



## Short Communication

Perceived support from a caregiver's social ties predicts subsequent care-recipient health<sup>☆</sup>Dannielle E. Kelley<sup>a,\*</sup>, Megan A. Lewis<sup>b</sup>, Brian G. Southwell<sup>a,b,c</sup><sup>a</sup> School of Media and Journalism, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA<sup>b</sup> Center for Communication Science, RTI International, Research Triangle Park, NC, USA<sup>c</sup> Social Science Research Institute, Duke University, Durham, NC, USA

## ARTICLE INFO

## Keywords:

Informal caregiving  
Social support  
Social support network  
Patient-caregiver dyads

## ABSTRACT

Most social support research has examined support from an individual patient perspective and does not model the broader social context of support felt by caregivers. Understanding how social support networks may complement healthcare services is critical, considering the aging population, as social support networks may be a valuable resource to offset some of the demands placed on the healthcare system. We sought to identify how caregivers' perceived organizational and interpersonal support from their social support network influences care-recipient health.

We created a dyadic dataset of care-recipient and caregivers from the first two rounds of the National Health and Aging Trends survey (2011, 2012) and the first round of the associated National Study of Caregivers survey (2011). Using structural equation modeling, we explored how caregivers' perceived social support is associated with caregiver confidence to provide care, and is associated with care-recipient health outcomes at two time points. All data were analyzed in 2016.

Social engagement with members from caregivers' social support networks was positively associated with caregiver confidence, and social engagement and confidence were positively associated with care-recipient health at time 1. Social engagement positively predicted patient health at time 2 controlling for time 1. Conversely, use of organizational support negatively predicted care-recipient health at time 2.

Care-recipients experience better health outcomes when caregivers are able to be more engaged with members of their social support network.

As the US population continues to grow older, it is important to understand how various sources of social support affect patient health and wellbeing, as such an understanding may have implications for integrating social support with traditional healthcare services. As outpatient procedures and shorter hospital stays have become standards of practice to make medical care more efficacious (O'Brian and Elias, 2004), patients have become more reliant on members of their social support network to voluntarily provided care without monetary compensation for health-related issues. These people are known as informal caregivers (US Department of Health and Human Services, 1998). Furthermore, about 80% of the aging population receiving care live in private residences, and forty-four million informal caregivers provide care to these patients (Alzheimer's Association, 2016). A recent study estimated that informal caregivers provide about 30 billion hours of care to the aging population (Chari et al., 2015). Thus, understanding of

the system of informal caregiving is necessary in order to identify which factors influence care provision and care-recipient and caregiver health.

Social support has been conceptualized and operationalized in various ways, e.g., description of a multi-person network versus interactions between dyads (Reblin and Uchino, 2008) and measured from the perspective of the care-recipient (DiMatteo, 2004; Uchino, 2006) or caregiver (Lu and Wykle, 2007; Cohen et al., 2015). Social support influences care-recipient and caregiver health through behavioral as well as psychological and emotional processes (DiMatteo, 2004; Uchino et al., 1996). Support can be a negative force, for example, if the support provided is miscalibrated and increases caregiver stress, or if support undermines a caregiver's goals for themselves or their care-recipient (Rook, 2015). Support can also be a protective force if the support provided reduces caregiver stress and burden (Uchino et al., 1996; Rook, 2015). Much caregiver research has focused on negative

<sup>☆</sup> Dannielle E. Kelley has no financial disclosures or conflicts of interest to report. Megan A. Lewis has no financial disclosures or conflicts of interest to report. Brian G. Southwell has no financial disclosures or conflicts of interest to report.

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health outcomes associated with care provision. However, understanding scenarios in which caregiver social support may also be protective could be beneficial as social support is associated with caregiver and care-recipient outcomes (Pakenham et al., 2007; Thorpe et al., 2015; Weaver et al., 2011; Gere et al., 2014). Recent studies have looked at various factors in the context of care-recipient/caregiver dyads (Thorpe et al., 2015; Weaver et al., 2011; Gere et al., 2014). These studies have shown that behavioral concordance, such as smoking behavior (Weaver et al., 2011), are associated with care-recipient and caregiver psychological and emotional health. These studies have provided compelling evidence for the need to understand disease outcomes in a broader context.

In the following analysis, we sought to identify how various organizational (e.g. social workers) and interpersonal (e.g. family) sources within a caregivers' social support network influence care-recipient health. We expect that the extent to which caregivers perceive themselves to be supported as they provide should affect their confidence in their ability to provide care and have an effect on the health of care-recipient as an indirect consequence that underscores the importance of investing in social support systems not only for care-recipient, but also for those who work with them. To test this argument, we constructed a unique dataset using existing data to look at the predictive power of caregiver's perceived social support on the health outcomes of their care-recipients.

## 1. Design and methods

We obtained care-recipient data from the first (2011) and second (2012) waves of the National Health and Aging Trends Study (NHATS) (Kasper and Freedman, 2014). The NHATS is nationally-representative of Medicare beneficiaries age 65 and older and includes a variety of constructs relevant to disease type, management, and consequences collected through in-person interviews conducted by trained research personnel. Although NHATS allows for proxy respondents when participants are unable to respond on their own, for consistency across the sample we focus here on those who provided their own data as our outcome is self-reported health status. Further, of self-responding participants, those reporting Alzheimer's or Dementia (< 5%) were excluded as the experiential and care-provision burdens associated with such cognitive impairment are fundamentally different from other morbidities measured in the NHATS (e.g. diabetes, arthritis, high blood pressure). Caregiver data was obtained from the associated National Study of Caregiving (NSOC), which was collected in 2011 (Kasper et al., 2014). NSOC data were collected via telephone-interviews with trained research personnel. Caregivers were eligible if 1) identified as a caregiver by an NHATS participant, and 2) indicated that they provided unpaid care to the nominating participant. Measures included constructs such as the consequences of caregiving, social support, and caregiver health.

In order to access sensitive NHATS data (e.g. participant age) and NSOC data, we obtained approval to access sensitive data from the NHATS Data Confidentiality Committee. We downloaded and merged public and sensitive datasets for wave 1 ( $N = 8245$ ), wave 2 ( $N = 7075$ ) NHATS participants, and respective caregiver data from NSOC ( $N = 2007$ ). The current study focuses on a subset of patients who responded to both waves 1 and 2), lived in traditional community residences, and identified at least one informal caregiver. Because patients could have up to five caregivers, caregiver data was averaged to avoid over-representing care-recipient with multiple caregivers. We also created an additional variable to capture the number of caregivers for any one particular patient. Our analysis consists of  $N = 780$  care-recipient and their associated caregivers ( $N = 1412$ ). It is important to note that while the NHATS and NSOCs datasets are weighted, we do not use sample weights as the dyads in this analysis are distinguishable (i.e. non-independent). Considering the purpose of data weights is to define the total population, it is unclear how to define the population of care-

recipients and caregivers, especially when a care-recipient has multiple caregivers, and covariation is a function of common influences (e.g. geography) and within-dyad relational aspects that affect thoughts, feelings, and behaviors. Thus, the use of such weights would be misleading and not contribute to the overall goal of understanding the relationships between these variables in order to better understand how to bolster caregiving efforts.

Multiple items comprised our key predictor variables. Four computed variables represented four domains within the broader context of social support, and a single item represented the mediating variable of caregiver confidence.

**Aide finding support** was computed from six-items which asked caregivers to identify who provided aide in caregivers' search for support. These sources included government/community agency, medical care provider or social worker, church/synagogue, employer, self-guided or from a friend, and other sources of support. Caregivers responded yes or no to each of the six sources. Responses to the six sources were summed to capture the total number of sources who aided caregivers' search to find support.

**Use of organized supportive services** was computed by summing the number of organizational supports (respite care, training, and financial help; three items) caregivers indicated having used in the past year.

**Social engagement** was computed from five items which asked caregivers to identify whether or not in the past month they attended religious services, went to a support group, visited with friends or family not living in the same home, participated in club meetings or group activities, or went out for enjoyment.

**Instrumental support** was computed from two items which asked if caregivers received help from friends or family with their own daily activities, such as running errands, and if friends or family helped the caregiver provide care to the care-recipient.

**Caregiver confidence** was measured with one item, "helping [care-recipient] has made you more confident about your abilities," measured on a scale of 1 = *very much* to 3 = *not so much*.

**Care-recipient self-reported health** at wave one and wave two were the primary outcome variables of interest. Self-reported health was measured with the item, "would you say in general your health is..." with 1 = *very good* and 5 = *poor*.

We used structural equation modeling (SEM) to assess how caregivers' perceived organizational and interpersonal supports predict care-recipient health status as reported in the first and second waves of the NHATS survey. We controlled for the severity of care-recipient illness by accounting for the number of chronic illnesses reported by the care-recipient by creating a unique variable to represent the sum of chronic conditions reported). Additional patient demographic characteristics (i.e. patient age, gender, and educational attainment) found to be significantly correlated with the primary outcomes of interest (care-recipient self-reported health in 2011 and 2012) were controlled, as well as caregiver characteristics (i.e. caregiver health status, educational attainment, and marital status) associated with caregiver confidence in ability to provide care (hypothesized to mediate the relationship between caregiver network support and care-recipient health). To select predictors to include in the SEM, we conducted a series of preliminary correlational and multiple regression analyses to exclude non-significant predictors following the method outlined by Bugge et al. (1999). Caregiver age and duration of caregiving, for example, were not associated with caregiver confidence and were thus excluded from the model to enable clearer interpretation of the relationship between various aspects of social support and caregiver confidence and care-recipient self-reported health. Intensity of caregiving was removed as it is highly correlated with numerous care-recipient factors such as health status and number of chronic diseases, thus introducing multicollinearity that would confound the SEM results. We used SEM with maximum likelihood estimation in STATA version 13. To assess model fit, multiple indicators were consulted: chi-square,

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