How Do Kin and Non-Kin Informal Elder Caregiving Jointly Shape Care Recipient Psychological Well-Being?

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Abstract

Informal elder caregiving is an increasingly common social role in the United States. Family members who provide informal care often are overburdened by work demands or raising children, or are geographically separated from ailing kin. In such cases, non-kin instrumental support, such as daily living assistance from neighbors, friends or coworkers, can be important to care outcomes. However, the consequences of non-kin instrumental support for recipient psychological well-being remain unclear. In this study, we will draw on longitudinal data from the National Health and Aging Trends study (NHATS) to better understand longitudinal changes in care recipient well-being as they relate to the source, nature and extent of informal caregiving. By analyzing the caregiving division of labor between kin and non-kin, we will shed light on the well-being of older individuals who informally rely on multiple, unrelated individuals in order to navigate daily mobility, self-care, household, medical care and transportation tasks.
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Informal elder caregiving is becoming an increasingly common social role due to population aging and longer life expectancy (Pavalko 2011). Much research has been directed at understanding the numerous challenges that informal caregivers face, such as balancing work and family commitments, providing adequate help, and avoiding personal distress (Marks et al. 2002; Pavalko and Henderson 2006; Robison et al. 2009). However, relatively little attention has been directed at the changing well-being of care recipients themselves (Kwak et al. 2014; Lin and Wu 2011).

Although research has demonstrated that ongoing levels of care recipient well-being are linked to health conditions or limitations that necessitate care in the first place, networks of social relationships linked to the onset or progression of informal care remain poorly understood as basic factors influencing care recipient well-being (Carpenter and Ducharme 2003; Kwak et al. 2014). Because social integration is a cornerstone of psychological well-being (Cohen and Wills 1985; Thoits 2011), changes in the level or nature of social integration experienced by a care recipient may carry profound consequences for psychological well-being as informal care unfolds, net of recipient health conditions. In addition to reflecting the overall quality of life of those receiving care, psychological well-being shapes the prognosis of health conditions by impacting hope and coping processes (Lin and Wu 2011; Taylor and Stanton 2007), making it broadly relevant to caregiving outcomes.

Social networks of informal care often show a division of labor between kin and non-kin. Prior work has shown that caregiving performed by kin, such as spouses, siblings, or adult children, may contribute positively to care recipient well-being, depending on the quality, extent and nature of instrumental kin help (e.g., Djundeva et al. 2014; Kwak et al. 2014; Wolff and Agree 2004). However, the well-being contribution of non-kin informal help, often provided by neighbors, friends, or coworkers, remains poorly understood. While formal care from social services or health care providers sometimes can lower psychological well-being through unmet needs for support (e.g., Scharlach et al. 2007), a lack of empirical research into the well-being consequences of non-kin informal care leaves room for further inquiry into the topic (Koehly et al. 2015; Wolff and Agree 2004).

In many cases, non-kin help may be viewed as usefully compensating for kin care. That is, kin and non-kin caregivers may work in tandem, by providing different, compensatory forms of assistance with mobility, self-care, household tasks, medical care or transportation, for example. Such hybrid arrangements of kin and non-kin may be advantageous in terms of conveniently covering all necessary forms of instrumental support when work- or parenting-related or geographic barriers keep family members apart. From a care recipient’s perspective, compensatory informal care between kin and non-kin may improve psychological well-being by creating an overall sense of support.

However, if non-kin help occurs in the context of little or no kin care, then non-kin care effectively is a substitute for kin instrumental support, and its meaning and consequences for psychological well-being may be entirely different. This may represent a situation in which a
spouse is deceased or not present and siblings or adult children are geographically distant or overburdened by their prior work or family commitments. In such cases, where kin informal care is limited or perhaps even absent, provision of non-kin care may lower recipient psychological well-being by triggering an acute sense of being left behind or overlooked by loved ones.

Moreover, provision of non-kin help in place of kin care may violate cultural expectations about task-specific provisions by family members or hierarchical deployment of help according to degree of biological relatedness (Cong and Silverstein 2009; Litwak et al. 2003), creating a sense of resentment, anger, loneliness, or not mattering in a care recipient. While cultural and political climates and their consequences for care recipient well-being have been researched in a variety of nations (e.g., filial piety in rural China, Cong and Silverstein 2009; social welfare regimes, Djundeva et al. 2014; Suanet et al. 2012), it still remains unclear how recipient well-being may be culturally influenced by the interplay or balance of non-kin and kin informal care provision in the United States (Silverstein, Gans and Yang 2006). If cultural models of caregiving hold, we expect to observe synergistic effects of kin and non-kin help on recipient well-being, given how kin and non-kin help have meaning not independently but rather in the context of each other. Alternatively, kin and non-kin help may make purely independent contributions to well-being, which would be consistent with classic models of social support and well-being that emphasize the extent or nature of help provided independently of its source (Thoits 2011).

DATA AND MEASURES

In this study, we will draw on longitudinal data from the National Health and Aging Trends study (NHATS) to analyze changes in care recipient well-being as they relate to the source, nature and extent of informal caregiving. NHATS is a nationally representative sample of Medicare beneficiaries aged 65 or older in 2011, conducted by the Bloomberg School of Public Health at Johns Hopkins University. Two follow-ups occurred annually, in 2012 and 2013.

We will focus on how recipient well-being varies with specific divisions of labor between kin and non-kin. In NHATS, the Other Persons file is available for three waves or rounds, and it includes detailed information on instrumental help performed for sample respondents. The nature of help is queried, in terms of mobility, self-care, household tasks, medical care or transportation. Time commitment for each type of help also assessed, as is the relationship type of the person who provides help.

Recipient well-being will be measured using indices of depression (PHQ-2), anxiety (GAD-2) and overall well-being (positive and negative affect, self-realization, self-efficacy, and resilience). Important control variables will include sociodemographic characteristics of caregivers and care recipients, care recipient morbidity and activity limitations, and any utilization of formal care services.

ANALYTIC PLAN

The initial analyses will establish main effects of the source, nature and extent of non-kin informal caregiving on recipient well-being. In additional models, we will then consider how non-kin and kin care statistically interact to shape overall levels of recipient well-being. Taking
advantage of the NHATS follow-up surveys, we will conduct a variety of longitudinal analyses in order to gain better insight into temporal ordering and any potential causal association between informal caregiving division of labor and care recipient well-being. Following prior work, we also will examine whether associations between informal support networks and recipient well-being vary according to gender or specific recipient health conditions.

CONCLUSION

In this study, we will examine psychological well-being among Medicare recipients in the United States who are receiving informal help for a variety of daily activity limitations. We first seek to determine cross-sectional and longitudinal associations between recipient well-being and diverse forms of non-kin instrumental assistance. Then, we will examine whether these associations are contingent on the nature and degree of kin help also being provided.

By understanding care recipient well-being at the intersection of kin and non-kin informal assistance, we are poised to reveal how well-being is influenced by common yet understudied care arrangements in which family members who are struggling to negotiate barriers of work-family balance and geographic distance, for example, cannot be entirely present or available to help a family member in need. Such care arrangements are routinely encountered in today’s society, given the intensification of work-family conflict in a “sandwiched generation” that raises children while caring for parents and also the geographic dispersal of family members.

REFERENCES


