned by a majority of respondents across categories; other somatic domains included physical pain, sleep disturbance, fatigue and loss of appetite. Finally, the scope of spillover was reported to include other family members by at least some respondents in all categories, and reports were variable about whether effects attenuated over time (Tables 3, 4, 5).

Domains affected by relationship of patient to respondent—General emotional health was commonly reported as affected across relationship types, as were general daily activities and general mental health, although with less frequency (Table 3). Sadness and depression, worry and fear, stress and anxiety, effects on social activities, and loss of old activities with the ill person were also reported across relationship types, again with less-consistent frequency. Compared with all other relationship types, adolescents with ill parents reported the fewest domains affected.

Adults with ill children (n=9) were most consistent in the domains that they reported affected by spillover compared with other relationship categories. In our sample, the majority of adults with ill children reported effects on general physical health, physical pain, general mental and emotional health, stress/anxiety, daily activities, and caretaking, and most reported being confined to home due to their child's illness. For example, the mother of a child with depression described emotional and physical health effects:

“...it's a constant state of worry...it's definitely emotionally difficult and physically difficult...stomach upset, headaches, nervous, things like that.”

And the father of a depressed child described effects on social activities:

“...I'm kind of more withdrawn because I spend a lot more time taking care of her than actually doing other things...I have to change certain activities...like going out to play basketball, going out to dinner by myself, I have to cancel a lot of social things.”

Notably absent in reports from this group were feelings of frustration/impatience and resentment. Most of these adults reported their lives becoming focused on their child's illness, and some described finding purpose through their focus. Two mothers of children with cerebral palsy explained:

“We keep his bed in the living room so he can feel like he's part of the family... He's a big part of our family. We wouldn't know what to do without him.”

“I mean, he's got to have 24-hour care...this is my life.”

Adult respondents with ill spouses (n=16) reported experiencing every domain of spillover mentioned within the sample responses. Most common for spouses were effects on general emotional health, worry/fear, and sadness/depression, and also non-health domains including general daily activities, caretaking, and finances. The spouse of an Alzheimer's patient described sadness and depression:

“I'm alone, I'm alone in this...I feel like I'm in a sink-hole and... it's just like my life is spiraling down.”

Spouses also mentioned effects on their work/job:

“You have to adjust your work schedule to meet their medical requirements, physician requirements, and clinical requirements. You have to address issues of food preparation, meals, cleaning, bedding, transportation. It’s just one thing after another.”

Sexual intimacy was mentioned by spouses of cancer patients only. The spouse of a prostate cancer patient described her feelings:

“The intimacy is gone. We still hug and kiss because we love each other but the rest of it is gone and I do miss it.”

Positive spillover effects were also described by spouses, including an increased focus on one’s own well-being and improved relationships. The spouse of an individual with Alzheimer’s disease reported:

“[I have] more determination to take care of myself.”

And a spouse of someone with arthritis said:

“It’s brought us closer together.”

Adults with ill parents (n=16) reported a very similar experience to that of adults with ill spouses, though with less-frequent mention of somatic health, daily activities, and financial effects. The sense of purpose associated with caring for ill children was absent from reports of adults with ill parents, and often replaced with resignation, obligation or resentment. Adults with parents with arthritis reported:

“...family members are there to be taken care of and to be caretakers...that’s our job as family members to join in those illnesses.”

“...it puts a burden on the rest of the family...She has to be changed and watched after and everything done for her...I have no life. I can’t leave the house for more than 2.5 hours and that’s just to get medicine and groceries...Sometimes I don’t even eat because we don’t have the money for things she needs...I couldn’t do that, personally, for myself, but if that’s how she wants to be I will do it.”

“I can’t go do anything...It’s like I’m in jail is what it feels like.”

An adult with a parent with depression said:

“My mother’s burden is really my burden.”

The emotional burden of having an ill parent was similar to that experienced by respondents with ill spouses and ill children. An adult whose parent had arthritis said:

“It’s almost worse for the caretaker than for the [ill] person because they have to see them in this pain.”

In contrast, adolescents with ill parents (n=8) reported far fewer domains affected by spillover than did adult respondents, with a majority of adolescents reporting effects on general emotional health and sadness/depression. None of the adolescent respondents reported somatic effects from their parent’s illness. Some reported feeling stress/anxiety, worry/fear, and frustration/impatience, and some also reported effects on their daily activities, social activities, and the loss of activities with their parent. One teenager, for example, reported regret that her mother’s arthritis prevented them from playing sports together. On the positive side, a boy whose father had skin cancer reported increased attention to self-care (motivation to use sunscreen) because of his father’s diagnosis.

Domains affected by patient’s condition—Across relationship types, some conditions appeared to affect more domains than others (Table 4). Relatives of patients with arthritis

and Alzheimer's disease/dementia reported fewer somatic spillover effects than did relatives of patients with other conditions in our sample. In particular, parents of children with cerebral palsy reported more effects on physical health (Table 4). Pain was mentioned by fewer than half of respondents in all conditions except those with family members with cerebral palsy. Other occasionally-mentioned somatic effects were sleep disturbance, fatigue, and loss of appetite.

Effects on emotional health were consistently reported by the majority of respondents across conditions. General daily activities and caretaking were reported as non-health domains affected for all conditions. Feelings of resentment toward patients were absent in reports from relatives of patients with cancer and cerebral palsy, while these feelings were present for some family members of patients with all other conditions in our sample. In contrast with the other conditions, Alzheimer's disease was not reported as affecting family members' work/ jobs and their social activities. Sexual intimacy was reported only by respondents whose spouses had cancer.

Cerebral palsy was described as creating particularly high spillover burden, including physical, emotional, and non-health effects (all patients with cerebral palsy were children). The overwhelming emotional effect was described by a mother as:

"It's hard, it's scary...you think about him 24/7, all the time...it's non-stop thinking about him all the time."

Caregiving or simply being in the presence of an ill relative often resulted in changed attention to one's own health, either decreased attention because of the burden of caregiving or heightened attention because of witnessing ill health. As mentioned above, an adolescent boy reported being motivated to use sunscreen because of his father's diagnosis of skin cancer. The spouse of an Alzheimer's disease patient reacted to her spouse's dependency with an increased focus on her own well-being; she said:

"[I have] more determination to take care of myself."

Across conditions, at least some respondents reported spillover effects decreasing over time. The reasons varied, and often included improved relationships with the ill relative and increased understanding. The spouse of someone with arthritis reported about the condition:

"It's brought us closer together."

An adult whose father had prostate cancer said:

"I became closer to him but I also feel like we became more dependent on each other...We rely on each other more and we spend a lot more time [with] each other now."

And an adolescent described understanding and compassion when her father was diagnosed with depression:

"...I feel a little bit closer than I used to be. I kinda can feel his pain and I can understand him better because I know what's wrong with him."

The improved bond was also described by the daughter of an elderly woman with Alzheimer's disease:

"I see her more and think about her more. She's more a part of my life now than when she was. I'm fine with it; it's a good thing really."

Nearly all respondents reported that family members besides themselves were affected by the ill relative's illness.

Domains affected by caregiver status—Respondents who reported being the primary caregiver for the ill relative reported mainly similar effects on their health and well-being as did family members who were not the primary caregivers (Table 5). Those who were not the primary caregivers still reported caretaking responsibilities. Most respondents in both groups of family members reported effects on their general emotional health and general daily activities. There was somewhat more worry and fear reported by non-caregivers, and less stress/anxiety and sadness/depression. A minority of respondents in both groups reported somatic effects on themselves, with no mention of fatigue or loss of appetite among the non-primary caregivers. Caregiving burden was described in varying levels of intensity, with the most extreme resulting in social isolation for the caregiver. A mother of a child with cerebral palsy described:

“Well, if nobody happens to be here it’s kind of hard for me to get out because, like I said, I can’t lift him anymore. Somebody either has to be here to help me load him or watch him while I go out to the store or wherever I’m going.”

IV. Discussion

This study demonstrates that spillover effects of illness onto family members encompasses a wide range of domains of health and well-being, extending beyond those included in traditional health related quality of life measures. The domains affected vary both by the patient’s condition and the relationship between people, and include somatic, psychological, and non-health effects. While current recommendations endorse the inclusion of informal care in economic evaluation^[31], few studies in fact include caregiver outcomes both because of challenges in measurement^[1], and because of a slowly emerging consensus that such benefits are appropriately included.^[32–34] Existing measurement instruments are generally limited to caregiver outcomes and have just recently published preference weights allowing for incorporation into economic evaluation.^[22,23] This study informs the measurement of spillover effects of illness by providing insight into the range and type of effects that illness incurs on family members, the extent to which such effects disperse within the family beyond the primary caregiver, and the variability in where and when effects occur. Our results may guide future development and use of instruments to capture the far-reaching effects of illness on family members and their incorporation into outcomes research.

Most notable in our findings was the breadth of areas of life and individuals affected by having an ill relative. While the “collateral” effects of health have been widely noted^[28], research has mainly focused on effects of caregiving, both positive and negative.^[26] This study describes how spillover effects extend beyond those associated with caregiving, and includes effects of simply being related to someone who is ill; these effects have been quantified previously but not described.^[2,11] Such is the case of children with ill parents who are not caretakers but are nevertheless affected by the illness. Moreover, our results confirm that spillover effects are quite nuanced, mixing burden with purpose, such as the mother whose life becomes defined by taking care of her child. This finding suggests an interdependence between the patient and family member’s outcomes that may be difficult to disentangle and therefore even more important to capture together for a full rendering of outcomes. We found that the effects of illness in the family seemed to differ markedly by whether the ill person was a dependent: a child’s chronic illness was reported as more consuming than a spouse’s illness. Spillover effects on spouses seemed more universal across domains, however, perhaps due to the interdependence of that relationship; an ill spouse may produce a cascade of effects on the healthy spouse because of responsibility shifting, in addition to the direct burden of the illness. In general ill parents produced less spillover than other types of ill relatives, perhaps due to expectation that creates a type of

anticipatory adaptation to ameliorate spillover effects, or simply that elderly parents' life spans are shorter even when ill so the spillover effects of illness are time-limited.

Though prominent in the literature^[35], the physical effects of illness in the family were the least emphasized domains among our sample. We intentionally included individuals with family members with disabling conditions that might be expected to require physical assistance from caregivers, as well as conditions that were not associated with substantial physical caretaking but that we expected to be relatively more mentally and emotionally taxing on family members. Though there were few in our sample whose family member had cerebral palsy, these respondents were the only ones who consistently emphasized spillover effects on their physical health. These respondents were parents who frequently had to physically transport adult children, and had lived with the child's condition for many years. More illuminating to us was the depth of spillover reported by individuals whose family members had depression. Our sample included respondents with depressed children, spouses and parents, who nearly uniformly emphasized the severe repercussions the relative's illness had on them. The unpredictability of the manifestations of depression seemed to contrast with other conditions that were more known in this regard, such as arthritis. There was a sense of unknowing of when and what might happen with the depressed relative that created anxiety and worry among family, and a need for vigilance. Cancer was predictably difficult for family members to bear, though seemingly had a more known quality: many family members of cancer patients focused on managing treatment options and tangible aspects of caregiving.

While the positive aspects of caregiving, such as altruism and purpose, have been noted and were mentioned by our sample as well^[26], we also heard a sense of adaptation or resignation to the situation that created calm among some family members. Individuals spoke of "coming to terms" with their relative's illness, and developing new relationships with their relative that were sometimes more fulfilling than those of the past. It is possible that this is true adaptation to circumstances, akin to adaptation to illness among patients.^[36] Such experiences are important to understanding caregiver burden and are relevant to the measurement of spillover effects: if measured as a single entity, positive and negative spillover effects may negate one another resulting in little or no observable effect, whereas if measured separately both may be apparent. It will be important to identify the occurrences of these individual effects to accurately measure and include them as outcomes.

Our findings are limited in some ways: our results are based on a relatively small sample size, respondents self-selected into the study, and spillover effects were all self-reported. The nature and content of the interviews required self-selection and self-reporting, and budgetary constraints limited the sample size. We intentionally restricted our sample to five health conditions that encompassed a range of physical and mental disorders to limit the variability of spillover effects among our respondents, but we did not further differentiate among ill relatives' health status or prognosis. We recognize that patients' condition-specific factors such as disease severity and duration may influence spillover effects on family members; we collected data on years since diagnosis and the family member's perception of their relative's health status to understand these factors in our sample, but our analysis focused on the condition and the relationship between ill person and family member because we *a priori* hypothesized that these factors would significantly affect the range of spillover effects experienced.

Our sample included both caregiving and non-caregiving family members as we were interested in the differences in spillover effects between these two groups. We recognize that caregivers may self-select into their role based on their own characteristics, which may in turn be associated with factors that could affect how they perceive the burden or benefits of

the caregiver role. In fact, only about one-third of our sample reported full-time employment, indicating either selection bias into our study or into the family member/caregiver role, or both. To the extent that illness in a family member is accompanied by certain characteristics among other members, our results inform the spectrum of spillover effects experienced and the overall disease burden. Our study suggests that the breadth of spillover effects is wide and may include nuanced differences among and between conditions and the relationship between the patient and the affected family member. An ill spouse may have a different effect on the other spouse than the children in the family, and the ill spouse's parents may also be affected whether cohabitating with the family or not. Each individual's effect may differ in both nature and magnitude, yet to fully understand the burden of disease as well as the benefit of treatment, we must identify this entirety of effect across individuals and domains. This effect exceeds most measures currently in use and will require multiple instruments or new approaches, or both, or a reconsideration of what normatively should be included in measures of spillover.

V. Conclusion

In conclusion, the effects of illness on family members are substantial and widespread, affecting areas of life as diverse as physical pain and ability to sustain social connections, and affect family caregivers as well as all members of all ages. Inclusion of the complete spectrum effects in considerations of disease burden and treatment benefit is crucial to accurately understand the entirety of disease outcomes.

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EW, AS and LAP each has no conflicts to declare. EW and LP conceived of the study; EW and AS performed data analysis; EW wrote manuscript; all authors reviewed and approved final manuscript. EW serves as guarantor for results.

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Key points for decision makers

Illness affects all family members beyond the affected patient; Family members report many non-health domains of life affected by having an ill relative;

Caregiving and not-caregiving family members are affected though somewhat differently, and the relationship between the family member and relative (child, spouse or parent) changes effects.

Economic evaluation and outcomes research calls for the inclusion of effects on caregivers and others, so measurement efforts must be expanded to accurately capture these effects.

Fig. 1.
Interview sample selection process

Table 1

Sample characteristics (n=49; 41 adults and 8 adolescents)

Variable	Categories	n	%
Age (mean years)		47.1 (range: 14 – 86)	
Gender	Female	28	57.1
Race	White	40	81.6
	Black or African American	3	6.1
	American Indian/Alaska Native	2	4.1
	Asian	3	6.1
	More Than One Race	1	2.1
Ethnicity	Non-Hispanic	46	93.9
	Hispanic	3	6.1
Education ^a	High school or less	14	34.1
	Some college	16	39.0
	Bachelor's degree or more	11	26.8
Marital status ^a	Married	23	56.1
	Divorced or separated	10	24.4
	Widowed	2	4.9
	Never married	4	9.7
	Living with partner	2	4.9
Employment status ^a	Employed	14	34.2
	Unemployed	6	14.6
	Disabled	8	19.5
	Retired	13	31.7
Annual household income (\$US)	\$49,999	19	38.8
	\$50,000-\$99,999	18	36.7
	\$100000	12	24.5
Region of US	Northeast	9	18.4
	Midwest	14	28.6
	South	15	30.6
	West	11	22.4

^aReported for adults in sample only.

Respondents' characteristics by ill person's condition and relationship to respondent (n=49; 41 adults and 8 adolescents)

Table 2

		Ill person's condition:					Ill person's relationship to respondent:				
Variable	Categories	All	Depression	Arthritis	Cancer	Alzheimer's Disease/ Dementia	Cerebral Palsy	Child	Spouse	Parent (of adult respondent)	Parent (of adolescent respondent)
Total		49	16	11	10	8	4	9	16	16	8
Years since diagnosis (mean, sd)		7.0 (7.2)	5.3 (4.8)	7.4 (6.1)	8.6 (8.5)	2.8 (1.7)	16.8 (13.4)	10.7 (10.4)	5.9 (4.6)	7.3 (8.3)	4.3 (3.6)
Respondent is primary caregiver for ill person (of adults only, n=41)		24 (58.5%)	7(58.3%)	4 (50.0%)	3 (33.3%)	7 (87.5%)	3 (75.0%)	5 (55.6%)	11 (68.8%)	8 (50.0%)	–
Respondent lives in same household as ill person		37 (75.5%)	13 (81.3%)	10 (90.9%)	8 (80.0%)	2 (25.0%)	4 (100.0%)	7 (77.8%)	14 (87.5%)	10 (62.5%)	7 (87.5%)
Health status of ill person as reported by respondent	Excellent	0	0	0	0	0	0	0	0	0	0
	Very good	12 (24.5%)	4 (25.0%)	2 (18.2%)	5 (50.0%)	0	1 (25.0%)	2 (22.2%)	6 (37.5%)	2 (12.5%)	2 (25.0%)
	Good	20 (40.8%)	7 (43.8%)	6 (54.5%)	3 (30.0%)	3 (37.5%)	1 (25.0%)	5 (55.6%)	7 (43.7%)	4 (25.0%)	4 (50.0%)
	Fair	12 (24.5%)	4 (25.0%)	3 (27.3%)	1 (10.0%)	2 (25.0%)	2 (50.0%)	2 (22.2%)	1 (6.3%)	7 (43.7%)	2 (25.0%)
	Poor	5 (10.2%)	1 (6.2%)	0	1 (10.0%)	3 (37.5%)	0	0	2 (12.5%)	3 (18.8%)	0

sd=standard deviation

Table 3

Domains affected by spillover, by relationship of ill person to respondent (n=49)

DOMAINS AFFECTED BY FAMILY SPILLOVER <div> <div></div> Mentioned by ≥50% of respondents <div></div> Mentioned by <50% of respondents <div></div> Never mentioned </div>	Ill child (n=9)	Ill spouse (n=16)	Ill parent of adult (n=16)	Ill parent of adolescent (n=8)
SOMATIC HEALTH	GENERAL PHYSICAL HEALTH			
	physical pain			
	sleep disturbance			
	fatigue			
	loss of appetite			
PSYCHOLOGICAL HEALTH	GENERAL MENTAL HEALTH			
	GENERAL EMOTIONAL HEALTH			
	stress/anxiety			
	worry/fear			
	helpless/lost			
	sadness/depression			
	frustration/impatience			
	resentment			
	GENERAL DAILY ACTIVITIES			
NON-HEALTH	caretaking			
	work/job			
	finances			
	social activities			
	church attendance			
	confined to home			
	loss of old activities with ill person			
	sexual intimacy			
	decreased attention to self-care			
	heightened attention to self-care			
SCOPE/DURATION OF SPILLOVER	other family members affected			

DOMAINS AFFECTED BY FAMILY SPILLOVER <div><div>☒ Mentioned by ≥50% of respondents</div><div>☐ Mentioned by <50% of respondents</div><div>☐ Never mentioned</div></div>		Ill child (n=9)	Ill spouse (n=16)	Ill parent of adult (n=16)	Ill parent of adolescent (n=8)
spillover decreased over time					

Table 4

Domains affected by spillover, by ill person's condition (n=49)

DOMAINS AFFECTED BY FAMILY SPILLOVER <div> <div></div> Mentioned by ≥50% of respondents <div></div> Mentioned by <50% of respondents <div></div> Never mentioned </div>		Depression (n=16)	Arthritis (n=11)	Cancer (n=10)	Alzheimer's Disease/Dementia (n=8)	Cerebral Palsy (n=4)
SOMATIC HEALTH	GENERAL PHYSICAL HEALTH					
	physical pain					
	sleep disturbance					
	fatigue					
	loss of appetite					
PSYCHOLOGICAL HEALTH	GENERAL MENTAL HEALTH					
	GENERAL EMOTIONAL HEALTH					
	stress/anxiety					
	worry/fear					
	helpless/lost					
	sadness/depression					
	frustration/impatience					
	resentment					
NON-HEALTH	GENERAL DAILY ACTIVITIES					
	caretaking					
	work/job					
	finances					
	social activities					
	church attendance					
	confined to home					
	loss of old activities with ill person					
	sexual intimacy					
	decreased attention to self-care					
SCOPE/DURATION OF SPILLOVER	heightened attention to self-care					
	other family members affected					

DOMAINS AFFECTED BY FAMILY SPILLOVER ■ Mentioned by ≥50% of respondents □ Mentioned by <50% of respondents □ Never mentioned	
Depression (n=16)	
Arthritis (n=11)	
Cancer (n=10)	
Alzheimer's Disease/ Dementia (n=8)	
Cerebral Palsy (n=4)	

Table 5Domains affected by spillover, by respondent caregiver status (n=41^a)

DOMAINS AFFECTED BY FAMILY SPILLOVER		Primary caregivers (n= 24)	Non-caregivers (n= 17)
<div>■ Mentioned by ≥50% of respondents</div> <div>□ Mentioned by <50% of respondents</div> <div>□ Never mentioned</div>			
SOMATIC HEALTH	GENERAL PHYSICAL HEALTH		
	physical pain		
	sleep disturbance		
	fatigue		
	loss of appetite		
PSYCHOLOGICAL HEALTH	GENERAL MENTAL HEALTH		
	GENERAL EMOTIONAL HEALTH		
	stress/anxiety		
	worry/fear		
	helpless/lost		
	sadness/depression		
	frustration/impatience		
	resentment		
NON-HEALTH	GENERAL DAILY ACTIVITIES		
	caretaking		
	work/job		
	finances		
	social activities		
	church attendance		
	confined to home		
	loss of old activities with ill person		
	sexual intimacy		
	decreased attention to self-care		
	heightened attention to self-care		
	other family members affected		
SCOPE/DURATION OF SPILLOVER	spillover decreased over time		

^a only adults included in caregiver/non-caregiver comparison