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Exploring the Association Between Chronic Condition Symptoms and Treatment Burden in a Skilled Nursing Population

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Abstract

The purpose of our study was to test the relationship between chronic condition symptoms and treatment burden in the older adult population transitioning from skilled nursing facility to home. Treatment burden is defined as burden associated with adhering to a prescribed, chronic condition self-management regimen. Analysis of correlations between chronic condition symptoms and treatment burden revealed symptom and treatment burden are positively correlated ($p < .05$). Multivariate analysis (adjusted $R^2 = .40$, $F(10,63) = 5.96$, $p < .000$), controlling for other known antecedents of treatment burden, demonstrated fatigue (standardized beta coefficient = .47; $p < .000$) predicted higher levels of treatment burden. Post-hoc analysis revealed caregiver presence partially mediated the effect of fatigue on treatment burden, decreasing treatment burden during transition. Our findings support existing transitional care literature suggesting clinical assessment including symptom screening, treatment of symptoms, and/or intervention reducing the impact of symptoms on patients' health and well-being, may lower treatment burden thus improving self-management adherence.

In 2015, 1.7 million older adults received post-acute care in skilled nursing facilities (SNF) (Crosson, Christianson, & Miller, 2017). The health of this population is characterized by chronic multi-morbidity requiring complex medical care in acute settings and often rehabilitation in a SNF before returning to a home setting (Centers for Medicare & Medicaid Services, 2012; Toles et al., 2016; Mor et al., 2010). As a result of complex multi-morbidity, post-discharge health trajectories in this population are often poor, with twenty percent of individuals discharged from SNF care readmitted to an acute care setting or seen in an emergency department setting within 30 days (Toles et al., 2014).

Research designed to improve these poor health outcomes in this population is emerging (Toles et al., 2016), borrowing concepts and methods from the body of inpatient transitional care research (Berkowitz et al., 2013; Hirschman et al., 2015). These transitional care studies focus on coordination and continuity of care by assessing and meeting a patient's discharge

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care needs in order to improve health outcomes and reduce readmission rates. A key, sometime overlooked, component to improving health outcomes in this population is the need for self-management of chronic conditions. Poor self-management of chronic conditions can result in an acute exacerbation of the condition or increase in symptoms, thus delaying recovery from the acute illness. Additionally, ineffective self-management of chronic conditions has been shown to be a major factor in readmission and emergency department usage within 30 days of discharge (RTI International, 2016).

High levels of treatment burden are associated with ineffective self-management of chronic conditions and contributes to poor health outcomes in the population after discharge from SNF. Treatment burden is defined as the burden associated with adherence to a prescribed chronic condition self-management regime (Tran et al., 2014; Sav et al., 2013). Treatment burden has been found to increase with the number of chronic conditions, or multiple chronic conditions (MCC), diagnosed in a patient (Sav et al., 2017; Schreiner and Daly, 2018). As the number of MCC increases, so does the risk for polypharmacy, including the number, times, and cumulative side effects of medications as well as the number of collaborating physicians and health care providers associated with the individual's care, with associated appointments and necessary follow-ups. As treatment burden increases, so does the risk of the individual's partial or full non-adherence to the prescribed treatment regimen (Demain et al., 2015; Sav et al., 2013; Sav et al. 2016). Non-adherence to a prescribed treatment regimen then can result in ineffective self-management of MCC leading to poor health outcomes, such as exacerbation of a chronic condition or the inadequate resolution of an acute health condition (Kymes et al., 2016; Viswanathan et al., 2012).

Current literature suggests many antecedent factors are associated with treatment burden. Chronic condition factors such as the number of chronic conditions (Sav et al., 2017; Schreiner and Daly, 2018), the severity of the chronic condition (Sav et al., 2016; Schreiner and Daly, 2017), and the diagnosis of diabetes or other endocrine related conditions (Sav et al., 2016) increase the level of treatment burden experienced by individuals diagnosed with chronic conditions. Care-related variables of receiving homecare after discharge from a SNF (Schreiner and Daly, 2018) and having a caregiver assist with the self-management of chronic conditions (Sav et al., 2016) were associated with higher level of treatment burden, though Schreiner and Daly (2018) showed that the presence of a caregiver who assisted with self-management decreased treatment burden. Disease related symptoms, such as pain, have also been identified as an antecedent factor affecting treatment burden, but this relationship has not been quantitatively measured (Sav et al., 2016). Additionally, those younger in age experience higher treatment burden (Sav et al., 2016). These studies answered important questions about which conceptually related variables are associated with treatment burden in various populations diagnosed with chronic conditions, but many potential antecedent factors associated with treatment burden remain untested.

There is vast body of literature addressing symptoms associated with chronic conditions. Symptoms such as impaired physical functioning (Stenholm et al., 2015), depression (Read et al., 2017), anxiety (Guo et al., 2017), fatigue (Connolly et al., 2013), and pain (Scherer et al., 2016) are associated with chronic conditions. While the relationship between chronic condition symptoms and treatment burden has not yet been examined, this relationship is

highly probable. For example, a person who has impaired physical functioning may find it extremely burdensome to accomplish basic chronic condition related self-management tasks, such as adhering to an exercise regimen or managing fluid and nutritional intake. Confirmation of the hypothesis that chronic condition symptoms are related to treatment burden will have implications for care of persons transitioning from SNF to home. Measuring and identifying this potential antecedent relationship can inform suggestions for potential interventions to effectively reduce treatment burden in this population. For instance, if a clinician can adequately reduce symptoms, such as pain, associated with a chronic condition, he/she may decrease the amount of treatment burden experienced by the patient. By decreasing treatment burden, that patient may be more adherent to the prescribed treatment regimen, thus effectively managing the chronic condition, improving health outcomes and reducing 30-day readmission and emergency department visits.

Purpose

The purpose of our study was to examine the relationship between chronic condition symptoms and treatment burden in the older adult population transitioning from SNF. We hypothesized that chronic condition symptoms were positively correlated with treatment burden. The aim of our study was to examine the relationship between chronic condition symptoms (physical function, fatigue, depression, anxiety, pain interference, and pain intensity) and treatment burden, controlling for known antecedent factors (the severity of MCCs, the number of homecare visits, and the presence/absence of a caregiver).

Methods

Design and Sample

Our study was conducted using a prospective, correlational, cross-sectional design that examined the relationship between chronic condition related symptoms and treatment burden 30-days after the participants were discharge from SNF to home. The study was conducted over a period of approximately 5 months beginning September 2016 continuing through January 2017. Study participants included 74 adult men and women recruited via convenience sampling. Participants were identified and approached for consent into the study if they were: (1) age 18 or older, and (2) diagnosed with two or more chronic conditions as defined by CMS (Centers for Medicare and Medicaid Services, 2017). Participants were excluded from enrollment into the study if they scored less than eight on the Brief Interview of Mental Status (BIMS) exam, indicating severe cognitive impairment (Chodosh et al., 2008).

Setting and Ethical Approval

We conducted our study at a 100 bed, privately owned SNF in Northeast, Ohio. The participating SNF's population was representative of other Northeast Ohio area SNFs, comprised of a medically complex, multi-morbid patient population discharged from an acute hospital setting who required additional skilled care, such as physical/occupational therapy or complex wound care prior to discharge to a home setting. We obtained

Institutional Review Board approval from the authors' university prior to identification, recruitment, and enrollment of participants.

Data Collection

Facility staff identified potential participants for the study and gave a list to the Principal Investigator (PI). The PI approached, consented, and collected data from all participants. Data were collected in the SNF at enrollment and via phone at the 30-day time point after the participant was discharged home. The PI was solely responsible for all data collection from all participants. Data collection in-facility included demographic questions. Data collection at home via phone took approximately 20 minutes and included the PROMIS short form questionnaires for physical function, fatigue, depression, anxiety, pain interference, and pain intensity (Cella et al., 2010; Deyo et al., 2015) and the Treatment Burden Questionnaire-15 (Tran et al., 2014). We also collected measures of other known antecedent treatment burden factors (the severity of MCCs, the number of homecare visits, and the presence/absence of a caregiver) at the 30-day time point in order to control for the influence of these factors in our statistical analysis (Sav et al., 2015; Schreiner and Daly, 2018).

Prior to the study we conducted a sensitivity analysis using G*Power software (Faul et al., 2009) for our proposed multivariate analysis. Inputting parameters of an alpha of .05, a power of .80, 10 independent variables, and sample size of 74 participants, we would need a medium effect size of .25 to detect statistical significance.

Measures

Treatment Burden—The previously validated 15-item, Treatment Burden Questionnaire-15 (TBQ-15) was used to measure participant treatment burden (Tran et al., 2014). Each questions posed by the questionnaire inquires about burden related to performing specific aspects of self-management, such as medication administration, dietary changes/restrictions, or arranging/getting to scheduled physician appointments. The questionnaire prompts the participant to rank the level of treatment burden for each of the 15 questions with responses ranging from 0- *No Burden*, to 10- *Very High Burden*. After all questions are answered, scores are summed and range from 0–150, with higher scores indicating greater treatment burden. Construct validity has been evaluated via correlations with medication adherence using the Morisky's Medication Adherence Scale and quality of life using the PatientsLikeMe Quality of Life Scale (Tran et al., 2014). Participants with low medication adherence, as compared to participants with moderate or high adherence, had significantly higher levels of treatment burden (mean [SD] TBQ score 61.8 [30.5] vs. 37.7 [27.5]; $P < 0.0001$). Global treatment burden was inversely correlated with quality of life; those with high treatment burden reported a lower quality of life ($r = -0.50$; $p < 0.0001$). Reliability for the TBQ-15 was determined via a one-month test-retest with an intra-class correlation of 0.77 (Tran et al., 2014).

Symptoms—We used the 4-item, short form Patient-Reported Outcomes Measurement Information System (PROMIS) instruments (Cella et al., 2010) to measure participant physical function, fatigue, depression, anxiety, pain interference, and pain intensity.

PROMIS measures are a set of standardized, subjective instruments that evaluate physical, mental, and social health in adults. We chose to use the 4-item PROMIS instruments to measure chronic condition symptoms as they are widely used in scientific research and display strong psychometric properties. Additionally, using the 4-item variant of the PROMIS instruments reduced survey fatigue in our participants. For each variable, scores range from 1 (low severity) to 5 (high severity of the symptom, with scores summed ranging from 4 to 20, with higher scores indicating greater symptom severity. Unlike the other symptoms, we used a single item scale to measure pain intensity, which was scored on a 0 to 10 scale with higher score indicating greater pain. Construct validity has been established through significant positive correlations with increasing claims for workers' compensation, falls, and Pain Catastrophizing Scale (Deyo et al., 2015). Reliability has been tested via internal consistency between items with Cronbach alpha's ranging from 0.85 (anxiety) to 0.94 (fatigue) (Deyo et al., 2015); 0.89 (anxiety) to .0.93 (depression) (Kroneke et al., 2014).

Severity of MCC—The severity of MCC was measured using a participant answered, self-report question for each diagnosed, CMS defined chronic condition: “What is the impact of the chronic condition (0- no impact, 10- high impact) on your health and overall well-being?” We summed the total score for all chronic conditions and treated the summed score as continuous independent variable for analysis. This index was developed by the investigator to capture the impact of all chronic conditions on a participant's health and well-being, as we acknowledge all chronic conditions are not equal in severity. The summed severity score of all MCCs was treated as a continuous independent control variable.

Homecare Visits—We defined homecare visits as provider ordered in-home nursing care to following discharge to home. We verified the order for homecare via the facility's electronic medical record system. During data collection, we asked the participant how many visits he/she had during the 30-day transition period home. We treated the total number of homecare visits indicated by the participant as a continuous independent control variable for statistical analysis.

Caregiver—We defined a caregiver as an individual (spouse, family member, friend, or employee) who provided assistance in the self-management of MCCs after the participant returned home from the SNF. For data collection and analysis, we treated this independent variable as dichotomous: no caregiver assisting with self-management or caregiver(s) assisting with self-management.

Demographics—The PI collected patient demographics during the baseline visit via interview and confirmed responses with an electronic medical record review. Age, gender, race, education, income, and the number of MCC were collected.

Data Analysis

We analyzed study data using SPSS software, version 24 (IBM, 2016). We evaluated frequency distributions and univariate statistics to ensure our data met statistical assumptions of our planned analyses. Statistical assumptions of linear regression and multi-collinearity

were tested before conducting multivariate statistical analysis. We set *a priori* statistical significance at 0.05.

Reporting of descriptive, univariate statistics included: (1) range, mean, standard deviation, of continuous variables and (2) number and percentage of categorical and dichotomous variables. Bivariate, correlational analysis between chronic condition symptoms (impaired physical functioning, depression, anxiety, fatigue, pain interference, and pain intensity) and treatment burden was conducted using the Pearson R test reporting r-statistics and p-values. Multivariate analysis of our independent variables (impaired physical functioning, depression, anxiety, fatigue, pain interference, and pain intensity controlling for the number of MCC) on the dependent variable of treatment burden was conducted using linear regression reporting the overall model fit (F-test, degrees of freedom, adjusted r^2 , p-value), and unstandardized/standardized beta coefficients, t-score, and p-value for each independent variable analyzed in the model. The total number of MCC was significantly associated with treatment burden in a previous analysis using this data set, thus the relationship between the number of MCC and treatment burden was controlled for by adding the summed total of MCC in our analysis as a continuous variable in our multivariate analysis.

Results

Study demographics are found in Table 1. We found no significant relationships between age, sex, race, education, income and treatment burden in our sample, thus we did not control for these characteristics in our multivariate analysis.

We first examined the relationship between chronic condition symptoms and treatment burden by analyzing bi-variate correlations (Table 2). All chronic conditions symptoms were positively associated with treatment burden, thus the more severe the reported symptom, the higher the level of treatment burden. Fatigue ($r=.64$, $p<.001$) and Pain Interference ($r=.38$, $p<.000$) were the two most strongly correlated symptoms with treatment burden 30-days following discharge from SNF to home.

In a multivariate analysis (Table 3) including the 6 chronic condition symptoms as independent variables, 39% of the variance in treatment burden was explained (adjusted $R^2=.39$, $F(6,67)=8.64$, $p<.000$), with the symptom of fatigue (standardized beta coefficient=.55; $p<.000$) predicting treatment burden. We then controlled for other known antecedent factors of treatment burden (the number of MCC, severity of MCC, presence of a caregiver, and the number of home care visits). In this multivariate analysis, the model was significant (adjusted $R^2=.40$, $F(10,63)=5.96$, $p<.000$). Fatigue still predicted treatment burden (standardized beta coefficient=.47; $p<.000$). The presence of the caregiver assisting with chronic condition self-management task also remained significant in this multivariate analysis (standardized beta coefficient= -.21; $p=.04$).

We conducted post-hoc analysis of our findings and found that the presence of the caregiver in the multivariate model partially mediated the relationship between fatigue and treatment burden (standardized beta coefficient=.47; $p<.000$) reducing the impact of fatigue on treatment burden during the 30-day transition period. Splitting the file between those

individuals with caregivers and those individuals without caregivers, we found fatigue severity was lower in those participants with caregivers (11.53) versus those without caregivers (14.04). Additionally, fatigue was not a significant predictor of treatment burden in individuals with caregivers (standardized beta coefficient= .33, $p = .08$) as compared to those participants without caregivers (standardized beta coefficient= .63, $p < .000$).

Discussion

The study results confirmed the associations between chronic condition symptoms and treatment burden, with more severe symptoms being directly correlated with higher levels of treatment burden during the 30-day transition period. Additionally, the results of the multivariate analysis demonstrated that higher levels of fatigue predict greater treatment burden and that the presence of a caregiver partially mediated the effect of fatigue on treatment burden. Our initial findings support current clinical practice of assessment, education, and allocation of resources outlined in current transitional care literature. Based on our results, these transitional care practices are indicated, but further testing is needed to determine if these actions are effective in decreasing treatment burden and improving clinical outcomes.

For SNF providers (physicians, nurse practitioners, nurses, social workers), understanding that a patient who displays high levels of MCC associated symptoms is at risk for potential non-adherence to part or all of needed management of MCC when discharged home allows the provider to mitigate these effects prior to discharge. Addressing MCC related symptoms should be a priority for providers during a patient's SNF stay and effective interventions, both pharmacologic and non-pharmacologic, should be incorporated into the discharge plan of the patient. Toles et al., (2016) demonstrated that individualized, early transitional care planning improves health outcomes in patients discharged from SNF to home. Improved pain management, mental health assessments, and additional in-home resources can increase the probability of effective self-management. For example, more frequent and/or longer duration homecare, in-home provider follow-up from a physician or nurse practitioner, or putting community resources in place (such as assistance with obtaining medical transport to appointments) may help ensure that patients suffering from significant MCC symptoms have the in-home assistance and support needed for effective management of MCC during the transition period home.

The finding of fatigue predicting treatment burden in our multivariate analysis has substantial implications for clinical practice. Studies have found that a decline in activities of daily living (ADL), a decrease in mobility, or an increase in care needs increase the risk of readmission in patient populations discharged from hospital to home (Berain et al., 2016, Hoyer et al., 2014). A priority of SNF care is rehabilitation through physical therapy and/or occupational therapy modalities. However, even though a patient is able to meet therapy goals during his/her SNF stay, the increase in fatigue due to increased/unforeseen demands after returning home, when the readily available services of the SNF are no longer available, may impair the patient's ability to adequately self-manage chronic condition(s), thereby increasing risk adverse outcomes. Examining the impact of patient fatigue on mobility and

ADL performance after transition home may provide further direction for approaches to improve health outcomes during the transition period.

Our finding of the positive influence of caregiver presence decreasing transitional fatigue and mediating the effect of this fatigue on treatment burden highlights the importance for SNF providers to assess the availability of caregivers and interface with these individuals prior to discharge to home in order to include them in the plan of care. This finding also demonstrates that the presence of the caregiver assisting in MCC self-management is an essential mechanism for reducing treatment burden, even when controlling for other associated factors. Previous studies of treatment burden have highlighted the role of caregivers in assisting with self-management of MCC (Koch, Wakefield & Wakefield, 2015) and decreasing treatment burden in the MCC population (Schreiner and Daly, 2018; Sav et al., 2013).

Our findings also have implications for transitional care/homecare providers. Studies have shown that home health visits within a week can reduce the risk for readmission after SNF discharge (Carnahan et al., 2017). Our results suggest that transitional/ homecare providers should specifically assess severity of MCC symptoms and treatment burden. This assessment could identify what additional resources are needed during the transitional period in order to improve MCC self-management and reduce the risk for readmission.

Our results also point to the need for further examination of the relationship between the fatigue/pain cluster and impaired physical function in the role of chronic conditions self-management. For instance, higher levels of fatigue and pain are associated with impaired physical functioning in a multitude of chronic conditions (Cook et al., 2016), and poor physical function is related to the risk of readmission after discharge to a home setting (Favley et al., 2018). We found that all three variables are positively associated with treatment burden, thus as symptom severity increases, so does the level of treatment burden. Additionally, these three symptoms may have other deleterious effects on other aspects of self-management, such as self-efficacy. Further exploration of these variables in future studies may provide valuable insight in how to improve chronic condition self-management through improved symptom management.

This study was not without limitations. We had a limited sample size and thus were underpowered for our multivariate analysis, though our effect size in the sample was large enough to detect statistical significance. The cross-sectional design and convenience sampling in a single SNF limited generalizability to disparate populations, particularly those with lower income. Also, our cross-sectional design limited our ability to test for causation; a longitudinal design with a cross-legged structural equation model analysis should be incorporated in further testing of our findings. The use of additional, objective measures of functioning (6-minute walk tests, ADL/IADL scoring, and SNF physical therapy scores) should be correlated with subjective reports of physical functioning and be tested as independent variables in future models exploring MCC symptoms and treatment burden. Comparing pre and post levels of fatigue and related measures of physical functioning/ mobility also should be addressed in future study designs.

Conclusion

This study addressed a substantial gap in the treatment burden/transitional care literature concerning the association of chronic condition related symptoms and treatment burden during the transition of older adults from SNF to home. Our findings demonstrate that worsening condition symptom severity are associated with higher levels of treatment burden, which would be expected to lead to patient non-adherence to the prescribed treatment plan, ineffective self-management of MCC, and poor health outcomes, such as high 30-day readmission rates. Our findings indicate an opportunity for clinicians to screen for MCC symptoms and treatment burden pre-SNF discharge and post-discharge at home. Interventions such as adjustment to medications, patient/caregiver education, or allocation of additional resources to reduce symptom severity can then be implemented. By reducing symptom severity, clinicians may reduce treatment burden, improving adherence to the prescribed treatment/transitional care plan, and improving health outcomes.

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Table 1:

Study Sample Variable Univariate Statistics (n= 74)

Variable	Range	Mean	Standard Deviation
Age:	48 – 96	75.40	10.26
Number of Chronic Conditions:	2 – 8	4.30	1.53
Severity of MCCs	0 – 50	17.65	12.14
Homecare Visit(s):	0–30	7.62	8.48
Physical Function:	4–20	15.15	5.07
Anxiety:	4–20	8.09	4.01
Depression:	4–20	7.36	3.77
Fatigue:	4–20	12.42	5.08
Pain Interference:	4–20	11.57	5.56
Pain Intensity:	0–10	5.45	3.22
Treatment Burden:	0–100	37.01	24.45
Variable	Number of Participants (n)	Percentage of Participants (%)	
Sex: Male	19	25.70	
Female	55	74.30	
Race: White	68	91.10	
Black	6	8.90	
Education:			
Grades 1–11	16	21.60	
High School	27	36.50	
Some College	19	25.70	
College/ Post -college Graduate	13	16.30	
Income:			
\$5,000 or less	2	2.70	
\$5,001 – 10,000	5	6.80	
\$10,001 – 25,000	58	78.40	
\$25,001 – 50,000	6	8.10	
\$>50,001	3	4.10	
Caregiver assisting Self-Management at Home:			
Yes	48	64.90	
No	26	35.10	

Table 2:

Correlations between Chronic Condition Symptoms and Treatment Burden

	1	2	3	4	5	6
1. Treatment Burden	-					
2. Physical Function	0.32**	-				
3. Anxiety	0.28**	0.08	-			
4. Depression	0.29**	0.14	0.55***	-		
5. Fatigue	0.64***	0.48***	0.35**	0.29**	-	
6. Pain Interference	0.38***	0.43***	0.21*	0.19*	0.46***	-
7. Pain Intensity	0.35**	0.30**	0.09	0.10	0.38***	0.65***

Note:

* =
p .05;** =
p .01;*** =
p .001

Table 3:

Multivariate Analysis of Independent Chronic Condition Symptoms Variables and the Dependent Variable Treatment Burden

	Unstandardized Beta Coefficients	Standardized Beta Coefficients	T Statistic	P Value
(Constant)	-7.26		-0.86	0.39
Physical Function	-0.06	-0.01	-0.12	0.91
Anxiety	0.07	0.01	0.10	0.92
Depression	0.70	0.11	0.97	0.34
Fatigue	2.66	0.55	4.68	0.00
Pain Interference	0.20	0.05	0.34	0.74
Pain Intensity	0.78	0.10	0.84	0.40

Note: Dependent Variable- Treatment Burden