



Health Status and Burden in Caregivers of Patients With Multimorbidity

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Abstract

Caregivers of patients with multimorbidity are important for improving patient outcomes. This descriptive study examines health status and burden of 22 caregivers of patients with multimorbidity discharged from the hospital who were enrolled in a self-management intervention study. Caregivers did not receive an intervention. Factors that increased caregiver burden were financial issues, caring for others (e.g., family members), and home obligations. Caregivers averaged between 2 and 3 chronic conditions themselves. Perceived caregiver burden remained unchanged over time for the caregiver whether the patient was in the intervention or the usual care group. We recommend rigorous research with larger samples to better understand the caregiver role, needed resources and potential interventions to mitigate caregiver burden in the multimorbid population during and after care transitions. Longitudinal studies that include assessment and interventions for the caregivers of patients with multimorbidity are needed.

Keywords

Caregiver, informal caregiver, multimorbidity, burden, multiple chronic conditions

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Introduction

The prevalence of multimorbidity, having two or more chronic diseases, (World Health Organization, 2015) is estimated near 50% among older adults (Xu et al., 2017). As multimorbidity continues to rise in the aging American population, health-related decline and limited financial resources often necessitate an increased need for family or friends to provide care in the home. These informal caregivers of patients with multimorbidity face challenges that are especially burdensome as a result of having to provide care related to two or more chronic illnesses. Although traditionally patient focused, multimorbidity research increasingly acknowledges the important but arduous task of caring for those with multiple chronic conditions (Alemi et al., 2016; Duggleby et al., 2016; Mason et al., 2016; Nordin et al., 2018).

Providing care for multimorbid patients can be especially burdensome for informal caregivers (Riffin et al., 2019). Poor communication among providers, multifaceted responsibilities, psychosocial burden, and difficulty accessing respite services were themes identified in a literature review that examined experiences and support needs of informal caregivers (Price et al., 2020). Other

studies identify demands specific to caregivers of multimorbid including multiple provider appointments, the stress of managing medications, and uncertainty in disease and symptom management that may contribute to detriments in mental health and give way to depression or anxiety (Denno et al., 2013; Mason et al., 2016). Multimorbid caregiver exigencies may be further compounded by their own physical or mental health issues, but many studies focus on caregiver burden and omit variables such as caregiver health status or quality of life (Nordin et al., 2018).

Complexities of caring for a loved one with multimorbidity require significant stamina and often results in considerable burden that may negatively impact caregivers' quality of life and health (El-Jawahri et al., 2017; Farzi et al., 2019). Spousal caregivers have reported

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more psychological symptoms (depression and stress) than non-spousal caregivers (Oldenkamp et al., 2016; Pinquart & Sörensen, 2011) underscoring the need to address spousal caregivers' psychosocial well-being. Increased caregiver burden is directly related to increased anxiety and depression (Denno et al., 2013). Likewise, decreased caregiver burden was associated with positive mental health in those caring for the multimorbid (Duggleby et al., 2016). Caregivers also report physical symptoms such as fatigue, weakness and weight loss (Choi & Seo, 2019). Furthermore, reallocation of time and resources may result in difficulty maintaining relationships which can manifest additional caregiver distress (Choi & Seo, 2019). Understanding how caregiver burden effects health outcomes is essential to supporting needs of caregivers for the multimorbid.

Exploring the health status of the patient and caregiver dyad may be of interest following a hospitalization. Discharge from acute care results in numerous changes that must be coordinated by the caregiver. In the case of a care recipient with multiple chronic conditions the care needs are greater and result in significantly more time being spent on caregiving activities (Lebrech et al., 2016). Another limitation among literature relates to examination of longitudinal changes in caregiver burden (Price et al., 2020). Assessing caregiver's needs over time should not be overlooked. Extra family caregiver support directly after hospitalizations is needed to increase caregivers' sense of control and social support (Hwang et al., 2011).

This sub-study provided an opportunity to explore the health status and quality of life of a patient/caregiver dyad and examine caregiver burden over time following a recent patient hospitalization. Caregivers of the multimorbid patients enrolled in a care transition intervention were invited to participate in this descriptive study. Caregivers did not receive an intervention. Understanding more about the demands and needs of caregiving over time for a patient with multimorbidity following a recent hospitalization is a gap that must be addressed to provide caregiver support and lessen the burden of caregiving. Therefore, the purpose of this descriptive study was to examine health status and demographics of patients and caregivers at baseline and to describe caregivers and their burden caring for patients with multimorbidity in the home setting following hospital discharge. Specifically, this project addressed the following aims:

1. Describe baseline and 60-day characteristics (demographic and health status) of caregivers and patients with who participated in a care transition self-management intervention.
2. Compare perceived caregiver burden between caregivers of patients receiving the intervention compared to patients receiving usual care on time demand of tasks for caregivers; difficulty of task of caregiving; and outside resources utilized by caregivers.

3. Describe health status measures (EQ-5D and PROMIS) between caregivers of patients receiving the intervention compared to caregivers of patients receiving usual care at baseline and 60 days after the intervention.

Methods and Measures

Study Design

Caregivers in this exploratory descriptive study were identified by the patient enrolled in the primary care transition study. No specific intervention was designed for the caregiver; however, they were asked to be available and part of the patient intervention. The primary study for this analysis was a repeated measure stratified randomized controlled pilot study. The intervention was designed to encourage self-management by promoting patient activation based on level of cognition. Patients were enrolled in the study prior to discharge from the acute hospital setting. Results of the cost-effectiveness of the self-management care transition interventions, in addition to a thorough description of the intervention and methods used are reported in the primary article (Zimmerman et al., 2017). Though the purpose of the primary study was not related to the caregiver or caregiving, we recognized the importance of gaining more knowledge of caregiver burden and health status when caring for the multimorbid patient. Due to the descriptive nature of our aims, we were not looking for effect differences therefore a power analysis to determine sample size was not done.

Sample

The sample included 22 caregivers who were adults and understood English. Thirteen caregivers were for patients in the intervention group and nine in the usual care group. Institution review board approval was obtained prior to initiating the study. The caregiver was a spouse, partner, friend, or family member who defined themselves as such and resided in the same home as the patient in the intervention study. Eligible caregivers were identified by the patient and present in the room when the patient enrolled in the intervention study. Once the patient agreed to participate, the caregiver was invited to participate in this caregiver study. While there were 90 potential caregivers who lived with patients enrolled in the study, most caregivers were not available in the patient room and therefore unable to consent. Twenty-seven caregivers signed consents, 22 were actively involved in the study. If the patient dropped out of the study or did not meet inclusion or exclusion criteria (e.g., discharged somewhere other than home), the caregiver also was dropped from the study. Reasons for and numbers of refusals to participate was not collected.

Measures

1. Caregiver burden. Oberst Caregiving Burden Scale (OCBS) is a two-dimensional 15-item scale that addresses time and difficulty of performing each of the items measuring tasks to be performed. Caregivers rate their level of time and then difficulty using a 5-point Likert scale from 1 (none) to a 5 (a great deal) with higher scores indicate more time and difficulty (Bakas et al., 2004; Oberst et al., 1989). Scores were calculated by averaging across the 15 items of the time and difficulty subscales, thus achieving an average score between 1 and 5 for each subscale. Summed scores were obtained by multiplying mean scores by 15 (which was used to compare results against other studies using OCBS, with possible range of 15–75). Evidence of construct validity and internal consistency reliability have been documented (Chung et al., 2016). Cronbach's alpha for this instrument has been reported at .90 and .94 for OCBS time and difficulty scale respectively, (Bakas et al., 2004) and for this study the Cronbach's alpha at baseline was .93 and .93, respectively.
2. Health Related Quality of Life. EQ-5D Well-being Index consists of a weighted sum of five dimensions by rating the amount of difficulty with five items: mobility, self-care, usual-activities, pain/discomfort, and anxiety/depression. This scale ranges from none, slight, moderate, and severe problems to being unable to perform the task which provided a simple descriptive profile. It also has one item visual analog scale (VAS) that rates health on a scale of 0 to 100 (100 being the best health) for a single index value for health status. The EQ-5D has been reviewed for validity and reliability and approved for use. Intraclass correlation for the EQ-5D VAS score was .82 for reliability and responsiveness as reported for the acute coronary syndrome population (Schweikert, 2006). The tool has been validated in several chronic populations and in several different countries (Berg et al., 2015; Jia et al., 2014; Schweikert, 2006).
3. Health Status. PROMIS 29 Profile measure was administered to assess caregiver self-reported mental, physical and social health status. PROMIS 29 is a collection of four-item short forms assessing physical functioning, anxiety, depression, fatigue, pain interference, sleep disturbance, ability to participate in social roles or activities, and a single pain intensity item. Each item has five responses ranging in value from 1 to 5 except for the pain intensity that ranges from a 0 to 10 value. The lowest score is 4 and highest possible is 20. Higher scores in the anxiety, depression, fatigue, pain interference, and sleep

disturbance indicate worse health status, and lower scores in the physical and social functioning domains indicate worse health status. Cronbach's alphas for the PROMIS-29 subscales ranged from .88 to .94 (Cella et al., 2010). PROMIS has been validated in a variety of clinical settings in the US general population and in several chronic disease populations (Cella et al., 2010; Goswami et al., 2019).

Procedures

After explanation of the study and written consent, baseline questionnaires including demographic data, OCBS, EQ-5D, and the PROMIS 29 were administered and repeated via telephone 60 days after initiation of the patient intervention. No specific intervention strategies were given to the caregiver; however, they were present at the discharge teaching and encouraged to be present during the care transition patient intervention. The project director of the primary study trained research assistants in administering caregiver questionnaires by demonstration and teach back. Fidelity checks were completed at least once with each research assistant during a 60-day follow up telephone call.

Data Analysis

Descriptive statistics (i.e., mean, standard deviation, and/or frequency distributions and percentages) were conducted on all variables. For aim 1, we used descriptive statistics and *t*-tests to compare baseline and 60-day characteristics on demographic and health status measures of caregivers and patients. For aim 2, Mann-Whitney *U* statistics were used to compare caregiver burden and health status measures between caregivers of patients receiving the intervention compared to caregivers of patients receiving usual care at baseline and 60 days. Descriptive statistics were used for aim 3.

Results

A total of 22 caregivers were included in this study. Patients were, on average, 67 (*SD*=10.8) years old while their caregivers averaged 61 (*SD*=9.8) years old. All patients and caregivers were Caucasian, and 68% were female. Most caregivers (91%) were spouses of the patient, others were family members. Half, *n*=11, of the caregivers reported they were currently working however, patients were even working more hours (28 hr/week) at baseline than the caregiver (23.78 hr/week). Hypertension (*n*=8, 31%), depression (*n*=5, 19%), and diabetes (*n*=4, 15%) were the most common caregiver chronic diseases. Most caregivers and patients had private insurance and over one third were on Medicare. There were only two significant differences (*p*≤.05) in demographic variables between patients and caregivers

Table 1. Comparison of Baseline Demographic Characteristics and Health Status Measures of Patients and Caregivers.

	Patients N=22	Caregivers N=22	Test statistic
	M (SD)	M (SD)	
Demographics			
Age	66.68 (10.79)	60.95 (9.78)	$t = 1.45$
Years of education	14.23 (3.28)	14.39 (2.79)	$t = .174$
Total number of comorbidities	6.46 (2.41) Range = 4–12	2.31 (2.44) Range = 0–10	$t = 5.677^{**}$
Number of hours worked	28.00 (21.89)	23.78 (12.18)	$t = -.506$
Interference in ability to do daily non-work activities (e.g., housecleaning or shopping)	5.76 (3.27)	2.65 (2.94)	$t = 3.055^*$
Patient activation	61.35 (13.82)	65.07 (12.76)	$t = .928$
	<i>f</i> (%)	<i>f</i> (%)	
Gender			
Female	8 (36%)	15 (68%)	$\chi^2 = .3367$
Male	14 (64%)	7 (32%)	
Race			
Caucasian	22	22	
Employment			
Yes	9 (41%)	11 (50%)	
No	13 (59%)	11 (50%)	
Marital Status			
Married	20 (91%)		
Not married	2 (9%)		
Caregiver relationship to patient			
Spouse		20 (91%)	
Family member		2 (9%)	
Health status measures			
EQ-5D index	.685 (.203)	.865 (.086)	$t = 3.818^*$
EQ-5D VAS	65.90 (18.59)	80.57 (13.17)	$t = 2.95^*$
Anxiety	54.81 (7.39)	52.86 (7.13)	$t = -.880$
Depression	55.13 (8.83)	49.24 (6.27)	$t = -1.658$
Fatigue	58.63 (8.23)	49.15 (4.74)	$t = -4.599^{**}$
Physical function	39.77 (7.22)	50.41 (7.42)	$t = 4.762^{**}$
Pain interference	59.23 (10.86)	49.45 (7.55)	$t = -3.276^*$
Sleep disturbance	54.83 (6.33)	48.26 (6.39)	$t = -3.386^*$
Ability to participate in social roles and activity	41.64 (6.61)	49.98 (4.90)	$t = 4.064^{**}$

* $p < .01$. ** $p < .001$.

(see Table 1). Patients had significantly more comorbidities and a greater interference in their ability to do non-job type activities such as housekeeping and shopping compared to caregivers.

While this study was not designed or powered to test for differences between caregivers and patients, some interesting trends were noted when comparing results for these two groups. Caregivers as compared to patients reported better health related quality of life (EQ-5D scores), higher functioning and increased social life, and less fatigue, pain, and sleep disturbances. Depression and anxiety were two measures of health status that showed caregivers and patients being more similar in score responses. See Table 1 for results for each health status measure.

Using Mann-Whitney U , there were no significant differences on the OCBS between caregivers in the

intervention and usual care group in the time spent or with the difficulty of the caregiving at baseline or 60 days, see Table 2. Time spent and difficulty at baseline were close to indicating differences, the caregivers with patients in the intervention group had higher median scores on both measures compared to the caregiver of patients in the usual care group. Median number of comorbidities of the caregiver were not different by group, with a median of 2 (range 0–10) in the intervention group of caregivers and 1 (range 0–5) in the usual care group of caregivers, see Table 2.

In relation to other resources commonly used by caregivers for patients in both the intervention and usual care group was other family members (intervention = 6, usual care = 5) and friends (intervention = 2, usual care = 2). Individual caregivers also were supported by neighbors and adult day care programs. One

Table 2. Time and Difficulty of Caregiving Tasks Reported by Caregiver at Baseline and 60 days After Patient's Hospital Discharge.

OCBS	Caregivers of intervention patients <i>n</i> = 13 median	Caregivers of usual care patients <i>n</i> = 9 median	Mann-Whitney <i>U</i> statistic (<i>N</i>)	<i>z</i>	<i>p</i> value
Time spent baseline	31.5 (12)	28 (9)	45.50 (21)	-.605	.554
Time spent 60 days	32 (11)	23 (6)	18.50 (17)	-1.459	.149
Difficulty baseline	22 (13)	20 (9)	52.50 (22)	-.402	.695
Difficulty 60 days	19 (11)	15.5 (6)	17.00 (17)	-1.633	.122

Note. *N* = 22.

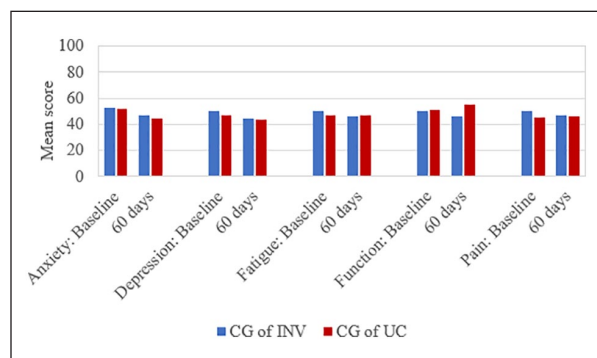


Figure 1. Promis-29 baseline and 60 days: caregivers of patients in intervention (CG of INV) or usual care (CG of UC) group.

caregiver in the intervention group used the American Association for the Blind for support. Church and hospice were used by a caregiver in the usual care group. When specifically asked about other factors that increased burden in caregivers, financial issues (loss of second paycheck, one vehicle), caring for additional individuals (elderly parents, in-laws), and other obligations at home (housecleaning, yardwork) were reported by both groups.

Comparison of the caregivers means by patient group (intervention vs. usual care) on EQ-5D index ($M=0.878$, $SD=0.083$; $M=0.876$, $SD=0.074$, respectively) and EQ-5D VAS ($M=79.27$, $SD=16.33$; $M=84.00$, $SD=9.62$, respectively) were similar at baseline and showed negligible differences at 60 days. Figure 1 depicts group means on the PROMIS-29 subscales near the population mean and negligible differences between groups at 60 days.

Discussion

Study findings are consistent with existing research related to caregiver burden of multimorbid and suggest implications for future research and nursing practice. As one might expect, the caregivers reported fewer comorbidities as compared to patients. Caregivers had between 2 and 3 chronic conditions on average, with one caregiver having as many as 10 comorbidities. We assumed that caregivers would be “healthier” than the patient they were caring for, however, sometimes the caregiver

also has many comorbidities, as was the case in our study.

Perceived caregiver burden remained unchanged in both the intervention and usual care groups. This finding aligns with results from a systematic review performed by (de Bruin et al., 2012) that observed no change in caregiver burden despite a comprehensive care program implemented for patients with multimorbidity and their caregivers. Additionally, it should be noted that the intervention in this study was directed at the patient with multimorbidity, not the caregiver. Additional study of this population of caregivers of multimorbid patient is needed.

Caregiving burden is difficult to compare across studies because of the heterogeneity of populations and assessment tools (Nordin et al., 2018). When compared to studies that utilized the same OCBS, caregivers of patients with heart failure (Chung et al., 2016) and stroke (Ganapathy et al., 2015) both reported higher levels of burden than participants in our study. Higher median scores of time spent and difficulty at baseline for caregivers in the intervention group may favor a simpler, less time-consuming self-management intervention. However, without statistical significance or explanation for increased time demands or difficulty, this observation is recognized as speculative. Research participation itself may account for the variation in scores. Though intervention studies are intended to improve processes and health outcomes for patients and caregivers, participation itself is time and energy consuming and may unintentionally contribute in a negative manner. This potential sequela advocates for caregiver assessment as an important component of a transitional care program. Subsequently, resources that caregivers have available to them to provide support is important to consider.

Caregivers in our study reported that managing finances, caring for others, and home obligations contributed to caregiver burden. In a similar manner, Price et al. (2020) describe multifaceted responsibilities that create challenges for caregivers of patients with multimorbidity. Consideration of baseline responsibilities are thus important to consider when assessing needs for caregivers of patients with multimorbidity.

As patients reported the ability to perform fewer household tasks, caregivers reported increased home

obligations, these results may suggest some burden during care transition could arise from home obligations being shifted from patient to caregiver. Insightful discharge planning may help alleviate caregiver burden by assessing anticipated needs to replace the usual home responsibilities of patients with resources such as house-keeping, grocery delivery, or lawn care services.

Family, friends, and neighbors were identified by caregivers as commonly sought out resources suggesting high-risk patients with multimorbidity may utilize a network of informal caregivers rather than just one primary person to assist with needs following hospital discharge. Further investigation of multiple non-resident caregivers and the roles they play during care transitions is needed. Accessing respite services is important to support the needs of caregivers (Price et al., 2020). Caregivers in our study identify options of seeking out adult day programs or church members to help relieve burden of caring for patients with multimorbidity.

We anticipated that quality of life and general health status would be impacted by the level of burden these caregivers were experiencing caring for the multimorbid patient, however, in our study that was not the case. Additional research with larger sample sizes is needed to better understand the caregiver role, needed resources and potential interventions to mitigate caregiver burden of the multimorbid during and after care transitions.

Limitations

Limitations in this study were primarily related to self-report of participants, small sample size, and generalizability issues. Our primary purpose was not the caregiver subset and recruitment of caregivers present in the room during patient enrollment resulted in a smaller number of caregivers. Caregivers for this study were also required to reside with the patient which may have excluded informal caregivers such as neighbors or friends that may assist with cares. In addition, only one caregiver was enrolled per patient although multiple caregivers may be involved in a patient's everyday care.

This study was part of a transitional care intervention study for patients, and the results may have poor generalizability. As an exploratory study, strong conclusions cannot be drawn, and results need validated in larger study with the primary focus on the caregiver and patient/caregiver dyad. In addition, the scope of caregiver assistance was not well-described, particularly regarding specific caregiving tasks that contributed to burden and whether caregivers of the patients with multimorbidity and low cognition required additional caregiving attention during hospital to home transitions.

Conclusion

Caregivers have major chronic diseases themselves as shown in this study. Caregiver comorbidities and the need for self-care place additional burden on an already

burdened situation. Determining caregiver comorbidities, areas of need, strategies for successful implementation, and accessible resources for caregivers of patients must be considered. Caregivers relied most heavily on other family members for assistance with caregiving activities. Respite care and adult day programs to mitigate fatigue and allow time for self-care by the caregiver could be explored. Some states have adopted programs that allow family caregivers to receive pay for caregiving services to relieve some of the financial burden, exploration of such programs may be of great benefit. Social supports in the form of neighbors or church members may provide additional assistance such as helping with transportation to help alleviate caregiver burden.

In addition to perceived burden, we agree with other authors that the general well-being of those caring for individuals with multiple health problems is important to consider (Duggleby et al., 2016; Price et al., 2020). Patients and caregivers may both experience similar degrees of anxiety and depression, so mental health should be considered when implementing a transitional care program. Physical health status and quality of life are also variables that deserve additional inquiry (Nordin et al., 2018). Discovering ways to improve experiences of caregivers may help preserve the vital role of individuals providing care to increasingly complex multimorbid patients. Longitudinal approaches are desirable, as care needs may change over time.

As multimorbidity continues to rise in the ageing population, family members of the patients with multimorbidity will most likely be called upon to serve in the multi-faceted role of informal caregiver. Understanding the burden of caregiving along with the necessary support to provide care and to remain healthy to continue as a caregiver will be paramount. Additional research is needed to better understand caregiving burden and the necessary resources and interventions to mitigate the burden of caregiving.

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