

# Presence of a Secondary Caregiver Differentiates Primary Cancer Caregiver Well-being

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## Research Article

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# Abstract

## Background

Informal caregivers play a fundamental role in the care of hematological cancer patients, but less is known about how secondary caregivers are involved. We assessed the presence or absence of a secondary caregiver, the types of caregiving activities performed by primary and secondary caregivers and examined whether the presence of a secondary caregiver was associated with primary caregiver characteristics and wellbeing over time.

## Methods

A case series of hematological cancer patient-caregiver dyads (n = 171) were recruited from oncology clinics in Virginia and Pennsylvania and followed for 2 years. Multi-level models were developed to examine the associations between presence of a secondary caregiver and the primary caregivers' well-being.

## Results

Most (64.9%) primary caregivers reported having secondary caregivers. Multilevel models showed primary caregivers without help had higher baseline mental and physical health, but experienced deteriorating physical health overtime, compared to supported primary caregivers. Supported primary caregivers reported improvements in mental health over time that was associated with improvements in physical health.

## Conclusions

Primary caregivers in good physical and mental health at the beginning of their caregiving journey but who have the least assistance from others may be at greatest risk for detrimental physical health effects long term. Attention to the arrangement of caregiving roles (i.e., who provides what care) overtime is needed to ensure that caregivers remain healthy and well supported.

## Introduction

By 2030 there will be an estimated 22.1 million cancer survivors in the US<sup>1</sup> with a growing proportion of cancer care delivered at home by unpaid caregivers, typically family and friends. Shifts in cancer care delivery from clinical to home settings have reshaped caregiving by increasing both the amount and type of care tasks that caregivers perform. Caregivers report many instrumental activities of daily living (IADL) including assisting and supporting the patient with meals and housekeeping. Increasingly caregivers are asked to deliver injections, monitor symptoms, use complex medical equipment and advocate for

patients.<sup>2</sup> Many caregivers report positive outcomes as a result of providing care to a loved one, such as improved relationships and increased spirituality<sup>2</sup> but there is increasing recognition of the often concurrent financial, emotional and physical burdens placed on caregivers<sup>3,4</sup>. Predictors of poorer mental health (i.e., distress, depression) among primary cancer caregivers include sex (female caregivers), younger age, caring for a spouse, and decreased access to the resources necessary for providing care (insurance, adequate finances, employment benefits, social support).<sup>5,6,7</sup> Moreover, distress and depression associated with caregiving can remain or even emerge several years after the patient's cancer diagnosis.<sup>3</sup> These longer term experiences of caregiver burden and poorer psychological health (e.g., depression) may mediate the relationship between caregiving and caregiver physical health. Compared to non-caregivers, those who provide informal care to a friend or family member have been found to report greater overall health,<sup>8</sup> and it has been suggested that individuals who become and remain primary caregivers may be chosen, in part, by their overall higher health and physical ability to continue to provide care.<sup>9,8</sup> However, physical health can deteriorate over time due to the wear and tear of providing care, perceived burden and poor or worsening mental health (depression or distress).<sup>4,9,10</sup> In one study, increased mortality risk was associated with greater mental and emotional strain;<sup>4</sup> another study showed that caregiver physical health was associated with perceived burden and depression.<sup>11</sup>

Evaluations of caregiver mental and physical health have largely been cross sectional or with short periods of follow-up, occurring at a variety of time points along the care continuum for different cancers<sup>10,12</sup> Some examinations have looked at interdependence of caregiver and patient mental and physical health<sup>13,14</sup> finding some support for partner effects overtime.<sup>15,16</sup> Missing from the literature is an examination of the effects of having other, secondary caregivers present to help with care provision. For example, adult children caring for a parent are more likely to have additional caregivers, report greater social support, perform fewer tasks and report fewer hours of caregiving as compared to spousal caregivers.<sup>5</sup> To understand if the presence of secondary caregivers act as additional resources to assist with care provision or, conversely, increase conflict and complexity in providing care at home, this prospective, observational study sought to describe: the kinds of support activities performed by primary and secondary caregivers; and the differences between support activities provided by the primary versus secondary caregiver. The study further evaluated whether, 1) having a secondary caregiver was associated with mental and physical well-being of the primary caregiver compared to unsupported primary caregivers, 2) if mental health was protective of the physical health of supported compared to unsupported primary caregivers.

## Methods

### Participants

Study methods have been previously reported<sup>17</sup>, but briefly, of 171 adult patients (> 18 years) diagnosed with 1 of 3 hematological cancers (multiple myeloma [MM], Non-Hodgkin's Lymphoma [NHL], chronic

lymphocytic leukemia [CLL]), at any stage of disease, who had begun initial systemic treatment within the previous six months of diagnosis were enrolled. Patients were excluded if they had not been employed or were not actively searching for employment immediately prior to diagnosis, did not have an informal caregiver, had cognitive impairments, were receiving hospice care, or spoke a language other than English. Employment was a criterion for participation as one of the goals of the study was to examine the effect of cancer treatment on patient employment. Caregivers had to be adults (> 18 years), cognitively able to participate and provided unpaid care. Primary caregivers were defined as a patient identified family member or friend who provided the majority of help and care. Institutional research review board approval was obtained (IRB # HM13074).

## **Recruitment**

Patients were recruited from 8 oncology clinics (academic and community) located in Pennsylvania or Virginia. A complete case series of patients who fit disease and treatment status parameters were identified using electronic medical records and clinic staff confirmed preliminary eligibility (cancer diagnosis, no cognitive impairment or hospice care). A telephone screen assessed employment and caregiver parameters for final eligibility. Interested patients provided contact information for their primary informal caregiver and baseline interviews were scheduled. Of the 818 patients contacted, 57% were ineligible (primarily due to unemployment or the absence of a caregiver), 21% declined and 21% provided informed consent. The final sample size (n = 171 dyads) represented a 79% participation rate among eligible patients.

## **Interviews**

Patients and primary caregivers were interviewed separately every 6-months for 2 years. Between 2013–2018, semi-structured interviews were conducted either in the participants' home or in a private room at the cancer center. A small number of follow-up interviews were completed over the phone, for example for dyads who moved during the study period. Standardized scales were used to collect demographic information and physical and mental health status. Consent was obtained to extract information from the patient's medical record. Baseline interviews were approximately 90 minutes and follow-up interviews lasted 30–60 minutes. Interviews were audio recorded and conducted by trained graduate-level research staff. The standardized scales were self-administered by the participant. Honorariums (\$50.00) were provided per interview. The current analysis is based on all five data waves.

## **Measures**

Demographics included patient and caregiver age, sex, race/ethnicity, attained education and annual household income, marital status and the patient-caregiver relationship (spouse, parent, offspring, sibling, friend). Cancer type, stage and date of first systemic treatment were extracted from the medical record.

Secondary Caregiver. The primary caregiver was asked whether others assisted in the patients care using the following structured prompt: "Is there anyone else who is helping to care for [patient] or is otherwise

involved in [patient's] care?" Primary caregivers were classified as unsupported (absence of a secondary caregiver) and supported (presence of a secondary caregiver).

**Primary and Secondary Caregiving Activities.** Primary caregivers were asked "Can you tell me a little about *how* you are involved in his/her care?" to elicit the types of caregiving activities completed. Responses were open ended with structured prompts to ensure uniform capture of common caregiving tasks while allowing unique responses from each caregiver. For those who indicated the presence of a secondary caregiver, research assistants were trained to further prompt the primary caregiver to enumerate the relationship of the secondary caregiver to the patient and the types of activities performed by the secondary caregivers. Open ended responses were categorized by the research team to develop a comprehensive list of primary and secondary caregiver activities. Any caregiver activity classification discrepancies were discussed at weekly team meetings and consensus reached.

## Standardized Scales

Mental health and physical functioning of the primary caregiver was assessed using the MOS SF20 subscales. Using the published scoring protocol, scores were transformed linearly to 0-100 scales, with 0 and 100 assigned to the lowest and highest possible scores, respectively. The SF-20 was administered every 6 months over 5 data collection time points and higher score represented better outcomes.

## Statistical Analysis

We examined descriptive information for patient and caregiver demographics. Types of support provided to the patient by the supported and unsupported primary caregiver and the secondary caregiver were summarized by timepoint and examined for stability and change over time using the chi-square statistic; differences between the two types of primary caregivers (ANOVA) were noted. Descriptive statistics (mean, (sd)) were computed for SF-20 physical and mental functioning across all available timepoints and examined for the overall sample as well as for supported and unsupported primary caregivers. Using multilevel mixed effects models we examined the association of SF-mental with SF-physical health (dependent variable) over time. MLM accounts for the nesting of observations within participants and nesting of participants within sites. To estimate average linear and person-specific change over time in the SF-20 (physical and mental) sub-scales we created four separate within-person unconditional models ( $Y_{it} = \pi_{0i} + \pi_{1i}(time_{it}) + e_{it}$ ). For example,  $Y_{it}$  is the SF-20 score at time  $t$  for participant  $i$ ;  $\pi_{0i}$  is initial status of the SF-20 score for participant  $i$ . The linear time parameter  $\pi_{1i}$  was coded as 1, 2, 3, 4, 5 (time) and represents the point of measurement for the linear change in SF-20 physical score;  $e_{it}$  is the error for participant  $i$  at time  $t$ . These provide the form of the change and average slopes and were tested separately for supported and unsupported primary caregivers.

All available waves of data were used in multilevel models; participants had to have baseline and at least one additional interview. Model results are presented as regression parameter estimates ( $\beta$ ) with the associated standard errors reflecting the strength of the association of each variable and change in caregiver well-being (see  $Y_{it}$  above), and the significance test assessed as  $p$ -values less than .05. Fit

indices for model comparison include  $-2 \text{ Log Likelihood}$ , AIC, AICC, BIC and  $\chi^2$ , all of which are interpreted as smaller is better. Analyst used SAS 9.4.

## Results

Table 1 presents descriptive statistics for the sample. Both patients and caregivers were 54 years on average, and the majority married (83%) and white (73%). The most common diagnosis was NHL (63.7%) followed by MM (24.6%) and CLL (11.7%). Twenty-one (12.9%) patients died over the course of this study and for 5 dyads (3%) the primary caregiver changed at least once during the study period. More than half of the primary caregivers reported the presence of a secondary caregiver ( $n = 111, 64.9\%$ ). Comparison of supported and unsupported primary caregivers revealed no differences on demographics except sibling caregivers were more likely to have secondary caregiver support ( $\chi^2 (4) = 10.2, p < .05$ ) and supported primary caregivers were somewhat younger (53 years) compared to unsupported (56.8 years) ( $t = 2.8, p < .02$ ).

Table 1  
Demographics (N = 171)

	Caregiver	Patient
Age (M (sd))	54.2 (12.9)	54.2 (12.1)
	N (%)	
Sex (Male)	44 (25.7)	108 (63.2)
Race		
African American	39 (22.9)	37 (22)
Caucasian	125 (73.5)	122 (72)
Other	6 (3.5)	11 (6)
Education		
< HS /HS/GED	41 (29.8)	35 (20.5)
Some college	52 (30.4)	59 (34.5)
Bachelors' degree or higher	68 (39.1)	77 (45.0)
Income		
< 15–29,999	20 (11.7)	23 (14.2)
30–59,999	21 (12.3)	20 (35.3)
60–100,000+	119 (69.6)	108 (66.7)
Missing	11 (6.4)	9 (5.2)
Married	142 (83.0)	129 (75.4)
Relationship to patient		
Spouse/partner	126 (73.7)	
Parent	15 (8.8)	
Adult child/Sibling	22 (12.9)	
Friend/Other	8 (4.7)	
Diagnosis		
NHL	109 (63.7)	
NHL Stage		
0	9	

	Caregiver	Patient
1-2	33	
3-4	50	
Unknown/Unclassified	17	
CLL	20 (11.7)	
CLL Stage		
0	3	
1-2	6	
3-4	5	
Unknown/Unclassified	6	
MM	42 (24.6)	
MM Stage		
0	2	
1-2	10	
3-4	19	
Unknown/Unclassified	11	
Secondary Caregiver (yes)	111 (64.9)	

Types of Caregiver Support. Four categories of caregiver support activities were identified from primary caregiver descriptions. Frequencies for the provision of support by primary caregivers (supported and unsupported) and secondary caregivers are in Table 2.

Table 2  
Caregiver Support Activities Over time

	T1	T2	T3	T4	T5	Chi-sq, p
Unsupported Primary	N = 60	N = 53	N = 49	N = 47	N = 44	
Supported Primary	N = 111	N = 102	N = 93	N = 88	N = 83	
	N (%)	N (%)	N (%)	N (%)	N (%)	
<b>Treatment-related Caregiving</b>						
<b>MD Appointments</b>						
Unsupported Primary	47 (78.3)	33 (62.3)	23 (46.9)	19 (40.4)	16 (36.4)	25.7, .0001
Supported Primary	89 (80.2)	69 (67.6)	49 (52.7)	40 (45.4)	29 (35.0)	51.1, .0001
Secondary	30 (17.5)	30 (19.3)	18 (12.7)	12 (8.9)	5 (3.9)	19.9, .0005
<b>Treatment/medical Advice</b>						
Unsupported Primary	4 (6.7)	6 (11.3)	2 (4.1)	1 (2.1)	0 (0.0)	7.8, .09
Supported Primary	13 (11.7)	10 (9.8)	5 (5.4)	2 (2.3)	4 (4.8)	8.9, .06
Secondary	18 (10.5)	4 (2.6)	1 (0.70)	1 (0.74)	0 (0.0)	38.5, .0001
<b>Medical assistance</b>						
Unsupported Primary	<b>17</b> <b>(28.3)</b>	11 (20.7)	<b>12</b> <b>(24.5)</b>	<b>9 (19.1)</b>	7 (15.9)	2.8, .59
Supported Primary	<b>23</b> <b>(20.7)</b>	22 (21.6)	<b>10</b> <b>(10.7)</b>	<b>9 (10.2)</b>	9 (10.8)	10.1, .04
Secondary	2 (1.2)	5 (3.2)	0 (0.0)	0 (0.0)	0 (0.0)	12.4, .0001
<b>Reminders</b>						
Unsupported Primary	20 (33.3)	18 (34.0)	<b>15</b> <b>(30.6)</b>	12 (25.5)	8 (18.2)	4.0, .40
Supported Primary	35 (39.1)	32 (31.4)	<b>20</b> <b>(21.5)</b>	19 (21.6)	15 (18.1)	10.8, .03
Secondary	1 (0.58)	4 (2.6)	4 (2.8)	3 (2.2)	2 (1.6)	2.7, .60
<b>Advocates</b>						

	<b>T1</b>	<b>T2</b>	<b>T3</b>	<b>T4</b>	<b>T5</b>	<b>Chi-sq, p</b>
Unsupported Primary	7 (11.7)	3 (5.7)	2 (4.1)	4 (8.5)	3 (6.8)	2.7, .61
Supported Primary	9 (9.9)	7 (6.9)	5 (5.4)	7 (7.9)	3 (3.6)	3.4, .48
Secondary	1 (0.58)	6 (3.9)	7 (4.9)	1 (0.74)	0 (0.0)	14.03, .007
<b>Domestic-related Caregiving</b>						
<b>Chores/Housework</b>						
Unsupported Primary	<b>27 (45.0)</b>	<b>23 (43.4)</b>	<b>17 (34.7)</b>	<b>17 (36.2)</b>	<b>13 (29.6)</b>	3.5, .47
Supported Primary	<b>71 (64.0)</b>	<b>53 (52.0)</b>	<b>47 (50.5)</b>	<b>41 (46.6)</b>	<b>38 (45.8)</b>	8.7, .06
Secondary	43 (25.1)	45 (29.0)	31 (21.8)	25 (18.5)	23 (18.1)	7.0, .14
<b>Help ADL</b>						
Unsupported Primary	7 (11.7)	1 (1.9)	2 (4.1)	0 (0.0)	0 (0.0)	13.7, .009
Supported Primary	12 (10.8)	7 (6.9)	3 (3.2)	3 (3.4)	2 (2.4)	9.3, .05
Secondary	4 (2.3)	0 (0)	0 (0)	0 (0)	0 (0)	1.9, .75
<b>Errands</b>						
Unsupported Primary	<b>4 (6.7)</b>	<b>5 (9.4)</b>	<b>2 (6.1)</b>	4 (8.5)	3 (6.8)	0.58, .96
Supported Primary	<b>24 (21.6)</b>	<b>25 (24.5)</b>	<b>21 (22.6)</b>	11 (12.5)	11 (13.2)	7.4, .12
Secondary	14 (8.2)	11 (7.1)	9 (6.3)	11 (8.1)	4 (3.15)	3.7, .45
<b>Transportation</b>						
Unsupported Primary	26 (43.3)	<b>19 (35.8)</b>	12 (24.5)	9 (19.5)	7 (15.9)	13.6, .009
Supported Primary	55 (49.6)	<b>46 (45.1)</b>	27 (29.0)	24 (27.3)	13 (15.7)	32.4, .0001
Table 2. 'continued'						
Secondary	37 (21.6)	37 (23.9)	21 (14.8)	10 (7.4)	9 (7.1)	26.7, .0001
<b>Socio-emotional Caregiving</b>						
<b>Companionship</b>						

	T1	T2	T3	T4	T5	Chi-sq, p
Unsupported Primary	7 (11.7)	6 (11.3)	6 (12.2)	<b>0 (0.0)</b>	<b>0 (0.0)</b>	11.6, .02
Supported Primary	13 (11.7)	10 (9.8)	11 (11.8)	<b>7 (8.0)</b>	<b>4 (4.8)</b>	3.6, .46
Secondary	17 (9.9)	21(20)	24 (16.9)	16 (11.8)	11 (8.7)	9.1, .06
<b>Emotional Support</b>						
Unsupported Primary	33 (55.0)	28 (52.8)	<b>19 (38.8)</b>	<b>18 (38.3)</b>	<b>15 (34.1)</b>	7.5, .11
Supported Primary	58 (52.2)	47 (46.1)	<b>53 (57.0)</b>	<b>44 (50.0)</b>	<b>40 (48.2)</b>	2.7, .61
Secondary	40 (23.4)	52 (33.5)	44 (31.0)	41 (30.4)	34 (26.8)	4.9, .30
<b>Less Support (returning to normal)</b>						
Unsupported Primary		12 (22.6)	19 (38.8)	24 (51.1)	20 (45.5)	9.6, .02
Supported Primary		20 (19.6)	28 (30.0)	31 (35.2)	26 (31.3)	6.3, .10

Note: Bolded Primary caregiver means are significantly different for Unsupported v Supported Primary Caregivers

*Treatment-related Caregiving.* Primary caregivers (supported and unsupported) and secondary caregivers reportedly attended MD appointments with primary caregivers reporting very high rates (78–80%) that significantly tapered over time. Over a third of all primary caregivers reported giving reminders (33–39%) and 20–28% provided medical assistance; rates for these activities declined over time only among supported primary caregivers. Fewer primary caregivers reported functioning as advocates (10–12%). Secondary caregivers were not reported to provide medical assistance, reminders, or advocacy.

*Domestic-related Caregiving.* Transportation was provided by up to 49% of primary caregivers and declined overtime (15.9% at final assessment). All primary caregivers (supported and unsupported) endorsed completing chores and housework (45–64%) however unsupported primary caregivers did this significantly less frequently throughout the study period. Supported primary caregivers reported running errands (22%) at a rate three times greater than unsupported primary caregivers (6.7%). Secondary caregivers were identified as providing help with transportation and chores.

*Clerical-related Caregiving.* All primary caregivers (both supported and unsupported) provided limited or no assistance with insurance related matters (1%) and financial support for the patient (2%) (data not

tabled). Secondary caregivers were not reported to have provided clerical-related caregiving.

*Socio-emotional Caregiving.* Supported and unsupported primary caregivers initially both reported providing companionship (10–12%); over time unsupported caregivers stopped reporting the provision of companionship while a smaller number of supported caregivers continued to do so. Similarly, both supported and unsupported primary caregivers reported high rates of emotionally supportive caregiving at the first two points of measurement (46–55%). By wave three this declined for unsupported primary caregivers (34%) but remained robust for supported caregivers (48%). Emotional support was reported as provided by secondary caregivers throughout the study.

### Physical and Psychological Health of Primary Caregivers Over Time

As displayed in Fig. 1 at baseline, supported primary caregivers had significantly lower (worse) self-reported physical functioning SF-20 scores (intercept = 79.7). Over time (Table 3.), these lower scores remained stable ( $\beta = -0.14$ ;  $t = 2.4$ ,  $p > .80$ ). Unsupported primary caregivers had significantly higher physical health at baseline (intercept = 92.2), but their physical function declined over time ( $\beta = -1.41$ ;  $t = 2.4$ ,  $p < .02$ ).

Table 3  
Primary Caregiver Outcomes Over Time

	T1	T2	T3	T4	T5
<b>Whole Sample</b>	N = 171	N = 155	N = 142	N = 135	N = 127
	M (sd)	M (sd)	M (sd)	M (sd)	M (sd)
SF20 Physical	84.11 (25.5)	82.15 (25.8)	81.5 (28.5)	81.7 (27.0)	80.5 (28.5)
SF20 Mental Health	70.9 (17.7)	74.8 (17.0)	72.8 (18.1)	74.7 (17.2)	76.8 (14.5)
<b>Secondary CG Present</b>	n = 111	n = 102	n = 93	n = 88	n = 83
	M (sd)	M (sd)	M (sd)	M (sd)	M (sd)
SF20 Physical	81.2 (28.3)	77.9 (28.5)	78.14 (31.1)	79.4 (28.9)	79.8 (29.0)
SF20 Mental Health	70.4 (17.6)	74.4 (16.0)	72.7 (18.0)	74.2 (18.2)	77.2 (14.1)
<b>No Secondary CG</b>	n = 60	n = 53	n = 49	n = 47	n = 44
	M (sd)	M (sd)	M (sd)	M (sd)	M (sd)
SF20 Physical	89.4 (22.1)	90.25 (17.3)	87.9 (21.8)	86.2 (22.9)	81.8 (27.6)
SF20 Mental Health	71.7 (18.1)	75.5 (18.9)	72.9 (18.4)	75.7 (15.5)	76.0 (15.2)

SF-20 mental functioning scores were similar at baseline for both groups of primary caregivers (intercepts 71.6 and 70.1 respectively). Mental functioning improved over time among supported primary caregivers ( $\beta = 1.14$ ;  $t = 2.7$ ,  $p < .01$ ) but showed no improvement for unsupported primary caregivers.

## Modeling Caregiver Physical Health.

A series of MLM models were run to examine longitudinal associations of risk factors including caregivers' demographics, patient cancer stage, and SF20-mental functioning with physical health (SF-physical functioning dependent variable). Stratified models were run to assess physical functioning separately for supported and unsupported primary caregivers (Table 4.).

Table 4  
MLM of Physical Health Over Time for Primary Caregivers with/without a Secondary Caregiver Examining Mental Health

	Secondary Caregiver Present		No Secondary Caregiver	
	Base Model $\beta$ (SE)	Mental Health $\beta$ (SE)	Base Model $\beta$ (SE)	Mental Health $\beta$ (SE)
Intercept	113.5 (10.5)	90.19 (12.7)	131.03 (12.6)	121.3 (14.2)
Time	-0.22 (.57)	4.77 (2.5)**	-1.40 (.59)*	-5.70 (2.7)*
Age (caregiver)	-0.81 (.16)**	-0.82 (.16)*	-0.63 (.18)**	-0.66 (.17)**
Education (caregiver)	5.03 (1.5)*	4.75 (1.4)	0.48 (1.5)	0.50 (1.4)
Male (patient)	-2.45 (4.7)	0.76 (4.7)	-6.24 (4.4)	4.13 (4.9)
NHL	-9.27 (4.7)*	-8.46 (4.1)*	-1.59 (4.2)	-0.42 (4.1)
Mental Health		0.31 (.11)**		0.08 (.11)
Mental Health*time		-0.07 (.03)*		0.056 (.04)
Fit Indices				
-2 LL <sup>a</sup>	4036.3	4028.6	2116.0	2105.7
AIC	4056.3	4052.6	2134.0	2127.7
AICC	4056.7	4053.3	2134.8	2128.8
BIC	4083.2	4084.9	2152.9	2150.7
$\chi^2$	3.30.7	302.57	130.25	117.60

Note:  $p < .05$  \*;  $p < .01$  \*\*

Supported Primary Caregiver. The initial model for the individuals with a secondary caregiver revealed no significant change in physical functioning over time ( $\beta = -.22, >.05$ ). Education was positively associated and increased age and diagnosis of NHL were negatively associated with physical functioning in the initial model. The addition of mental health (SF mental) revealed a significant positive main effect on physical functioning ( $\beta = .31, p < .01$ ). With the inclusion of mental health as an independent variable, the

trajectory of physical functioning became positive and significant ( $\beta = 4.77$   $p < .01$ ). The interaction between mental health (SF mental) and time was significant and negative ( $\beta = -.07$ ,  $p < .05$ ) suggesting the strength of the relationship between mental health and the change in physical functioning attenuates over the course of the study.

Unsupported Primary Caregiver. The initial model for the unsupported primary caregivers revealed a significant decline in physical functioning over time  $\beta = (-1.40$ ,  $p < .05$ ). Age was negatively associated with physical functioning ( $\beta = -.63$ ,  $p < .01$ ). The model introducing mental health (SF mental) as an independent variable failed to detect significant effects for mental health on physical functioning; there was no significant main effect, no change in the time parameter for physical functioning and no significant interaction between mental health and time.

## Discussion

Many primary caregivers reported assistance from other informal caregivers. Primary caregivers who self-reported greater physical functioning at the beginning of their caregiver role were less likely to report having assistance from secondary caregivers. This may be due, in part, to assessments by other family and friends that additional help was not needed. In a longitudinal cohort study McCann et al., found that older adults who became caregivers were physically healthier at baseline compared to those who did not become caregivers.<sup>18</sup> As suggested by the transactional model of stress and coping,<sup>19</sup> families who have sufficient resources to address the demands of caregiving have better caregiver outcomes compared to families with fewer resources.<sup>20</sup> Our findings expand this by suggesting that primary caregiver needs, particularly those who are unsupported by other family and/or friends, require reassessment throughout the caregiving trajectory in order to remain responsive and protect the long term physical health of primary caregivers. As seen in this sample, primary caregivers may seem to be in good physical and mental health at the beginning of their caregiving journey but those with the least assistance from others may be at greater risk for detrimental health effects over the long term. Families' internal assessments of support needs may be flawed because of a lack of familiarity with the course of the disease or the burdens placed on caregivers, no matter how well resourced they are economically. There are also those who do not have additional family or friends to provide assistance, which intensifies the need to better identify and mobilize resources available through external community and health system sources.

Few primary caregivers reported helping with the patient's financial or health insurance tasks. Given that most (74%) primary caregivers in this sample were the spouse or partner of the patient this was unanticipated. However, it might be that participation in financial and health insurance maintenance, particularly among those who are married or partnered, was not considered a caregiving task because it predated the cancer diagnosis.

## Limitations

Some limitations to be acknowledged include the reliance on primary caregiver reports of the presence and activities of secondary caregivers. This study was not designed to collect data from secondary caregivers, therefore secondary caregivers may view their involvement differently from the perspective provided by primary caregivers. However, the presence or absence of secondary caregivers was verified by the cancer patients. Because the study recruited cancer patients (who were employed at the time of diagnosis) and caregivers (no employment criteria) after receipt of a cancer diagnosis we do not have measures of physical or psychological health prior to becoming a caregiver and we did not assess whether the caregiver felt they had a choice in becoming a caregiver. In this sample, primary caregivers who were caring for a parent and caregivers who were younger were more likely to report the presence of secondary caregivers. Non-spousal/partner caregivers and those who have other adults available to assist with caregiving tasks may be more likely to create shared caregiving arrangements. Caregivers who feel that they did not have choice in becoming a caregiver report greater burden and caregiver strain.<sup>2</sup> Greater understanding of the social and relational components of how family and friends organize caregiving tasks, assign caregiver roles and the effects of these factors on caregiver psychological and physical health are needed.

## Conclusions

This work has highlighted the important role additional family and friends are likely playing in the provision of out-patient, informal cancer care. These results illustrate that caregivers who do not report additional informal person support are more vulnerable to declining health overtime. Further research is needed to more clearly understand the ways in which sociocultural arrangements of caregiver resources such as roles and expectations, task distribution, and periodic reassessment of caregiver needs both protect and compromise caregiver health overtime.

## Declarations

**Conflicts of interest/Competing interests:** None of the authors have conflicts or competing interests

**Availability of data and material:** dataset available upon request

**Code availability:** available upon request

**Authors' contributions:** MDT and LAS conceived of the presented idea, MWG completed the statistical modeling and analysis, MDT lead writing with co-writers MWG and LAS.

**Ethics approval:** Approval to perform the study obtained from institutional review board, IRB # HM13074

**Consent to participate:** Informed consent obtained from all participants IRB # HM13074

**Consent for publication:** Consent to publish was obtained IRB # HM13074

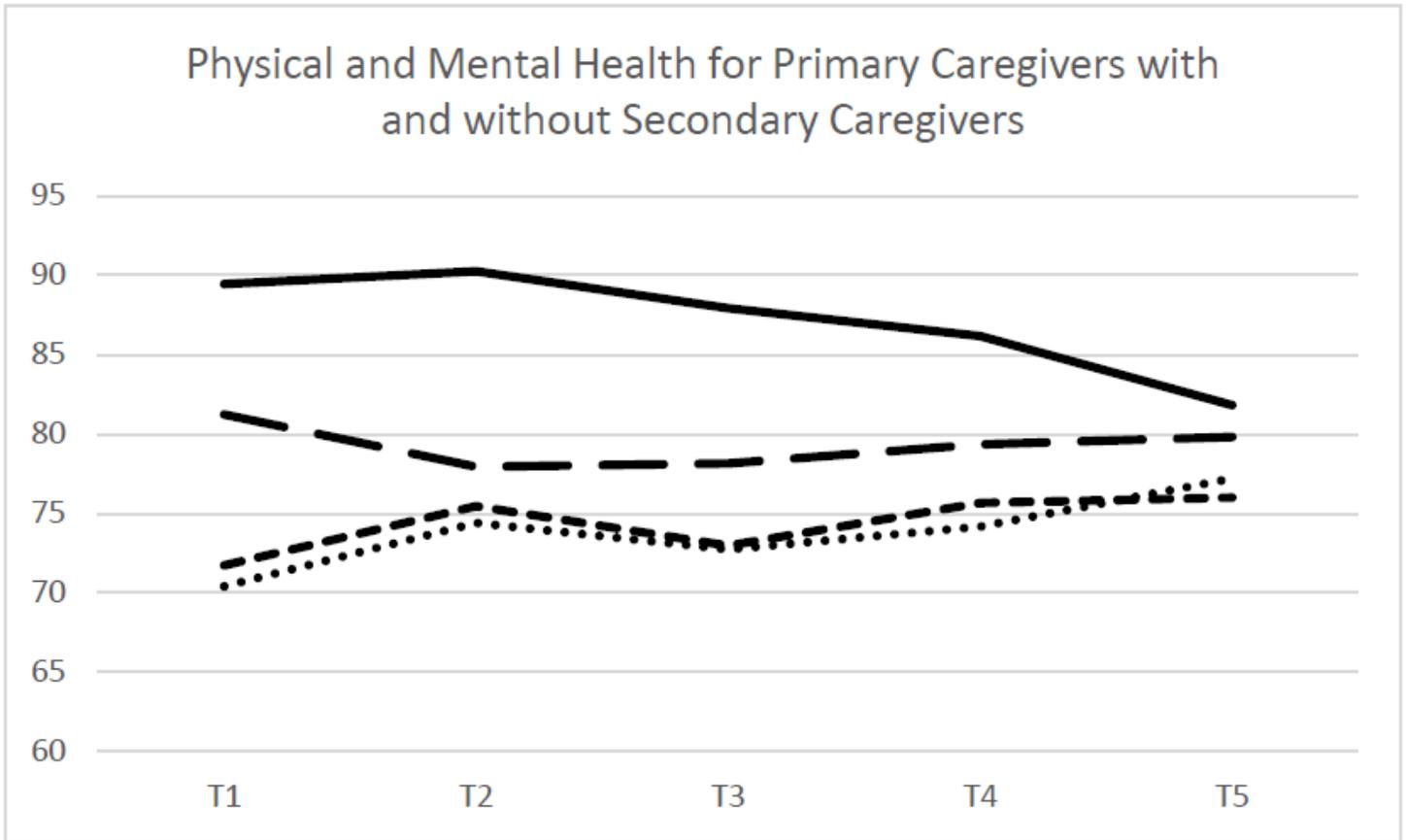
**Precis for use in the Table of Contents:** Primary cancer caregivers without help had higher baseline mental and physical health, but experienced deteriorating physical health overtime, compared to supported primary caregivers. Supported primary cancer caregivers reported improvements in mental health over time that was associated with improvements in physical health.

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## Figures



**Figure 1**

Physical and Mental Health for Primary Caregivers with and without Secondary Caregivers