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THREE ESSAYS ON THE CAREGIVING EXPERIENCE: INFORMAL CAREGIVERS' PERCEPTION OF BURDEN AND BENEFITS, THE IMPORTANCE OF SOCIAL SUPPORT, AND HOW CAREGIVER EXPERIENCES MATTER FOR CARE RECIPIENTS

By

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ABSTRACT OF THE DISSERTATION

THREE ESSAYS ON THE CAREGIVING EXPERIENCE: INFORMAL CAREGIVERS' PERCEPTION OF BURDEN AND BENEFITS, THE IMPORTANCE OF SOCIAL SUPPORT, AND HOW CAREGIVER EXPERIENCES MATTER FOR CARE RECIPIENTS

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Dissertation Directors:

Sharon Bzostek (co-chair), Deborah Carr (co-chair)

BACKGROUND: Informal caregiving is a key part of the US long-term care system. A growing number of older adults with chronic and degenerative illnesses live independently in their communities despite difficulties, and informal caregivers are often their only source of assistance. To support caregivers' well-being, facilitate continued caregiving, and enable older adults to age in place, it is important to better understand informal caregivers' experiences.

OBJECTIVES: This dissertation aims to better understand the experiences of providing informal care to US older adults by examining caregivers' perceived burdens and

benefits, how formal and informal social support shape caregivers' experiences, and the implications of these experiences for recipients' mental health.

DATA: I link National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC) data. NHATS is a nationally representative longitudinal study of aging and its social implications. NSOC is its nationally representative companion study, collecting information from persons from whom NHATS older adults indicated receiving assistance. I match NHATS and NSOC respondents to obtain self-reports from both caregiving dyad members.

METHODS: I conduct latent class analysis (LCA), LCA regression analysis, and binary logistic regression analysis on a nationally representative sample of informal caregivers to US older adults, matched to their care recipients. I use multiple imputation to address missing data and adjust all models for conceptually relevant caregiver, care recipient, and care arrangement factors.

RESULTS: I find five distinct caregiving experience types among US informal caregivers, and I identify demographic and socioeconomic factors associated with experience types. Combinations of the presence or absence, level, and dimension of perceived burden and benefits uniquely characterize each subtype. Further, receiving informal support from family and friends is associated with experience types characterized primarily by benefits, rather than burden. Conversely, caregivers reporting formal assistance use are more likely to have burdensome versus beneficial or ambivalent

experiences. Finally, older adults receiving care from persons who perceive caregiving as beneficial are less likely to experience depression three years post-baseline than their counterparts receiving assistance from caregivers reporting only burden. Older adults receiving care from persons reporting benefits, even alongside low to moderate burden, are also less likely to experience anxiety.

CONCLUSIONS: This dissertation shows that caregiving experiences can be ambivalent, but may respond to support provision, and that caregivers' beneficial experiences have positive implications for recipient mental health beyond care provision itself. Given that caregivers who perceive benefits continue on in their roles longer than those perceiving burden, researchers and decision-makers may use this knowledge to facilitate more beneficial caregiving experiences, and to design a long-term care system well-suited to the needs of both caregivers and care recipients.

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DEDICATION

To my grandparents; hvala za vse.

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Chapter 1

Introduction

Informal caregiving, or the unpaid assistance with basic and instrumental activities of daily living that family members, friends, and neighbors provide to older adults, is a key part of the US long-term care system (Lai & Thompson, 2011). In 2015, approximately 34.2 million, or 14% of all Americans, provided informal care to an individual aged 50 or older (AARP, 2015). With those aged 85 years and older being one of the fastest growing segments of the population, and an increasing prevalence of degenerative and chronic illness, the number of individuals living at home with impairments and disabilities is expected to rise further (He, Goodkind, & Kowal, 2016; US Census Bureau, 2016; US Department of Health and Human Services, 2003). Many of these older adults live with health conditions that will require long-term assistance (National Center on Caregiving, 2015). The majority of older individuals with care needs reside in the general community, outside of nursing facilities (Congressional Budget Office, 2013). Over 70% of US older adults live in single family homes—with an additional 20% living in attached or multifamily housing—and almost 90% of them express the desire to continue living independently in their chosen home as long as possible (AARP, 2012).

For more than two thirds of older persons, family caregivers are their only source of assistance, and these caregivers are crucial in enabling older adults to age in place and remain in their communities (Doty, 2015). Informal caregivers provide aging adults with 90% of all long-term care outside facilities (Centers for Disease Control and Prevention,

2011). Although private long-term care insurance may compensate for adult children and other relatives' provision of care to an aging family member, it is often unaffordable to lower socioeconomic status individuals who may need it most; only 7% of older Americans are covered by such insurance, and Medicare does not provide compensation for personal care in the home (Johnson, 2016). As using a combination of informal and formal care declines, exclusive reliance on informal care continues to grow (Federal Interagency Forum on Aging-Related Statistics, 2004).

Informal caregivers are therefore integral to US long-term care, but caregiving can be a financially, physically, and emotionally demanding activity. For many caregivers, the intensive nature of providing care to a family member or friend results in experiencing burden, or the "overall physical, psychological, emotional and financial toll of providing care" (Zarit, Todd, & Zarit, 1986). Many informal caregivers experience stress, worry, uncertainty, and feel overwhelmed with care tasks (Sanders, 2005). They report disturbed sleep and exhaustion (Kruithof, Post, & Visser-Meily, 2015; Robinson, 1983). The demands of caregiving frequently interfere with caregivers' family and work obligations, which may result in financial costs and social isolation (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009). Further, negative interactions with the care recipient may result in a poor caregiver-care recipient relationship (Montgomery, Borgatta, & Borgatta, 2000).

Although it may be experienced as burdensome, caregiving can also generate for the caregiver the feeling of benefits, or the "positive affective or practical return that is experienced as a direct result of becoming a caregiver" (Kramer, 1997: 219). In a nationally representative study, 80% of Canadian caregivers identified at least one

positive outcome from their caregiving (Cohen, Colantonio, & Vernich, 2002). Caregivers report developing a close relationship with the care recipient, having the feeling of companionship, and feeling appreciated (Andren & Elmstahl, 2005; Cohen et al., 2002; Kinney & Stephens, 1989; Lawton et al., 1989; Peacock et al., 2010). They indicate that caregiving provides them with the pleasure of seeing a loved one being cared for, and gives them meaning, a feeling of accomplishment, personal fulfillment, and growth (Andren & Elmstahl, 2005; Cohen et al. 2002; Kinney & Stephens, 1989; Netto, Goh, & Yap, 2009; Quinn, Clare, & Woods, 2012).

Caregiving for older adults can therefore be an ambivalent activity for the caregiver, giving rise to feelings of both benefit and burden (Walker, Pratt, & Eddy, 1995). At one extreme, caregivers can have experiences that are wholly burdensome; at the other extreme, their experiences can be entirely positive. Yet it is likely that few individuals experience such extremes; caregivers more likely perceive both burdens and benefits, and these perceptions may vary in intensity and across domains. Previous caregiving research has neglected to fully take into account ambivalent caregiving experiences, and nuances in benefit and burden intensity and domain when exploring the predictors, experience, and consequences of how caregivers perceive their care work (Kramer, 1997; Zarit, 2012). In this dissertation, I address three shortcomings of our current knowledge on the benefits and burden of informal caregiving to older adults. I outline the gaps and dissertation aims below.

Three Gaps in our Current Understanding of Caregiving Experiences

First, almost 40% of US older adults' informal caregivers describe caregiving as very stressful, with an additional 30% reporting moderate stress. At the same time, over 85% report being satisfied that their loved one is well cared for, and almost 70% say they developed a closer relationship with the recipient as a result of caregiving (AARP, 2015; NSOC, 2016). Although there is increasing recognition that negative and positive aspects of caregiving may co-occur, and some previous theoretical work jointly conceptualized both aspects of caregiving, subjective caregiving burden and benefits are seldom studied alongside each other in empirical studies (Lawton et al., 1989; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Pinquart & Sorensen, 2003; Walker et al., 1995). When researchers do consider both aspects in the same study, they often perform factor analysis to identify separate dimensions of the caregiving experience, resort to collapsing burden and benefits to indices, or use other global measures that mask the multidimensionality of both burden and benefits (Cohen et al., 2002; Kinney, Stephens, Franks, & Norris, 1995; Lin, Fee, & Wu, 2014). The beneficial and burdensome aspects of caregiving are also typically not strongly correlated and have different predictors (Braithwaite, 1996; Kramer, 1997; Lawton et al., 1991). In a regression analysis setting, examining both caregiving burden and benefits results in inconclusive findings (Lawton, Rajagopal, Brody, & Kleban, 1992; Riedel, Fredman, & Landenberg, 1998). These mixed findings may be due to traditional regression analysis and factor analysis techniques not being well-suited for examining the positive and negative aspects of caregiving simultaneously—they cannot account for the variation in the combinations of high and low burden and benefits that caregivers may experience. Further, caregiving studies often rely on convenience or clinical samples that are not representative of population

experiences and that focus on particular care recipient impairments (Abbate et al., 2011; Iecovich, 2011; Jennings et al., 2015; Norton et al., 2009). To better understand the experiences of informal caregivers to older adults, it is necessary to study a nationally representative sample of caregivers, and to take into account their burden and benefit perceptions simultaneously.

Second, over 80% of caregivers seek information about their situation, 40% report they need assistance managing stress, and 15% use respite services in a given year (AARP, 2015). Informal and formal social support are essential factors shaping caregivers' experiences, but research frequently focuses specifically on examining the association between support and burden only (Goldsworthy & Knowles, 2008; Pearlin, Mullan, Semple, & Skaff, 1990; van den Wijngaart, Vernooj-Dassen, & Felling, 2007; Verbakel, Metzelthin, & Kempen, 2016; Yates, Tennstedt, & Chang, 1999). Building on frameworks primarily interested in explaining burden, studies overlook the importance of formal and informal support for potentially engendering benefits (Pearlin et al., 1990). Given that burden and benefits are not mutually exclusive, examining support receipt in relation to positive and negative appraisals separately cannot explain how receiving informal or formal support may alter both appraisal types simultaneously, and for the same caregiver (Andren & Elstahl, 2005; Boerner, Schulz, & Horwitz, 2004; Brown & Brown, 2014; Kramer, 1997). To improve informal caregivers' experiences—especially in cases where it may not be possible to reduce burden, but it is possible to instead increase perceptions of benefits (Toohey, Muralidharan, Medoff, Lucksted, & Dixon, 2016)—it is necessary to understand how formal and informal support act with respect to changing burden and benefit perceptions at the same time.

Third, approximately 20% of older adults experience mental health issues that are not due to normal aging (Centers for Disease Control, 2008). About 15% of community-dwelling older persons exhibit clinically significant depression symptoms, up to 14% meet diagnostic criteria for anxiety, and more live with mental health conditions that remain undiagnosed (Administration on Aging, 2013; Blazer, 2003). A medical issue in its own right, poor mental health also puts older adults at risk of worse physical and social functioning (McGuire, Strine, Okoro, Ahluqalia, & Ford, 2007). Although caregiving experiences have personal dimensions for the caregiver, the caregiving relationship encompasses two parties; little is known about how receiving care from caregivers with different experiences is linked to recipient well-being (Roberto, Blieszner, & Allen, 2006; Lyons, Zarit, Sayer, & Whitlatch, 2002). Several studies offer initial support for the assertion that caregivers' perceptions and recipient health may be linked (Buck, Mogle, Riegel, McMillan, & Bakitas, 2015; Ejem, Drentea, & Clay, 2014; Gaugler et al., 2000; Gaugler, Kane, Kane, Clay, & Newcomer, 2003; Trivedi, Piette, Fihn, & Edelman, 2012). However, these studies often rely on proxy reports and do not link caregiver and recipient data, and only examine the association between a limited subset of caregiver factors and recipient well-being. They further do not comprehensively evaluate the importance of caregivers' burden and benefit perceptions for recipient outcomes. Most existing studies linking caregiver perceptions and recipient health are also cross-sectional and cannot establish whether strained caregivers contribute to negative recipient outcomes, or whether recipient health conditions add to greater burden (Ejem et al., 2014; Iecovich, 2015; Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2016). To better understand whether informal caregivers' experiences have implications

for recipient health beyond care provision itself, it is necessary to obtain reports from both caregivers and recipients, and to comprehensively evaluate the importance of caregiver burden and benefit perceptions for recipient health over time.

Analytic Chapters

Three aims addressing the above shortcomings and advancing our current understanding of informal caregiving for older adults guide my dissertation.

In the first analytic chapter, I use the caregiving appraisal conceptual framework and employ latent class analysis on a nationally representative sample of informal caregivers to US older adults to better understand how caregivers' burden and benefit perceptions simultaneously shape caregiving experiences (Collins & Lanza, 2010). I match caregivers to their recipients to obtain reports from both members of the caregiving dyad. Using reports from both caregivers and care recipients is an improvement over previous research, which often relies on one reporter who provides proxy reports for the other dyad member. I develop distinguishable caregiving experience subtypes; show how subjective burden and benefits uniquely characterize each experience type, and how prevalent the types are; and I identify caregiver, recipient, and care arrangement factors that predict experience types. This chapter highlights the multiplicity and potential ambivalence of perceptions, while providing a caregiving experience assessment for a population-based, rather than clinically select, informal caregiver sample (Norton et al., 2009). Further, identifying predictors of distinctive combinations of burdensome and beneficial experiences can help recognize groups of informal caregivers most in need of assistance. Given the increasing reliance of the US

long-term care on informal caregivers, it is important to know which groups are at risk of poor experiences to provide appropriate support (Federal Interagency Forum on Aging-Related Statistics, 2004).

In the second analytic chapter, I use the same nationally representative sample of informal caregivers to US older adults matched to their recipients and examine how receiving support shapes caregivers' experiences. I modify the caregiving appraisal framework and use the five experience types developed in the first analytic chapter to recognize ambivalent perceptions. I conduct latent class regression analysis to assess how receiving informal or formal social support is associated with caregivers' experience types (that is, with burden and benefit perceptions simultaneously). I further explore whether receiving social support buffers the association between stressors and caregiving experiences, or whether support operates independently of stress levels. Understanding how particular support types act with respect to burden and benefit perceptions at the same time may inform the design of more effective caregiver assistance programs (Folkman et al., 1991; Toohey et al., 2016). Identifying and helping caregivers use support resources effectively to decrease burden perceptions and increase benefits is particularly important because caregiver trajectories are long, and can become more difficult over time (Gitlin & Schultz, 2012; Schulz & Tompkins, 2010). Fourty-four percent of US informal caregivers provide between one and four years of assistance, and 50% continue caregiving for over four years (Wolff, Spillman, Freedman, & Kasper, 2017). Caregiving over time typically includes an increasing amount of tasks and responsibilities, from sporadic help with instrumental tasks such as shopping to more demanding personal care such as bathing, and to intensive end-of-life care. It is thus

essential to provide caregivers with skills and assistance that could mitigate burden and increase benefits perceptions; caregivers who experience benefits have better mental and physical health, and continue on in their role longer than those who do not perceive the experience positively (Cohen et al., 2002; Cohen, Gold, Shulman, & Zucchero, 1994; Pinquart & Sorensen, 2003).

Finally, in the third analytic chapter, I explore the association between caregivers' experience types and care recipient health. I use the modified caregiving stress appraisal framework and employ binary logistic regression analysis on two waves of data for a sample of caregivers matched to recipients. I assess the role of caregivers' experience types in recipients' risk of depression and anxiety, and I examine caregiver mental health and recipient unmet care need as potentially mediating factors. Contrary to existing studies that link limited caregiver characteristics to recipient outcomes, I evaluate the importance of experiences comprehensively—taking into account both burden and benefit perceptions—and prospectively. Using prospective, longitudinal data allows me to incorporate associations between caregiver experiences and recipient health that may take time to develop, and accounts for potential problems of temporal ordering in the relationship between caregivers' experiences and recipient health (Bolger, DeLongis, Kessler, & Schilling, 1989; Krause & Shaw, 2002; McEwan, 1998). Given that caregivers are likely to experience burden even alongside benefits and to develop poor mental and physical health, it is important to know whether such adverse factors have implications for recipient health that may be at odds with the health-improving and health-maintaining aims of caregiving itself (Capistrant, 2016; Cuijpers, 2005; Pinquart & Sorensen, 2003, 2007).

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Chapter 2

The Burden and Benefits of Caregiving: A Latent Class Analysis

Abstract

Informal caregiving to older adults is a key part of the US long-term care system. Caregiving experiences consist of both burden and benefits, and scholars have begun to jointly conceptualize both aspects (Kramer, 1997). However, informal caregiving experiences are not well understood because subjective caregiving burden and benefits are typically examined separately in empirical studies. Traditional quantitative analysis techniques yield inconclusive findings about their co-occurrence, and approaches that consider each dimension independently cannot account for the variation in the combinations of high and low burden and benefits that caregivers may experience. I link the 2015 National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC) data and conduct latent class analysis to explore how caregiving benefits and burden simultaneously shape the experience of caregiving to older adults. Using a modified caregiving stress appraisal framework, I identify five distinguishable subtypes of caregiving experiences within a nationally representative sample of US informal caregivers to older persons. I explore how prevalent the groups are, how the experience of subjective caregiving burden and caregiving benefits uniquely characterizes each group, and examine which structural and contextual factors are associated with a each of five types of informal caregivers' experiences of caregiving. Doing so, I identify subgroups of caregivers that may benefit most from caregiver support services. I further find that the experiences of burden and benefits may co-exist. Thus, in

cases where it may not be possible to reduce burden, caregiver assistance programs may instead focus on increasing the perception of benefits. Finally, I discuss study limitations and the theoretical, methodological, and policy-relevant implications of the study findings.

Keywords: informal caregiving, caregiving burden, caregiving benefits, latent class analysis, NSOC

Introduction

Informal caregivers to older adults frequently experience burden (Vitaliano, Russo, Young, Becker, & Maiuro, 1991; Zarit, Reever, & Bach-Peterson, 1980), also conceptualized as caregiver strain, stress, and costs (Cohen, Kamarck, & Mermelstein, 1983; Hunt, 2003; Robinson, 1983). Caregiver burden encompasses the physical, psychological, emotional, relational, social, and financial problems they encounter as a result of informal caregiving (George & Gwyther, 1986; Montgomery, Gonyea, & Hooyman, 1985). At the same time, a high proportion of informal caregivers to older adults report experiencing benefits from their role (Andren & Elmstahl, 2005; Farran, Miller, Kaufman, & Davis, 1997). Caregiving benefits, variously conceptualized as caregiving satisfaction, gains, rewards, or uplifts, describe the positive aspects of the experience (Braithwaite, 1996; Cohen, Colantonio, & Vernich, 2002; Tarlow et al., 2004; Kinney & Stephens, 1989; Kramer, 1997; Pearlin, Mullan, Semple, & Skaff, 1990; Pinquart & Sorensen, 2003; Raschick & Ingersoll-Dayton, 2004; Yap, Luo, Ng, Chionh, Lim, & Gob, 2010).

Caregiving for older adults can therefore be a rewarding, distressing, or ambivalent activity for the caregiver, generating both the feelings of benefit and burden for some caregivers (Walker, Pratt, & Eddy, 1995). Theoretical efforts such as the two-factor model of caregiving appraisal unite both facets of the caregiving experience (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991). The two-factor model suggests that burden and benefits are not mutually exclusive (Andren & Elstahl, 2005; Boerner, Schulz, & Horwitz, 2004; Brown & Brown, 2014; Kramer, 1997). Instead, the negative and positive aspects stem from the

perception of the caregiving situation and represent two separate dimensions of the same experience (Lazarus & Folkman, 1984). Despite theoretical efforts to jointly conceptualize both aspects, due to the literature's past focus on caregiving burden, subjective caregiving burden and benefits are still seldom studied simultaneously in empirical studies (Pinquart & Sorensen, 2003; Walker et al., 1995).

Even when research does examine both caregiving burden and benefits at the same time, traditional analytic approaches do not enable explorations of the nuanced and diverse ways in which the former co-occur. Current research uses factor analysis to identify separate dimensions of the experience or resorts to collapsing burden and benefits to single indices (Kinney, Stephens, Franks, & Norris, 1995; Lin, Fee, & Wu, 2014). Such global measures mask the multidimensionality of both caregiving benefits and burden and they do not consider the relative intensity of burden and benefits that caregivers may experience concurrently (Cohen et al., 2002). Further, the handful of studies examining both caregiving burden and benefits using standard regression analyses results in inconclusive findings. Although some studies suggest that perceiving greater caregiving burden is associated with also perceiving fewer caregiving benefits, others report that greater caregiving burden is associated with greater benefits (Lawton, Rajagopal, Brody, & Kleban, 1992; Riedel, Fredman, & Landenberg, 1998). The two aspects of caregiving also typically have different predictors and are correlated weakly or modestly, with zero-order correlations ranging from about 0.08 to about 0.35 (Braithwaite, 1996; Kinney & Stephens, 1989; Kramer, 1997; Lawton et al., 1991; Rapp & Chao, 2000). These mixed findings may be due to traditional regression analysis and factor analysis techniques not being well-suited for examining the positive and negative

aspects of caregiving simultaneously—they cannot account for the variation in the combinations of high and low burden and benefits that caregivers may experience.

Latent class analysis is an approach that can better inform our understanding of the experience of informal caregiving to older adults. As opposed to variable-centered methods like factor and regression analysis, which emphasize associations between variables that apply across a population, latent class analysis is person-centered (Collins & Lanza, 2010). Person-centered statistical analyses are used to study individuals' patterns and aim to identify subgroups of persons based on their pattern similarity (Bergman & Magnusson, 1997; Bergman, Magnusson, & El-Khouri, 2003). Latent class analysis uses observed categorical indicators of individual characteristics to identify homogenous subgroups, allowing for an investigation of caregiving experience types. Whereas techniques such as regression analysis or variable interactions focus on relative levels and project hypothetical combinations of burden and benefits, latent class analysis can uncover groups with distinctive configurations of caregiving experiences on the spectrum from burdensome to beneficial. A latent class-derived typology reflects underlying groupings of caregiving experiences that reflects the population experience. Further, latent classes are better able to account for both the level and types of burden and benefits that caregivers experience, a task that would be complex and require multiple comparisons in the case of interactions.

I perform latent class and latent class regression analysis after linking 2015 National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC) data, allowing me to access measures obtained from both the caregiver and the care recipient. Prior research frequently relies on measures obtained from a single

reporter, introducing potential bias due to one informant's underlying affect or viewpoint; using dyadic data, I am able to incorporate each party's self-reports. I use a nationally representative sample of informal caregivers to adults over the age of 65 to better understand the heterogeneity of experiences in informal caregiving to older persons. I consider the presence or absence, level, and type of subjective burden and benefits that caregivers report. I pursue two goals. First, I aim to identify distinguishable subtypes of the caregiving experience within a nationally representative sample of US informal caregivers to older adults. As part of this goal, I aim to understand how the perception of caregiving burden and caregiving benefits uniquely characterizes each one of these groups, and to estimate the prevalence of each caregiver group in the population. Second, I aim to identify the theoretically and practically relevant factors that are associated with each subtype of informal caregivers' experience of caregiving. In particular, I examine the extent to which structural and contextual factors (caregiver race, socioeconomic status, gender, age, and mental health) account for the association between caregiving stressors, their appraisal, and caregiving experiences.

Understanding how perceived negative and positive experiences of caregiving may co-exist and identifying profiles of subjective caregiving experience is methodologically but also theoretically and practically relevant. Knowing which combinations of subjective caregiving burden and benefits informal caregivers experience (only burden or benefits, burden and benefits simultaneously, particular types of burden or benefits), and how commonly each group of experiences occurs, contributes to the debates about the co-existence of both aspects. For example, although caregivers may perceive emotional or cognitive benefits from caregiving—feeling satisfied for

providing care to their loved one, or developing their skills in performing tasks successfully—they may simultaneously experience interpersonal burden if the recipient suffers from symptoms of dementia, or that they feel financially burdened due to caregiving interfering with their labor force participation. Investigating the coexistence of burden and benefits thus shows whether and in what pattern caregiving benefits and burden may stem from the caregiver's appraisal of the same situation (Kinney & Stephens, 1989; Lawton et al., 1989; Lawton et al., 1991). Further, identifying the groups and contextual factors associated with poor versus beneficial caregiving experiences may inform the design of interventions and policies aimed at improving caregiver satisfaction. Caregivers who perceive benefits have better mental and physical health, and continue on in their caregiving role longer than those who do not perceive the experience as beneficial (Cohen et al., 2002; Cohen, Gold, Shulman, & Zucchero, 1994; Pinquart & Sorensen, 2003). To better understand the heterogeneity of informal caregiving to older adults and to improve caregivers' experience, it is therefore important to examine the ways in which caregiving burden and caregiving benefits coexist.

Theoretical Framework

I use a modified stress appraisal conceptual model to examine experiences of subjective burden and benefits among caregivers of older adults (Verbakel et al., 2016; Yates, Tennstedt, & Chang, 1999). The stress appraisal framework combines the caregiving stress process model with the two-factor model of caregiving appraisal (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Pearlin et al., 1990b). The resulting stress appraisal conceptual model

suggests that primary stressors, primary appraisal, and structural/contextual factors shape secondary appraisal (Verbakel et al., 2016; Yates, et al., 1999). Secondary appraisal, or the subjective experience of caregiving, is commonly operationalized as caregiver burden in the model. However, the subjective experience of caregiving can be negative or positive (Lawton et al., 1989). To acknowledge this duality of experience, contrary to previous research, I explicitly conceptualize and operationalize secondary appraisal as both negative and positive (Verbakel et al., 2016; Yates, et al., 1999). Thus, in this framework, the negative and positive secondary appraisal of caregiving—caregiving burden and benefits, respectively—stem from the perception and evaluation of the caregiving situation, and represent two separate dimensions of the same experience (Lazarus & Folkman, 1984).

Caregiver burden refers to "the consequences of the activities involved with providing necessary direct care to a relative or friend that result in observable and perceived costs to the caregiver" (Hunt, 2003: 28). Qualitative studies and measurement instruments identify common negative caregiving experiences across several domains (Kruithof, Post, & Visser-Meily, 2015; Montgomery, Stull, & Borgatta, 1985; Robinson, 1983; Sanders, 2005; Zarit et al., 1980). In the emotional domain, informal caregivers report worry, uncertainty, and feeling overwhelmed with their tasks (Sanders, 2005). In the social domain, the demands of caregiving frequently interfere with family and work obligations (Lawton et al., 1989). In the interpersonal domain, upsetting care recipient behavior may result in negative interactions and a strained relationship (Montgomery, Borgatta, & Borgatta, 2000). In the physical domain, caregivers frequently experience disturbed sleep and exhaustion (Kruithof et al., 2015; Robinson, 1983). In the financial

domain, caregivers often contribute to environmental adjustments or purchasing assistive devices, and may lose potential income due to fewer work hours (Brown & Brown, 2014). Subjective caregiver burden is therefore a multidimensional construct that reflects the negative appraisal of the objective caregiving situation and encompasses the perceived negative consequences of caregiving. Caregivers may be more or less likely to perceive stressors in particular domains depending on their access to resources.

Conversely, caregiving benefits stem from a positive appraisal of the caregiving situation and refer to "any positive affective or practical return that is experienced as a direct result of becoming a caregiver" (Kramer, 1997: 219). Similarly to burden, benefits are multidimensional and can be interpersonal, emotional, cognitive, and behavioral (Cheng, Mak, Lau, Ng, & Lam, 2016; Carbonneau, Caron, & Desrosiers, 2010). In the interpersonal domain, caregivers may report developing a close relationship with the care recipient, having the feeling of companionship, and feeling appreciated (Andren & Elmstahl, 2005; Cohen et al., 2002; Kinney & Stephens, 1989; Lawton et al., 1989; Peacock et al., 2010). In the emotional domain, they may report the pleasure of seeing a loved one being cared for, meaning, a feeling of accomplishment, and personal fulfillment and growth (Andren & Elmstahl, 2005; Cohen et al., 2002; Kinney & Stephens, 1989; Netto, Goh, & Yap, 2009; Quinn, Clare, & Woods, 2012). In the behavioral domain, caregivers may report that caregiving allows them to develop new coping and caring skills, competencies, and abilities (Andren & Elmstahl, 2005; Carbonneau et al., 2010; Cheng et al., 2016; Peacock et al., 2010). Subjective caregiving benefits are therefore a multidimensional construct that reflect a caregiver's positive

appraisal of the caregiving situation, and they encompass the perceived positive consequences of caregiving (Brown & Brown, 2014; Zarit, 2012).

Primary stressors, primary appraisal, and structural or contextual factors shape the subjective experience of caregiving burden and benefits (Verbakel et al., 2016; Yates, et al., 1999). Primary stressors refer to distinct factors that give rise to the need for caregiving, such as care recipient mental health (depression and anxiety symptoms), physical health (number of medical diagnoses), and subjective (self-rated) health. Caregivers assisting recipients with mental health may be providing qualitatively and quantitatively different types of care than those caregivers assisting older persons with issues resulting from physical ailments like high blood pressure or osteoporosis; while the former type of caregiving may give rise to higher emotional burden, the latter may give rise to more physical burden, and they may each shape the perception of benefits differently.

Primary appraisal refers to the care given in response to primary stressors, such as the number of hours of help provided and the type of care provided (help with basic activities of daily living [ADL], instrumental activities of daily living [IADL], and help with medical tasks). Primary appraisal factors may thus partly explain the association between primary stressors and caregiving experiences. Further, both primary stressors and primary appraisal are linked to structural/contextual factors of caregiving. Contextual factors include indicators of structural inequality associated with the distribution of resources, which shape individuals' circumstances and response to stressors (Pearlin et al., 1990). Past research paid little attention to contextual factors shaping secondary appraisal (Lawton et al., 1991; Yates et al., 1999). However, several key

structural/contextual factors may partly account for the relationship between primary stressors, primary appraisal, and the caregiving experience, and may themselves shape caregiving appraisals.

Key structural/contextual factors

Caregiver race, socioeconomic status (SES), gender, age, and mental health are key factors that are associated with primary stressors and appraisal, and that may shape the subjective experience of caregiving (Pinquart & Sorensen, 2003; 2005; 2006). They may also help to explain the relationship between primary stressors, primary appraisal, and the caregiving experience.

Caregiver race and SES. Caregiver race and SES (education and employment status) are distinct but related constructs associated with care recipient health and use of assistance available to caregivers. In the US context, race is inextricably linked with SES, access to resources, and health outcomes through systems of racial discrimination (Reskin, 2012; Williams & Collins, 2995). Racial/ethnic minority individuals, as well as individuals of low SES, are more likely to experience health conditions earlier in life compared to their white or high SES counterparts, and minority and low SES caregivers may be more likely to provide care that is long-term and intensive (Evercare and National Alliance for Caregiving, 2008). Compared to white caregivers, Hispanic and Black caregivers are more likely to caring for recipients with multiple disabilities, to provide more hours of care, and to report poor health outcomes due to caregiving (Aranda & Knight, 1997; Pinquart & Sorensen, 2005).

Racial/ethnic minority and low SES individuals may also have fewer financial resources to access services and assistance, and they may encounter additional linguistic or educational obstacles to service use that are associated with low SES and discrimination (Aranda & Knight, 1997; Knight, Silverstein, & McCallum, 2000; Pinquart & Sorensen, 2005). For example, racial/ethnic minority caregivers are less likely to use nursing homes and home care arrangements to mitigate the demands of caregiving (Angel et al., 2014; Herrera, Lee, Palos, & Torres-Vigil, 2008). Racial/ethnic minority caregivers and low SES caregivers also report higher caregiving burden, more stress, and poorer personal outcomes than caregivers with more resources (Hong & Harrington, 2016; Koerner, Shirai, & Kenyon, 2010). Conversely, professional caregiving staff of high subjective SES report more caregiving benefits and lower burnout than caregiving staff of low subjective SES (Ayalon, 2008). Race and socioeconomic are thus indicators of structural inequalities that are associated with primary stressors and primary appraisal, and that may shape caregiving experiences in a similar way: racial/ethnic minority caregivers and caregivers of low SES may be more likely to care for recipients in poorer health, and to encounter barriers to assistance with caregiving, thus appraising caregiving as more burdensome and perceiving fewer caregiving benefits than their white or high SES counterparts.

Caregiver gender. The caregiving role is gendered, with women more likely to be socialized into caregiving than men. Women are more likely than men to become primary caregivers and to perform multiple caregiving tasks, to offer intensive assistance with tasks such as personal care, and to report poor health outcomes as a result of caregiving (Miller & Cafasso, 1992; Pinquart & Sorensen, 2006). Compared to men, they may

therefore be less likely to appraise caregiving as beneficial and more likely to experience burden. Women may also be more likely to accept caregiving tasks as their duty, while the role may not be voluntary as frequently for men (Neufeld & Harrison, 1998; Williams, Giddings, Bellamy, & Gott, 2017). At the same time, men may use more problem-focused coping behaviors, and ask for and receive more support for their caregiving activities than women (Kramer & Thompson, 2005). It is therefore also possible that men may perceive caregiving as beneficial more often than their female counterparts.

Caregiver age. At different life stages, caregivers may be balancing other competing demands with caregiving (Stone & Short, 1990). Compared to their younger counterparts, middle-aged caregivers are likely to be the recipient's adult children, who are high in the hierarchy of care and frequently called upon to provide care (Cantor, 1979; Penning, 1990). However, adult children are also likely to be active participants in the labor force who have obligations toward their own families (Longacre, Valdmanis, Handorf, & Fang, 2016). Older adult caregivers—likely to be spouses or partners—also frequently provide care, but they may be in poor health or require care themselves (Wharton & Zivin, 2017). With increasing age, caregivers may therefore encounter more stressors, provide higher levels of assistance, and appraise caregiving more negatively. Caregiver age may be further confounded with the relationship to the recipient and with recipient coresidence, as older caregivers are likely to be persons caring for their spouses (Johnson & Wiener, 2006; Wolff & Kasper, 2006).

Caregiver mental health. The primary stressors or demands of caregiving may worsen caregiver mental health and shape caregiving appraisal (Pinquart & Sorensen,

2003). Caregivers are more likely than non-caregivers to experience symptoms of depression and anxiety (Cooper, Balamurali, & Livingston, 2007; Cuijpers, 2005; Lu et al., 2007; MacNeil et al., 2009). Studies comparing caregivers and non-caregivers who do not initially differ in mental health status suggest that more caregivers than matched non-caregivers develop symptoms of depression and anxiety during a given timeframe (Dura, Stukenbert, & Kiecolt-Glaser, 1990; 1991). Caregiver anxiety should be considered separately from depression in studies of caregiving (Cooper et al. 2007), as these two conditions (depression and anxiety) are related but distinct: most caregivers with depression also develop anxiety, but primarily anxious caregivers less frequently also develop depression (Mahoney, Regan, Katona, & Livingston, 2005). Caregivers in poor mental health may rely primarily on negative information in their evaluations of their caregiving experiences, and caregiver depressive and anxious symptomatology is associated with reports of caregiving burden (Covinsky et al., 2003; Clark & Diamond, 2010; Vilchinsky et al., 2015; Epstein-Lubow, Davis, Miller, & Tremont, 2008). Thus, caregivers in poor mental health may be more likely than other caregivers to appraise their caregiving experience negatively and to perceive low caregiving benefits.

Confounding factors

Relationship to the care recipient, coresidence with the recipient, the duration of caregiving, the number of other caregivers present, and care recipient characteristics may confound and partly account for the relationships among primary stressors, primary appraisal, contextual factors, and caregiving experiences.

Relationship to care recipient. The caregiver's relationship to the care recipient is correlated with caregiver age, and may indicate the type and intensity of caregiving tasks, shape role identities and expectations, and may also be associated with caregiving appraisal. Spouses and adult children are most likely to assume the caregiving role, and they provide more intensive care than other caregivers (Johnson & Wiener, 2006; Wolff & Kasper, 2006). Although both groups of close family are likely to experience a sense of obligation and reciprocity, spouse caregivers are more likely than adult children to be older, to live with the care recipient, to report poor mental health outcomes, and to experience physical and financial burden (Hoyert & Seltzer, 1992; Lowenstein & Gilbar, 2000; Oldenkamp et al., 2016; Penning & Wu, 2015). Further, more women than men provide care to their spouse or parent, and adult children may also have competing obligations from other family and work roles (Pinquart & Sorensen, 2011). Compared to spouse or adult child caregivers, distant relatives and nonrelatives (such as in-laws, friends, or neighbors) are typically lower in the care hierarchy (Cantor, 1979; Penning, 1990). They may feel less obliged to provide care, and may therefore be more likely to take on the caregiving role voluntarily (Barber & Pasley, 1994; del-Pino-Casado, Frias-Osuna, & Palomino-Moral, 2011; Lee, Yon, & Kropf, 2007).

Caregiver coresidence. Like relationship type, caregiver coresidence is also associated with caregiver age. Coresident caregivers may provide care that is quantitatively and qualitatively different from that of caregivers who are not members of the care recipient's household. Coresident caregivers are also more likely to be spouses or adult children, who provide the highest levels of care (Johnson & Wiener, 2006; Wolff & Kasper, 2006). Accordingly, they are more likely than nonresident caregivers to report

negative outcomes such as isolation and poor mental health (Robison et al., 2009; Schulze & Rossler, 2005).

Number of caregivers. Secondary caregivers may act as a coping resource for the primary caregiver, sharing part of the latter's responsibilities (Barbosa et al., 2010). They may reduce the primary caregiver's burden, and persons who are not sole caregivers may thus appraise caregiving as less burdensome and more beneficial than those who are their recipient's only caregiver. Alternatively, the presence of secondary caregivers may indicate the recipient's greater need for care, or may give rise to interpersonal tensions and difficulties in making joint decisions or coordinating the recipient's care (Lou et al., 2013). Thus, the presence of other caregivers may alternatively indicate higher burden on the part of the primary caregiver.

Duration of caregiving. Caregivers may appraise their experience and respond to primary stressors differently depending on the duration of theirrole. Care trajectories are typically long; after an adjustment period, new caregivers may adapt to their role, strengthen their relationship with the recipient, and potentially begin to appraise caregiving as more beneficial than burdensome (Pinquart & Sorensen, 2003). Alternatively, as care spells? often transition from sporadic help to personal and end-of-life care, and especially if the recipient's health progressively declines, caregivers may appraise caregiving as increasingly burdensome over time (Gitlin & Schultz, 2012).

Additionally, care recipients and caregivers may have similar demographic and socioeconomic characteristics or live in a shared environment, and care recipient factors may explain part of the association between primary stressors, primary appraisal, contextual factors, and caregiving experiences. I follow prior research and control for

care recipient gender, race, age, and socioeconomic status in examining the experience of informal caregiving to older adults (Lawton et al., 1989; Pearlin et al., 1990; Pinquart & Sorensen, 2003; Yates et al., 1999). These factors may reduce the strength of association between primary stressors, primary appraisal, structural/contextual factors, and caregiving experience types.

Data and Method

Data

To evaluate the extent to which the experience of caregiving is distinguished by burden, benefits, or a combination of both, I use the 2015 wave of the longitudinal US National Health and Aging Trends Study (NHATS) (Kasper & Freedman, 2016). First started in 2011 and followed by annual re-interviews, NHATS is a nationally representative survey designed to monitor aging changes by subpopulations, and to explore the social implications of aging transitions. Using computer-assisted personal interviewing, it collects information on a stratified three-stage sample of Medicare recipients over the age of 65, who are either living in residential care or community-dwelling; 96% of all U.S. older adults are enrolled in Medicare. The survey oversamples black older adults and older adults over the age of 85. At baseline, the response rate was 71% (Montaquila, Freedman, Edwards, & Kasper, 2012).

I link the 2015 wave of NHATS with data from the most recent National Study of Caregiving (NSOC) supplement (Kasper, Freedman, & Spillman, 2016). NSOC is a nationally representative NHATS companion study of individuals from whom NHATS sample persons indicated receiving help with self-care, mobility, or household activities.

Through telephone interviews, the NSOC collects data about the role of family members and friends in providing care to the aging population, including the activities for which help was provided, duration and intensity of help, effects on helpers of providing assistance, and support services used by helpers. The 2015 wave response rate was 67.2%; the main reasons for non-response were…

Sample

The sample for my analyses consists of 2,204 informal (i.e., not associated with the formal service system) caregivers to US older adults. I use the analytic weights available in NSOC to account for differential probabilities of selection and nonresponse bias, making the sample representative of US informal caregivers to older adults over the age of 65.[1] I retain cases with missing data on latent class measurement items after performing sensitivity analyses to ensure the final latent class solution remains robust. I employ multiple imputation for cases with missing data on latent class covariates, and describe the procedure in more detail in the analytic plan section. Table 2.1 shows weighted sample descriptive statistics.

Measures

Latent Variable: Perceived Caregiving Experience

[1] I initially conduct all analyses only for a sample of caregivers providing care for community-dwelling older adults. However, including informal caregivers providing assistance to recipients in residential care such as retirement community (n=275) and nursing home (n=58), who may be receiving additional care, does not change the results obtained. Further, control variables for care recipient residential status are not statistically significantly associated with caregiver experience types. I therefore show analyses and results using the full sample of NSOC caregivers.

To construct the subjective caregiving experience latent class measurement model, I use indicators of caregiving burden and indicators of caregiving benefits available in NSOC. These indicators have been used in previous caregiving studies (Kang, 2006; Lin, Fee, & Wu, 2012; Scharlach, Li, & Dalvi, 2006; Ingersoll-Dayton & Raschick, 2004). All measures are dummy-coded with a value of 1 indicating agreement and 0 indicating disagreement. Four items (regarding interpersonal burden and benefits) were not originally measured dichotomously, and I recode these items by collapsing the original response categories of "a lot" and "some" to agreement (=1), and "not at all" and "a little" to indicating otherwise (=0).

Caregiving burden. I measure perceived caregiving burden using 15 caregiver-reported items. Four items measure emotional burden (agreement with the statements that due to caregiving: "you don't have time for yourself;" "you have more things to do than you can handle;" "as soon as you get a routine going, the care recipient needs change;" and that "helping is emotionally difficult for you"). Two items measure interpersonal burden (agreement with the statements "care recipient gets on your nerves," and "care recipient argues with you"). Seven items measure social burden (agreement with the statements that helping the care recipient kept the caregiver from: "visiting in person with friends and family not living with you;" "attending religious services;" "participating in club meetings or group activities;" "going out for enjoyment;" "doing volunteer work;" "looking after another person who cannot care for themselves;" and "working for pay or at a business you own"). Two items measure physical burden (agreement with the statements that as a result of caregiving, "you're exhausted when you go to bed at night," and that helping the care recipient is "physically difficult for you"). One item measures

financial burden (agreement with the statement that helping the care recipient is "financially difficult for you").

Caregiving benefits. I measure perceived caregiving benefits using six caregiver-reported items. One item measures emotional benefits (agreement with the statement that helping the care recipient "gives you satisfaction that they are well cared for"). Three items measure interpersonal benefits (agreement with the statements that helping the care recipient "brought you closer to them," that the caregiver "enjoys being with the care recipient," and that the care recipient "appreciates what you do for them"). Two items measure behavioral/cognitive benefits (agreement with the statements that helping the care recipient "made you more confident in your abilities," and "taught you how to deal with difficult situations").

Table 2.2 shows the items used to operationalize subjective caregiving burden and benefits, and the weighted sample percentages of caregivers endorsing each indicator.

Key Independent Variables and Control Variables

In line with the caregiving stress appraisal theoretical framework, I include primary stressors, primary appraisal, and structural/contextual factors as predictors of caregivers' caregiving experience latent class membership.

Primary stressors.

Care recipient self-rated health is a continuous measure of the care recipient's self-reported health, ranging from poor (0) to excellent (4).

Care recipient depressive symptoms (measured using PHQ-2) and care recipient anxiety symptoms (measured using GAD-2) are continuous measures of care recipient-reported depressive and anxious symptomatology, with higher scores indicating greater risk for depression or anxiety, respectively. I construct the measures and scores using validated two-item depression and anxiety screeners that consist of two questions reflecting DSM-V core diagnostic criteria (Lowe et al., 2010). Care recipient depression symptoms and care recipient anxiety symptoms are correlated at 0.43. I include each measure separately.

I measure care recipient's medical diagnoses with a dichotomous variable indicating whether the care recipient reported zero to two medical diagnoses (=0) or whether the recipient reported three or more health conditions diagnosed by a physician (=1). The measure is based on individual items asking the care recipient whether they were ever diagnosed with a heart attack, heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, Dementia or Alzheimer's, cancer, or broken or fractured hip or other bones.[2]

Primary appraisal.[3]

Hours per month spent in caregiving is a categorical variable indicating whether the caregiver reported spending fewer than 20 hours (reference), 21 to 63 hours, or 64

[2] Sensitivity analyses including hours per month caregiving as a continuous variable suggest that the measure does not have a linear association with the dependent variable. I therefore include the variable as categorical.

[3] The four primary appraisal measures are correlated at $p<0.05$ level, with the Pearson correlation coefficient ranging from 0.36 (medical and ADL assistance) to 0.58 (number of hours spent and IADL assistance).

hours or more providing informal care to the recipient in the past month. Cut-off points are based on terciles of the response distribution.[4]

Frequency of help with activities of daily living (ADL) is a continuous measure of how often the caregiver reported assisting the care recipient with activities of daily life. It is a mean score composed of two items (alpha = 0.77) asking the caregiver how frequently they help the recipient with "personal care such as eating, showering or bathing, dressing or grooming, or using the toilet," and how often they help the recipient with "getting around, that is, getting in and out of bed, getting around inside their home, or leaving their home to go outside." The original five-category response scale ranges from "never" to "every day."

Frequency of help with instrumental activities of daily living (IADL) is a continuous measure of how often the caregiver reports assisting the care recipient with instrumental activities of daily life. It is a mean score composed of four items (alpha = 0.66) asking the caregiver how frequently they help the recipient with "laundry, cleaning, or making hot meals," "shopping for groceries or personal items," "driving places," and how often they go with the recipient "in a van, shuttle or cab, or take public transportation with them." The original five-category response scale ranges from "never" to "every day."

Number of medical tasks assistance is a continuous measure of the number of medical tasks the caregiver reports performing for the care recipient. It is a count of six items (alpha = 0.76) asking the caregiver whether they help the care recipient: "order

[4] Sensitivity analyses including hours per month caregiving as a continuous variable suggest that the measure does not have a linear association with the dependent variable. I therefore include the variable as categorical.

their prescribed medicines;" "keep track of medications;" "make appointments with a medical provider;" "speak to or email medical provider about their care;" "change or add a health insurance plan or prescription drug plan;" or "handle any other health insurance matters related to their medical care." The original response categories for each item are "yes" (counted as 1) and "no" (counted as 0).

Key structural/contextual factors.

Caregiver race is a categorical variable indicating whether the caregiver identifies their race as non-Hispanic white (reference), non-Hispanic Black, Hispanic, or other.

Caregiver education is a categorical variable indicating whether the caregiver's self-reported highest level of education is less than high school (reference), high school or equivalent, some college or technical school, or college degree or above.

Caregiver employment status is a categorical measure indicating whether the caregiver reports being employed (reference), unemployed, or retired.

Caregiver gender is a dichotomous variable indicating whether the caregiver reports their gender as female (=1) or male (=0).

Caregiver age is a categorical measure of the caregiver's self-reported age, indicating whether the caregiver is a young adult (aged 18-39), middle-aged (40-60), a mature adult (61-74), or an older adult (75 or over).[5]

Caregiver depressive symptoms (measured using PHQ-2) and caregiver anxiety symptoms (measured using GAD-2) are continuous measures of caregiver-reported

[5] Sensitivity analyses including caregiver age as a continuous variable suggest that the measure has a non-linear association with the dependent variable. I therefore include the variable as categorical to examine the experience of caregiving by life stage.

depressive and anxious symptomatology, with higher scores indicating greater risk for depression or anxiety, respectively. I construct the measures and scores using validated two-item depression and anxiety screeners that consist of two questions reflecting DSM-V core diagnostic criteria (Lowe et al., 2010).[6] Caregiver depressive symptoms and caregiver anxiety symptoms are correlated at 0.32, indicating that it is not statistically problematic to include each measure separately.

Confounding factors

Caregiver relation type is a categorical variable indicating whether the caregiver reports they are the care recipient's spouse (reference), adult child, other relative, or nonrelative.[7]

Coresidence is a dichotomous variable indicating whether the caregiver reports residing with the care recipient (=1) or not (=0).

Long-term caregiver is a dichotomous measure indicating whether the caregiver reported providing care for the recipient for fewer than five years (=0) or for five years or more (=1).[8]

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[6] Sensitivity analyses in which I include the number of caregiver depressive and anxiety symptoms as dichotomous variables recoded in accordance with clinical cutoffs for cases at risk for depression or anxiety, respectively (Lowe et al., 2010) do not suggest a non-linear association of the measure with the dependent variable. I include the two variables as continuous for model parsimony.

[7] Because caregiver relation type includes information about caregiver marital status for spouses, caregiver and care recipient marital status are not included in final models due to collinearity. Neither caregiver nor care recipient marital status variables was statistically significant in any models, and sensitivity analyses including and excluding particular combinations and recodes of caregiver relation type, caregiver marital status, and care recipient marital status did not change the magnitude, direction, or significance of coefficients obtained. I therefore drop marital status variables from analyses.

[8] Sensitivity analyses including the number of years spent caregiving as a continuous variable suggest that the measure does not have a linear association with the latent variable. I include the variable as categorical to examine the possibility of adaptation to caregiving.

Number of other helpers is a continuous measure indicating the number of persons other than the caregiver from whom the care recipient reports receiving assistance.[9]

Care recipient gender is a dichotomous variable indicating whether the care recipient reports their gender as female (=1) or male (=0).

Care recipient race is a dichotomous variable indicating whether the care recipient reports their race is different than the caregiver's race (=1) or whether they identify as being of the same race (=0).[10]

Care recipient age is a categorical measure of the recipient's self-reported age, indicating whether the care recipient belongs to the "young old" (65-74), the "old old" (75-84), or the "oldest old" (85 and over) age group.[11]

Care recipient education is a categorical variable indicating whether the care recipient's self-reported highest level of education is less than high school (reference), high school or equivalent, some college or technical school, or college degree or above.

Homeowner is a dichotomous variable indicating whether the care recipient reports owning a home (=1) or not owning a home (=0).

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[9] Sensitivity analyses in which I include the number of other helpers as a categorical variable (coded as zero, one, and two or more other caregivers) do not suggest a non-linear association with the dependent variable. I therefore include the measure as continuous in the interest of model parsimony.

[10] The variable is dummy-coded and based on differences from the caregiver's race to avoid collinearity due to the high correlation between caregiver and care recipient race. Sensitivity analyses including and excluding the full information available about recipient race suggest no changes in the magnitude, direction, or significance of coefficients ultimately obtained. I therefore show results from the more parsimonious model.

[11] Sensitivity analyses in which I include care recipient age as a continuous variable measured in years suggests that the measure has a non-linear association with the latent variable. I therefore include the variable as categorical to examine caregivers' experience of caregiving by recipient age group.

Social assistance is a dichotomous variable indicating whether the care recipient reported receiving any type of social assistance in the past year (food stamps, other types of food assistance, or gas and electricity assistance) (=1) or not (=0).

Method

I employ latent class analysis (LCA) to identify distinguishable subtypes of the informal caregivers' experience of caregiving to US older adults and to examine the patterns of caregiving burden and caregiving benefits that characterize each subtype. LCA is a method of identifying a categorical latent variable using manifest polytomous measurement items (Collins & Lanza, 2010; Lazarsfeld & Henry, 1968). LCA attempts to discern mutually exclusive latent classes from these indicators, maximizing heterogeneity between classes and homogeneity within classes. Based on an individual's item response pattern, LCA assigns persons to the class for which they have most likely membership. Item probabilities are class-specific and indicate the likelihood that an individual in a class responds favorably to the item. Since LCA models employ polytomous indicators, there are no normality or linearity assumptions in this method.[12]

I do not make assumptions about the number of latent classes of the caregiving experience and therefore estimate latent class solutions of two through six classes, as models with more than six classes violate threshold-ordering assumptions (Nylund,

[12] LCA makes an assumption of local independence (Collins & Lanza, 2010). That is, it assumes that within a latent class, the relationship between item responses is due to class membership; further, this means that the item responses and covariates are assumed to be independent within a latent class. In social science applications, fully meeting the assumption of local independence is often unfeasible, especially when substantive criteria support the inclusion of multiple related variables (Reboussin, Ip, & Wolfson, 2008). Local independence assumption violation can lead to overestimating the number of classes. In this context, it is advisable to rely on both statistical and substantive criteria in deciding on the final model solution (Collins & Lanza, 2010).

Asparuhov, & Muthen, 2007). I specify 250 random sets of starting values with 20 iterations in the initial stage, and 10 optimizations for the estimation algorithm in the final stage of model estimation to ensure reaching a global maximum (Hipp & Bauer, 2006). All models reached convergence and none produced boundary solutions.

Class enumeration. I employ several model fit statistics to determine the statistically preferable model solution. Simulation studies indicate that the Bayesian Information Criterion (BIC) is the best-performing fit indicator when evaluating LCA models (Nylund et al., 2007; Yang, 2006). In comparing two models, the model with the lower BIC value is the preferred model. Additionally, I use relative entropy as a measure of classification uncertainty (Celeux & Soromenho, 1996). Entropy can take on values from 0 to 1, with 1 indicating perfect classification and better model fit. High classification certainty indicates an individual's membership probability is high for one class and low for others. Low classification certainty suggests class overlap and the possibility that individuals are likely members of multiple classes. Reliable class assignment (entropy > 0.75) is desirable before adding covariates to the latent class model (Wang & Wang, 2012). I also inspect estimated class population shares for congruence with class memberships predicted by modal posterior probabilities to further examine classification certainty (Hagenaars & McCutcheon, 2002). Finally, I take into account class size and interpretability. A favorable solution is one in which each class contains a non-negligible proportion of the sample and is substantively interpretable.

Measurement model. I begin the analysis using the full range of available subjective burden and subjective benefits items pertaining to the informal caregiving experience. I recode all items to dummy variables indicating the respondent reports

agreement with the item (= yes). Dichotomization reduces the number of possible response patterns and aids model identification (Collins & Lanza, 2010). To arrive at a parsimonious but meaningful solution, I examine indicators for quality. I define high quality indicators as those indicators that aid in class homogeneity and class separation (Collins & Lanza, 2010). I retain indicators that show variability in item response probabilities across classes and have strong marginal probabilities (probabilities close to 0 or 1). Using high quality indicators that discriminate between classes improves model fit and helps classification (Wurpts & Geiser, 2014). All indicators except for social burden indicators satisfied the homogeneity and separation criteria. Social burden indicators had strong marginal probabilities, but only showed differentiation for one class. However, since including an index instead of separate indicators did not change other item response probabilities, change class structure, or significantly improve model fit, I retain all social burden indicators on the grounds of substantive importance.

Sensitivity analyses. I conduct several measurement model sensitivity analyses to ensure robustness. Sensitivity analyses with differently coded indicators and more parsimonious solutions produced the same class structures. I show parameters and interpret results obtained from the solution with the best classification certainty while retaining the maximum number of substantively relevant indicators.

Inclusion of covariates. I use latent class regression analyses to identify predictors of latent class membership. I follow the three-step approach of including covariates (Asparuhov & Muthen, 2014). This approach first re-estimates the latent class measurement model without predictors, and assigns each observation to its most likely class based on latent class posterior distribution (Kim et al., 2016; Nylund-Gibson &

Masyn, 2016). It then uses class membership as an additional latent class indicator variable while preserving classification uncertainty. In this way, it avoids the difficulties of discarding measurement error information common to one-step approaches (Vermunt, 2010). To ensure model stability, I first examine changes in model fit, item response probabilities, and class prevalence after the inclusion of each predictor variable separately in the estimation of the final solution (Miche, Huxhold, & Stevens, 2013). I then proceed with including blocks of predictor variables (primary stressor factors, primary appraisal factors, key structural/contextual factors, confounding factors) before including the full array.

Multiple imputation. I conduct multiple imputation to impute data missing on covariates. Due to nonresponse, 15% of cases had values missing on at least one covariate included in the final covariate models. The variables with the highest percent of missing values were care recipient education (5.53%) and number of hours spent caregiving in the past month (5.49%); missingness did not exceed 1.5% on other covariates. With the assumption of data missing at random, I generate 20 imputed datasets using the variance covariance analysis algorithm recommended for models with a large number of categorical variables (Asparuhov & Muthen, 2010). I use all variables included in the final models, including analytic weights, strata, and the sampling unit variables to account for complex survey design. The imputation procedure did not produce any implausible values. Sensitivity analyses show that parameters obtained through complete case analysis do not differ in direction, magnitude, or pattern of significance from parameters obtained using multiply imputed data. I present results using the latter.

I perform data cleaning, preparation, and descriptive analyses in Stata 14.1. I conduct multiple imputation and run latent class analyses in Mplus 7.4. I conduct model diagnostics and postestimation analyses in Stata, Mplus, and R.

Results

Table 2.3 shows model selection indices for two- to six-latent class solutions for profiles of informal caregivers' perception of the caregiving experience. Although the bootstrapped likelihood ratio test is uninformative in model selection, other indices suggest that a five-class model provides an adequate balance of parsimony and fit to the data. Information criteria (AIC=40,287.38; BIC=40,574.65) are over 100 points lower for the five-class model than for solutions with a smaller number of classes. Across all fit criteria, gains from estimating an additional class level off after the five-class solution. The information matrix condition number for the five-class solution does not suggest problems with model identification. Finally, the five-class model provides high classification certainty (entropy=0.82) that enables the subsequent inclusion of covariates in the model, and has low classification error, with class assignment based on estimated posterior probabilities closely matching class assignment on most likely latent class membership (not shown). I proceed with the five-class solution.

Latent Class Analysis: Which Distinguishable Subtypes of the Caregiving Experience Exist Within a Nationally Representative Sample of US Informal Caregivers to Older Adults?

Five types of informal caregiving experiences emerged. Distinct combinations of

caregiving burden and caregiving benefit perceptions uniquely characterize each one of the types. In two types (labeled “Intensive Caregivers” and “Balanced Caregivers”), caregiving burden and benefits co-occur, differing in strength of endorsement of burden and benefits items, and in the extent of social burden experienced. In the third type (“Dissatisfied Caregivers”), informal caregivers report experiencing only burden. Finally, in two types (“Relationship Caregivers” and “Satisfied Caregivers”), caregivers indicate that they predominantly experience caregiving benefits, with the two classes again differing in magnitude and domain. Table 2.4 shows the latent class model-derived types of caregiving experiences, the predicted class membership for each type, and the item response probabilities associated with each indicator within each class.

Caregivers experiencing both caregiving burden and benefits.

Class 1: “Intensive Caregivers” (10% of all informal caregivers). Intensive Caregivers report high caregiving burden and moderate caregiving benefits across all domains. Compared to other caregivers, their perceived burden is the highest. At the same time, their perceived benefits are comparable to those of caregivers who report little to no burden.

In the emotional burden domain, these caregivers are likely to affirm that they find caregiving emotionally difficult (0.82), have no time for themselves (0.90), have too much to handle (0.82), and they are subject to changes in routine as soon as these are established (0.69). In the interpersonal domain, they have a high probability of reporting that care recipients argue with them (0.79) and get on their nerves (0.87). Further, they find caregiving physically demanding: they report that due to caregiving, they are

exhausted when they go to sleep (0.85) and that caregiving is physically difficult for them (0.57). Notably, this is the only class in which informal caregivers report social burden; they indicate caregiving has kept them from visiting friends and family not living with them (0.80), from religious services (0.59), from going out for enjoyment (0.84), and from attending informal leisure group meetings and activities (0.62). In sum, these caregivers experience the highest caregiving burden overall in the emotional, interpersonal, and physical domains, and are the only group that also perceives social burden.

Alongside high caregiving burden, however, caregivers in this class also report benefits across all domains. In the emotional domain, they are likely to affirm that caregiving gives them satisfaction (0.84). In the interpersonal domain, they indicate that caregiving brought them closer to the care recipient (0.57), that they enjoy spending time with the recipient (0.68), and that the recipient appreciates them (0.68). Finally, in the behavioral/cognitive domain, they report that caregiving taught them how to deal with difficult situations (0.56). Thus, these caregivers perceive multiple caregiving benefits. However, this group does not endorse caregiving benefits as strongly as the second group reporting the coexistence of burden and benefits, Balanced Caregivers.

Class 2: “Balanced Caregivers” (18% of all informal caregivers). While also reporting both caregiving burden and benefits, Balanced Caregivers differ from Intensive Caregivers by their comparatively lower probabilities of endorsing burden items (with a particularly notable absence of endorsing social burden items), and comparatively higher probabilities of endorsing benefits items. Balanced Caregivers report moderate caregiving

burden coexisting with high caregiving benefits, at levels that are comparable to those of caregivers who report no burden.

In the emotional burden domain, Balanced Caregivers are likely to report that they find caregiving emotionally difficult (0.61), that they have no time for themselves (0.77), that they have too much to handle (0.73), and that they are faced with frequent changes in routine (0.54). In the interpersonal domain, they are as likely as Intensive Caregivers to report that care recipients argue with them (0.79) and that recipients get on their nerves (0.84). In the physical domain, they report being exhausted when going to sleep at night due to caregiving (0.81), but they do not think of caregiving as physically difficult. Like Intensive Caregivers, they do not find caregiving financially difficult. However, contrary to Intensive Caregivers, who report significant social burden, Balanced Caregivers do not perceive social burden from caregiving. In sum, Balanced Caregivers perceive somewhat lower burden than Intensive Caregivers, and caregiving does not appear to interfere with their social activities.

Similarly to Intensive Caregivers, Balanced Caregivers also perceive caregiving benefits across all domains, and they are comparatively more likely to endorse benefits items. In the emotional domain, they indicate that caregiving gives them satisfaction (0.95). In the interpersonal domain, they report feeling closer to the care recipient (0.95), enjoy being with them (0.96), and that recipients appreciate them (0.91). In the behavioral/cognitive domain, they report being more confident in their abilities (0.62) and affirm that caregiving taught them how to deal with difficult situations (0.82). Thus, Balanced Caregivers' perception of benefits is somewhat higher than that of Intensive Caregivers; notably, it is comparable to that of Satisfied Caregivers, who report no

burden and benefits only.

Caregivers experiencing predominantly caregiving burden.

Class 3: "Dissatisfied Caregivers" (15% of all informal caregivers). Dissatisfied Caregivers perceive high caregiving burden and report the least benefits. Although their endorsement of burden items is comparable to that of Intensive or Balanced Caregivers, unlike these other two classes, Dissatisfied Caregivers do not find their caregiving experience beneficial: they endorse the fewest benefits items of any class, and they have the lowest probability of endorsing these items.

Similarly to Balanced Caregivers, Dissatisfied Caregivers report caregiving burden in the emotional, interpersonal, and physical domains, but not in the financial or social do. In the emotional domain, they indicate that they find caregiving emotionally difficult (0.79), that they do not have time for themselves (0.57), and that they have too much to handle (0.54). In the interpersonal domain, they report that the care recipient argues with them (0.79) as well as gets on their nerves (0.93). In the physical domain, they are likely to report difficulty going to sleep at night due to caregiving (0.54). Thus, Dissatisfied Caregivers' reports of burden are comparable those of Balanced Caregivers.

However, unlike Balanced or Intensive Caregivers, caregivers in this class are unlikely to report perceiving caregiving benefits. They do not report any benefits in the behavioral/cognitive domain, and their emotional and interpersonal burden endorsements are weaker than those of any other group. In the emotional domain, they are somewhat likely to agree that caregiving gives them satisfaction (0.60); in the interpersonal domain, they indicate that the care recipient appreciates them (0.56), but do not endorse any other

items. In sum, although Balanced Caregivers and Dissatisfied Caregivers report comparable levels of burden, Balanced Caregivers also report caregiving benefits, whereas Dissatisfied Caregivers do not.

Caregivers experience predominantly caregiving benefits.

Class 4: "Relationship Caregivers" (26% of all informal caregivers). Relationship Caregivers are unlikely to report perceiving caregiving burden, except in the interpersonal domain. Conversely, they have a high probability of reporting caregiving benefits, but these are similarly limited to the interpersonal and emotional domain.

Relationship Caregivers report relatively low levels of caregiving burden. Unlike any other caregiver groups reporting burden, Relationship Caregivers' perception of burden is limited only to the interpersonal domain, and the probability of them endorsing the interpersonal burden items is low; they comparatively weakly endorse items indicating that the care recipients argue with them (0.52) and that recipients get on their nerves (0.58).

At the same time, Relationship Caregivers strongly endorse interpersonal benefits items. They are likely to report that caregiving brought them closer to the care recipient (0.54), that they enjoy being with the care recipient (0.89), and that recipients appreciate them (0.95). In addition, in the emotional domain, they report that caregiving gives them satisfaction (0.80). They do not report benefits in the behavioral/cognitive domain. Thus, unlike Intensive Caregivers, Balanced Caregivers, or Dissatisfied Caregivers, Relationship Caregivers perceive predominantly caregiving benefits. However, they report benefits at a slightly lower level than Satisfied Caregivers, the second group of

caregivers who report perceiving benefits only.

Class 5: “Satisfied Caregivers” (32% of all informal caregivers). Satisfied Caregivers do not indicate experiencing any burden, and report perceiving caregiving benefits only. Their reported perception of benefits, comparable to that of Balanced Caregivers who also report considerable burden, is higher than that of any other group.

Satisfied Caregivers are highly likely to endorse caregiving benefits items across all domains. In the emotional domain, they report that caregiving gives them satisfaction (0.98). In the interpersonal domain, they affirm that caregiving brought them closer to the care recipient (0.96), that they enjoy being with the recipient (0.98), and that the recipient appreciates them (0.98). Compared to all other groups of caregivers, Satisfied Caregivers are most likely to experience benefits in the behavioral/cognitive domain: they have a high probability of indicating that caregiving made them more confident in their abilities (0.88), and that caregiving taught them how to deal with difficult situations (0.87). In sum, they report a highly beneficial caregiving experience.

Latent Class Regression Analysis: Which Factors Predict the Types of Caregiving Experience?

Table 2.5 shows the results of latent class regression analysis predicting membership in the five classes of caregiving experience. The table displays relative risk ratios and the associated confidence intervals. The reference class for comparison in all models is Dissatisfied Caregivers (Class 3), the class in which caregivers report experiencing only caregiving burden, with no caregiving benefits. I show the full model

with primary stressors, primary appraisal, key structural/contextual factors, and confounding factors included, as the coefficients obtained do not change appreciably after block additions of these factors, and the pattern of statistical significance remains constant. Table 2.6 shows the improvements in model fit following the addition of each block of variables; please see Appendix for coefficients obtained after each block addition.

Primary stressors

The inclusion of primary stressor variables in the latent class regression model increases classification certainty (entropy=0.819) and improves model fit from the unadjusted baseline model (ΔAIC=-533, ΔBIC=-494, ΔmaxLL=282) (Table 2.6).

In the fully adjusted model (Table 2.5), the care recipient's physical health and mental health are both associated with the caregiver's experience of caregiving. Specifically, the care recipient's self-reported depressive symptoms and number of medical diagnoses are associated with a lower likelihood of the caregiver reporting caregiving benefits or a combination of benefits and burden (being Balanced Caregivers, Relationship Caregivers, or Satisfied Caregivers), relative to burden only (Dissatisfied Caregivers). Compared to being Dissatisfied Caregivers who experience burden only (Class 3), with each one-point increase in the recipient's depressive symptoms score, caregivers have a 50% lower likelihood of being Balanced Caregivers and experiencing moderate caregiving benefits with burden (Class 2; rr=0.50, $p<0.000$), controlling for other factors. Similarly, they have a 52% lower likelihood of being Relationship Caregivers and experiencing interpersonal benefits and burden (Class 4; rr=0.48, $p<0.01$),

and a 53% lower likelihood of being Satisfied Caregivers and experiencing benefits only (Class 5; rr=0.47, p<0.001). In addition, compared to caregivers providing care for a recipient with fewer than three medical diagnoses, those who care to a recipient with three or more diagnoses have a 55% greater likelihood of being Balanced Caregivers experiencing moderate caregiving benefits with burden (Class 2; rr=0.45, p<0.000) than of being Dissatisfied Caregivers who experience burden only (Class 3).

The results thus suggest that higher levels of recipient depressive symptoms and more diagnosed recipient medical conditions are associated with caregivers' greater chances of being Dissatisfied Caregivers, who do not find their caregiving experience beneficial and report the fewest benefits from their caregiving.

Primary appraisal

The inclusion of primary appraisal variables in the latent class regression model increases classification certainty (entropy=0.822) and improves model fit, compared to the model only including primary stressors (ΔAIC=-3,000, ΔaBIC=-2,960, ΔmaxLL=1,519) (Table 2.6). The inclusion of these factors explains away the initial association between care recipient self-rated health primary stressor and caregiving experience types (p<0.05). However, it does not appreciably reduce or explain away the relationship between recipient depressive symptoms and medical conditions (primary stressors) and caregiving experience types. The association between these primary stressors and caregiving experience types therefore remains robust.

In the fully adjusted model (Table 2.5), the primary appraisal factors of number of hours of care provided, ADL assistance, and the number of medical tasks performed are

associated with one's caregiving appraisal, with those providing more intensive assistance reporting better caregiving experiences (being Intensive Caregivers or Balanced Caregivers, relative to being Dissatisfied Caregivers).

Compared to caregivers who provide 20 or fewer hours of care per month, those who provide 21 to 63 hours of care have an over two-fold higher relative probability of being Intensive Caregivers who experience a combination of high burden and benefits (Class 1; rr=3.82, $p<0.001$) than of being Dissatisfied Caregivers experiencing burden only (Class 3). Similarly, they have an almost two-fold higher relative probability of being Balanced Caregivers and experiencing moderate caregiving benefits with burden (Class 2; rr=2.86, $p<0.000$) than of being Dissatisfied.

In terms of ADL assistance, compared to being Dissatisfied Caregivers who experience only burden (Class 3), with each increase in their ADL help frequency, caregivers have a 73% higher relative probability of being Intensive Caregivers and experiencing a combination of high benefits and burden (Class 1; rr=1.73, $p<0.001$) and a 55% greater risk of being Balanced Caregivers experiencing moderate benefits and burden (Class 2; rr=1.55, $p<0.001$) versus being Dissatisfied Caregivers who experience only burden (Class 3).

Finally, each additional medical task performed is associated with a 43% higher relative probability of being Intensive Caregivers who experience a combination of high burden and benefits (Class 1; rr=1.43, $p<0.001$) than of being Dissatisfied Caregivers experiencing burden only (Class 3). Each additional medical task, however, is also associated with a 24% lower relative probability of being Relationship Caregivers and

experiencing interpersonal benefits and burden (Class 4; rr=0.76, p<0.01) versus Dissatisfied Caregivers.

The number of hours of care provided, ADL assistance, and assistance with medical tasks are thus associated with perceiving both caregiving benefits and burden, relative to perceiving only burden. In sum, results suggest that although providing time-intensive care may give rise to perceiving high caregiving burden, it may also facilitate the experience of caregiving benefits alongside the burden; persons providing such assistance are more likely to be Intensive or Balanced Caregivers.

Key structural/contextual factors

The inclusion of key structural/contextual variables in the latent class regression model increases classification certainty (entropy=0.837) and improves model fit, compared to the model only including primary stressors and primary appraisal (ΔAIC=-1,735, ΔaBIC=-1,606, ΔmaxLL=910) (Table 2.6). Although this block of measures? attenuates the association between primary appraisal (in particular, the number of medical tasks performed for the recipient) and caregiving experience types, the inclusion of these factors does not explain away the association. Conversely, it somewhat strengthens the association between primary stressors (care recipient depression symptoms and number of medical diagnoses) and caregiving experiences. The relationship between primary stressors, primary appraisal, and caregiving experience types therefore remains robust to the inclusion of structural/contextual factors.

In the fully adjusted model (Table 2.5), the key contextual factors of caregiver race, caregiver age, and caregiver mental health are all associated with the caregiver's

experiences of caregiving. Black caregivers have a higher likelihood than white caregivers of perceiving caregiving benefits, compared to perceiving burden only (being Dissatisfied Caregivers). Conversely, middle-aged caregivers, mature adult caregivers, and caregivers in poor mental health have a lower likelihood of perceiving benefits only or benefits alongside burden (being Balanced Caregivers, Relationship Caregivers, or Satisfied Caregivers) than younger caregivers and caregivers with better mental health, respectively.

Compared to white caregivers, Black caregivers have an almost two-fold higher relative probability of being Balanced Caregivers and experiencing a combination of moderate benefits and burden (Class 2; $rr=2.86$, $p<0.05$) and an over two-fold higher probability of being Satisfied Caregivers who experience benefits only (Class 5; $rr=3.32$, $p<0.01$), rather than of being Dissatisfied Caregivers experiencing burden only (Class 3). In other words, Black caregivers are considerably more likely than white caregivers to experience some benefits of caregiving (either with or without accompanying burden) versus only experiencing caregiving burden.

Middle-aged caregivers (aged 40 to 60 years) have a 60% lower relative probability than young adult caregivers (aged 18-39) of being Relationship Caregivers and experiencing interpersonal benefits and burden (Class 4; $rr=0.30$, $p<0.05$) versus being Dissatisfied Caregivers experiencing burden only (Class 3). Similarly, mature adult caregivers (aged 61 to 74) have a 77% lower relative probability than young adult caregivers of being Relationship Caregivers and experiencing interpersonal benefits and burden (Class 4; $rr=0.23$, $p<0.05$), and a 73% lower relative probability of being Satisfied

Caregivers experiencing benefits only (Class 5; rr=0.27, $p<0.05$), relative to being Dissatisfied Caregivers and experiencing burden only (Class 3).

Caregivers' own mental health is also significantly predictive of their experiences of caregiving burden and benefits, with greater problems with depression and anxiety both associated with reduced chances that a caregiver will experience caregiving benefits (either with or without burden), rather than just burden alone. With each increase in their own depressive symptoms score, for example, caregivers have a 45% lower relative probability of being Relationship Caregivers and experiencing interpersonal benefits and burden (Class 4; rr=0.55, $p<0.05$) and a 51% lower probability of being Satisfied Caregivers experiencing benefits only (Class 5; rr=0.49, $p<0.01$), relative to being Dissatisfied Caregivers and experiencing burden only (Class 3). Compared to the latter experience type, they also have a 52% lower likelihood of being Relationship Caregivers experiencing a combination of interpersonal benefits and burden (Class 4; rr=0.48, $p<0.01$), and a 50% lower likelihood of being Satisfied Caregivers experiencing benefits only (Class 5; rr=0.50, $p<0.05$) with increases in their anxiety symptoms score. The one exception to the finding that caregivers' mental health difficulties predict lower levels of experiencing caregiving benefits is that increased symptoms of anxiety are associated with a higher probability of being Intensive Caregivers perceiving high benefits and burden (Class 1; rr=1.73, $p<0.05$), rather than Dissatisfied Caregivers perceiving burden only (Class 3).

In sum, older age and experiencing symptoms of depression or anxiety may put caregivers at greater risk of perceiving caregiving as primarily burdensome. These

caregivers are more likely to be in the group of Dissatisfied Caregivers, who report experiencing the lowest amount of benefits from caregiving.

Confounding factors

The inclusion of control variables in the latent class regression model increases classification certainty (entropy=0.855) and improves model fit compared to the model only including primary stressors, primary appraisal, and structural/contextual factors (ΔAIC=-2,069, ΔaBIC=-1,941, ΔmaxLL=1,086) (Table 2.6). The inclusion of these factors does not account for the association between primary stressors, primary appraisal, structural/contextual factors, and caregiving experience types. However, it somewhat reduces the magnitude of association between race and caregiving experiences, and age and caregiving experiences. Thus, confounding factors partially account for the relationship between structural/contextual factors and caregiving experience types. In the fully adjusted model, relation to recipient, coresidence, years spent caregiving, care recipient gender and care recipient age are all associated with the caregiver's experiences of caregiving.

Nonrelative caregivers have a higher likelihood of perceiving caregiving benefits compared to perceiving burden only (being Satisfied Caregivers relative to Dissatisfied Caregivers). Compared to spouse caregivers, caregivers who are not related to the recipient have an over three-fold higher relative probability of being Satisfied Caregivers and experiencing benefits only (Class 5; rr=4.76, $p<0.05$) versus being Dissatisfied Caregivers experiencing burden only (Class 3). Coresident caregivers and caregivers who have spent five years or more providing care have a lower likelihood of perceiving a

combination of benefits and burden, or benefits only than experiencing only caregiving burden.

Compared to non-coresident caregivers, coresident caregivers have a 60% lower relative probability of being Intensive Caregivers experiencing a combination of high burden and benefits (Class 1; rr=0.40, $p<0.05$), a 56% lower probability of being Balanced Caregivers perceiving moderate benefits and burden (Class 2; rr=0.44, $p<0.05$), and a 62% lower probability of being Satisfied Caregivers perceiving benefits only (Class 5; rr=0.38, $p<0.01$), relative to being Dissatisfied Caregivers perceiving only burden (Class 3). Similarly, caregivers who have been providing care to the recipient for five years or more have a 49% lower relative likelihood of being Intensive Caregivers perceiving high benefits and burden (Class 1; rr=0.51, $p<0.05$) relative to being Dissatisfied Caregivers perceiving burden only (Class 3), compared to those providing care for fewer than five years.

Care recipient gender and age are also associated with the caregiver's experience of caregiving, with caregivers who care for women and those caring for the oldest old experiencing fewer benefits, on average, than those caring for men and younger care recipients, respectively. Compared to caregivers caring for males, caregivers for female care recipients have a 1.18-fold higher relative likelihood of being Satisfied Caregivers perceiving only benefits (Class 5; rr=2.18, $p<0.01$) than of being Dissatisfied Caregivers perceiving only burden (Class 3). Conversely, caregivers to the oldest old (aged 85 years and over) have a 57% lower relative probability of being Satisfied Caregivers experiencing only benefits (Class 5; rr=0.43, $p<0.05$) than of being Dissatisfied Caregivers perceiving only burden (Class 3), compared to caregivers to the young old

(aged 65 to 74). Care recipient race and care recipient SES (education, homeownership, and social assistance receipt) are not significantly associated with caregiving experience latent class membership.

Taken together, these results suggest that coresident and long-term caregivers and those who care for men and the oldest care recipients may be at greater risk of appraising caregiving as only burdensome. These persons are likely to be Dissatisfied Caregivers and to not perceive caregiving as beneficial.

Discussion

I use a nationally representative sample of informal caregivers to older adults to better understand how benefits and burden simultaneously shape the experience of caregiving. In contrast to research using clinical and convenience samples, I provide an assessment of the caregiving experience with findings that are generalizable to the population of informal caregivers to US older adults. Using a novel methodological approach and the caregiving appraisal theoretical framework, I identify five types of the caregiving experience and show that primary stressors, primary appraisal, and structural/contextual factors are all associated with the experience of caregiving. My findings highlight the multiplicity and ambivalence of caregivers' experiences, and help identify groups of informal caregivers who may be in need of assistance.

I find that informal caregivers' experiences can be classified into five distinguishable subtypes, each uniquely characterized by the level and nature of self-reported burdens and benefits. In two types (Intensive and Balanced), caregivers report experiencing both burden and benefits. This finding supports the understanding of

caregiving benefits and burden as two co-existing facets of the caregiving experience that can arise from the caregiver's experience and appraisal of the same caregiving situation (Kinney & Stephens, 1989; Lawton et al., 1989; Lawton et al., 1991). Caregivers in these two types report experiencing high burden, but they also report benefits at levels comparable with those who only experience benefits. This suggests that even at high levels of care, positive and negative experiences are not mutually exclusive, and that caregivers may derive interpersonal, behavioral, or other benefits from intensive care work (Andren & Elstahl, 2005; Boerner et al., 2004; Brown & Brown, 2014; Kramer, 1997). The two types differ primarily in the magnitude of burden that caregivers report, with one including and the other excluding social burden; the latter refers to being unable to visit friends and family, attend religious services, participate in organized activities, and to go out for enjoyment due to caregiving, as well as being unable to care for others, to do volunteer work, or to work for pay. This finding indicates that contrary to other types of burden, caregivers may only begin to experience social burden—isolation and interference with other roles—at high levels of care (Colvin & Bullock, 2016; Tebb & Jivanjee, 2008). Descriptive analyses (see Appendix) suggest this is the case, as caregivers reporting high social burden (Intensive Caregivers) are also more likely than caregivers in any other class to provide personal care such as help with caring for teeth or feet, and are most likely to assist with medical tasks such as helping with medical exercises, tracking medicines, and making medical appointments. These types of tasks are typically done regularly and may conflict with caregivers' lives more than occasional tasks such as assistance with shopping or banking.

In two caregiving experience types (Relationship and Satisfied), caregivers indicate that they predominantly experience benefits, with differences in magnitude and domain. The first type, Satisfied Caregivers, represents persons who report the highest level of benefits of any class, and they report such benefits across the emotional, interpersonal, and cognitive/behavioral domain. The second type, Relationship Caregivers, similarly reports benefits, but at a lower level and limited to the emotional and interpersonal domains; additionally, while these caregivers do not report other types of burden, they are somewhat likely to report interpersonal difficulties. It is common for the caregiver and recipient to develop a close relationship, and interpersonal tensions are a common feature of these relationships (McGraw & Walker, 2004; Quinn, Clare, & Woods, 2010). Mental health symptoms and old age conditions such as dementia may also impair the caregiving relationship (Hooker et al., 1998), giving rise to an experience in which caregivers perceive primarily benefits with some interpersonal burden. Descriptive analyses (see Appendix) support this explanation; caregivers who report interpersonal benefits and burden (Relationship Caregivers) are more likely than caregivers who report benefits only with no burden (Satisfied Caregivers) to be providing care for a recipient diagnosed with dementia or Alzheimer's disease, or a recipient meeting criteria for depression or anxiety. Finally, in one caregiving experience type (Dissatisfied Caregivers), informal caregivers report experiencing only burden. The absence of reported benefits in this type is notable, as the level of reported burden is comparable to that of caregivers who simultaneously report high caregiving benefits.

To explain such differences, I identify primary stressors, primary appraisal, and structural/contextual factors associated with burdensome versus beneficial caregiving

experiences. Among primary stressors, I find that persons caring for recipients with depressive symptoms are more likely than caregivers caring for non-depressed recipients to experience only burden rather than to experience a combination of burden and benefits, or benefits only. Although the pattern is similar but weaker for caregivers providing assistance to recipients with three or more medical conditions, it does not hold when the care recipient exhibits anxiety symptoms or has poor self-rated health. This suggests that recipient depression in particular may be more taxing for caregivers than other recipient conditions (Pinquart & Sorensen, 2003). Studies of married couples show that one's psychological wellbeing depends on both unique stressors and the stress that their partner experiences (Birditt, Newton, Cranford, & Ryan, 2016; Monin et al., 2010; Neff & Kearney, 2007). Similarly, a depressed care recipient may increase their caregiver's psychological distress, with the latter thus perceiving fewer benefits from this relationship and the care they provide (Dempster, McCorry, & Brennan, 2011; Ejem, Drentea, & Clay, 2014; Hooker et al., 1998). The finding is particularly notable, as my study uses reports about mental health symptoms that were collected from care recipients themselves, rather than by proxy through caregivers. Studies relying on a single reporter—the caregiver—may be confounding the factors of perceived caregiver burden and caregiver-reported recipient mental health status.

Among primary appraisal factors, I find that caregivers who offer frequent ADL assistance, assistance with medical tasks, and those who provide between 21 and 63 hours of care per week (as compared to those providing fewer than 21 hours) are more likely to perceive a combination of benefits and burden than to perceive burden only. All three factors indicate high levels of care, making the reported experience of burden

unsurprising. However, these caregivers simultaneously report the highest levels of benefits. Notably, frequent IADL assistance—such as with shopping and transportation and where care is less intensive and less intimate—does not shape the caregiving experience in a similar way. It is possible that frequent and high levels of care may facilitate a closer interpersonal relationship, or personal growth and a sense of accomplishment for the caregiver (Quinn, Clare, McGuinness, & Woods, 2012). This may give rise to the perception of caregiving benefits even when care is intensive or burden is high. Alternatively, caregivers providing intensive assistance such as with ADL may be caring for older adults to whom they are already close, or toward whom they feel a sense of reciprocity, thus focusing less on burden (Suitor, Gilligan, & Pillemer, 2013).

Several structural/contextual factors shape the caregiving experience. It is notable that the association between primary stressors, primary appraisal, and caregiving experience types remains robust to the inclusion of structural/contextual factors; the finding suggests that the link between primary stressors, primary appraisal, and caregiving experiences cannot be explained with caregiver characteristics or broader caregiving arrangement characteristics. Primary stressors (care recipient physical and mental health) and primary appraisal (the caregiver's work load and task profile) thus persistently shape caregiving experiences.

Likewise, confounding factors do not substantially reduce the magnitude of association between significant structural/contextual factors and caregiving experiences. I find that with increasing age, caregivers are more likely to appraise their caregiving experiences negatively. Middle aged (40 to 60 years old) and mature adult (61 to 74 years old) caregivers are less likely than their younger counterparts (aged 18 to 39 years) to

experience only caregiving benefits than to experience only burden. One explanation for the finding may be that middle-aged caregivers, likely to be adult children, are balancing multiple competing demands with caregiving, such as work-related responsibilities (Longacre, Valdmanis, Handorf, & Fang, 2016; Stone & Short, 1990). They may not have chosen the caregiving role voluntarily. Similarly, mature adults, who are likely to be providing care to their aging spouses, may themselves have health issues or care needs that could increase their objective as well as perceived burden (Wharton & Zivin, 2017).

My results run contrary to the expectation that low SES and racial/ethnic minority status would be associated with poor caregiving experiences (Ayalon, 2008; Hong & Harrington, 2016; Koerner et al., 2010). I instead find that relative to whites, Black caregivers are more likely to report beneficial experiences—either as a combination of benefits and burden, or only experiencing benefits—than to perceive only burden. I do not find that either caregiver education or employment status is associated with caregiving appraisal. This adds to research suggesting that at similar levels of care, racial and ethnic minority caregivers perceive more caregiving benefits than white caregivers (Aranda & Knight, 1997; Fredman et al., 1995; Haley et al. 1996; Janevic & Connell, 2001; Rapp & Chao, 2000; Roth et al., 2015). It is possible that Medicaid eligibility among racial/ethnic minorities and persons with lower SES provides access to more formal care services that buffer caregiving stress for primary caregivers (Albert, Brassard, Simone, & Stern, 2004). Alternatively, the cultural norms of familialism may encourage racial/ethnic minority caregivers to take on the role voluntarily, and it may facilitate access to social resources, making the experience of caregiving less stressful (Evercare and National Alliance for Caregiving, 2008; Knight & Sayegh, 2010; Lai,

2010; Wood & Wan, 1993). However, the finding does not hold for Hispanic caregivers, whose experience does not appear to differ from that of white caregivers. It is possible that the Hispanic category used in the present analyses is insufficiently nuanced—the norm of familialism may be more or less pronounced among Hispanic subgroups (Losada et al., 2006)—or that beliefs like Marianismo among Hispanics facilitate taking on caregiving, but not also its positive appraisal (Mendez-Luck & Anthony, 2016). Alternatively, Hispanic caregivers may be encountering different or more barriers to good caregiving experiences than Black caregivers (Aranda & Knight, 1997; Knight et al., 2000). Language difficulties may prevent Hispanic caregivers from using support services or obtaining caregiving education and information (Evercare and National Alliance for Caregiving, 2008).

In terms of the type of relationship between the caregiver and care recipient, caregivers who are not related to the care recipient are more likely to experience only caregiving benefits. As adult children and spouses are typically called upon first in the care chain and provide more intensive care than other caregivers, nonrelatives may be more likely to take on the caregiving role voluntarily (Johnson & Wiener, 2006; Wolff & Kasper, 2006). Descriptive analyses (see Appendix) also show that nonrelatives provide intensive care at lower levels than other caregivers. This is consistent with explanations suggesting that non-kin caregivers—typically lower in the care hierarchy—may perform quantitatively and qualitatively different tasks than kin caregivers (Barrett & Lynch 1999; Keating & Dosman, 2009; Litwin & Landau, 2000; Penning, 1990; Wellman & Wortley, 1990).

Conversely, caregivers who are at risk for depression or anxiety, caregivers who co-reside with the recipient, and caregivers who have been providing care for five or more years are likely to perceive their caregiving experiences negatively. As expected, caregivers at risk of depression or anxiety are more likely to perceive only caregiving burden than benefits only. However, they are no less likely to report a combination of burden and benefits, and caregivers with symptoms of anxiety appear more likely to report ambivalent rather than exclusively burdensome experiences. This result may reflect caregivers' greater likelihood of developing poor mental health compared to non-caregivers, especially at high level of care (Clark & Diamond, 2010; Cooper et al., 2007; Covinsky et al., 2003; Cuijpers, 2005; Epstein-Lubow et al., 2008; Lu et al., 2007; MacNeil et al., 2009; Vilchinsky et al., 2015). The finding also suggests that depression and anxiety may not interfere strongly with appraisal of caregiving benefits alongside perceived burden. This is contrary to the depression distortion hypothesis, which posits that depressed respondents rely primarily on negative information in their evaluations and may give negatively biased reports (Richters, 1992). In contrast, coresident caregivers and caregivers who have been providing care for five years or more are less likely to report any experience of benefits compared to only burden, including a combination of burden and benefits. Co-resident caregivers often report poor mental health themselves, and coresidence may indicate intensive care or interpersonal tensions that can shape the caregiving experience negatively (Guarnaccia & Parra, 1996; Robison et al., 2009; Schulze & Rossler, 2005). Further, transitioning from occasional to more intensive personal and end-of-life care as the recipient ages and their health declines may explain

the reported burden of caregivers who have been providing care for five years or more (Gitlin & Schultz, 2012).

Implications

With those aged 85 years and older being one of the fastest growing segments of the population (US Census Bureau, 2016), and an increasing prevalence of degenerative and chronic illness (He, Goodkind, & Kowal, 2016), the number of individuals living at home with impairments and disabilities is expected to rise (US Department of Health and Human Services, 2003). Already, the majority of older individuals with care needs live at home, and for more than two thirds of them, family caregivers are their only source of assistance (Congressional Budget Office, 2013; Doty, 2015). Informal caregivers provide aging adults with 90% of all long-term care outside facilities (Centers for Disease Control and Prevention, 2011), and are crucial in enabling older individuals to remain in their communities. However, my findings show that without adequate support, a large proportion of these caregivers may find their caregiving experience burdensome, which may compromise their capacity to provide quality care to their family members or friends.

The prevalence of Alzheimer's disease and related dementias in the US is increasing, with the number of older persons living with the disease projected to rise from five to 16 million in 2050 (Alzheimer's Association, 2017). My results indicate that caregivers providing care to recipients diagnosed with dementia or Alzheimer's disease perceive their caregiving as more burdensome than beneficial. Compared to other caregivers, they experience more emotional, financial, and physical distress (Alzheimer's

Association, 2017). Expanded access to support services, availability of respite care, and the provision of specialized care training may facilitate these caregivers' continued well-being. For example, state-sponsored programs such as the Caregiver Advise, Record, Enable (CARE) Act partner family caregivers with medical staff to train and educate the former in carrying out nursing tasks, alleviating the burden of navigating these tasks alone (Hunt & Reinhard, 2015). In addition to assistance, increased availability of respite care may allow these caregivers—as well as coresident and long-term caregivers, who also perceive caregiving as more burdensome than beneficial—to recuperate, especially in times of acute stress (Zarit, Kim, Femia, Almeida, & Klein, 2014).

Further, the expansion of the homecare workforce and of workplace programs may provide better financial security and more temporal resources for caregivers. I find that middle-aged caregivers, who are likely to be adult children also balancing the demands of their own families and work, are more likely than caregivers of other ages to perceive caregiving as exclusively burdensome. Especially with adult women—traditionally allocated the role of a family caregiver—increasingly working outside the home, and with a reduced pool of potential informal caregivers due to geographical mobility, it may become increasingly necessary to turn to paid caregivers to provide suitable long-term care (Allen, 2005). Although the number of homecare workers in the US is already growing, these workers frequently experience high rates of turnover and poor working conditions, and they have little education (Poo & Whitlach, 2016). Investments in developing an appropriately trained homecare workforce may help ensure high-quality long-term support for older persons in the context of fewer available family caregivers (Redfoot, Feinberg, & Houser, 2013). For those family caregivers wishing to care for

their loved ones themselves, paid and extended family leave, paid sick time, unemployment insurance, and employer-sponsored eldercare resources and referral services may help them balance the demands of work and caregiving (Shabo, 2015).

Finally, as the U.S. population ages, informal caregivers will necessarily age as well. Likewise, older adults are more ethnically and racially diverse than ever before, and caregiving services will have to adapt to the new caregiving landscape accordingly. My analyses show, for example, that Black caregivers are more likely than their white counterparts to experience caregiving benefits. However, ethno-racial health disparities and the growing proportion in future cohorts of disabled older adults who are African Americans, Hispanics, and Native Americans, may change the predominantly positive caregiving experience of minority caregivers (Manton & Gu, 2001; Older Women's League, 2002).

In the same way, as US families become smaller, more geographically mobile, and less able to provide care to family members, caregivers who are not related to the care recipients may be called upon more frequently to provide care. My results suggest that caregivers who are not related to the care recipient are more likely to experience only caregiving benefits than those who are related to the recipient. Non-relative caregivers, however, may increasingly provide more intensive, personal care that only family members may currently be providing, and their perception of caregiving as primarily beneficial may shift accordingly (National Alliance for Caregiving, 2009; Redfoot et al., 2013).

As using a combination of informal and formal care declines and exclusive reliance on informal care continues to grow, anticipating such changes in particular groups'

experiences of caregiving may help design programs and policies resulting in a health care system that is better prepared to support the quality of life of both US older adults and their caregivers (Federal Interagency Forum on Aging-Related Statistics, 2004).

Limitations

This analysis has several limitations. First, the data are cross-sectional and do not allow for an examination of caregiving experiences over time. Two waves of NSOC are available, but caregiver and care recipient attrition between the 2011 and 2015 time points results in a sample size with insufficient statistical power. Although I control for the duration of caregiving to partially account for potential changes in the perception of caregiving, as subsequent waves of NSOC become available, future research may use latent class transition analysis techniques to examine caregiving experience changes longitudinally. Future longitudinal research may also be able to incorporate measures of baseline relationship quality that were not available here, and thus be better able to discern whether interpersonal burden is a result of caregiving specifically, or a constant characteristic of the caregiver and the recipient's relationship. Finally, NSOC does not include information about whether or not individuals took on the caregiving role voluntarily. For many, caregiving may be an "unexpected career" or an unwanted transition, and the motivation for caregiving likely shapes the caregiving experience (Pearlin & Anashensel, 1994; Quinn et al., 2010; Quinn et al., 2012). The voluntary or involuntary nature of the caregiving role may also be associated with the finding that Black but not Hispanic caregivers are more likely than their white counterparts to perceive caregiving benefits, and that middle-aged caregivers are unlikely to experience

caregiving benefits. When possible, future research should account for whether individuals become caregivers voluntarily.

Conclusion

In sum, my findings show that even at high levels of reported burden, caregivers may still experience a high level of benefits. Especially in cases where it may not be possible to reduce burden, caregiver assistance programs may therefore instead focus on increasing the perception of benefits (Toohey et al., 2016). Caregivers who experience benefits from caregiving have better mental and physical health, and continue on in their role longer than those who do not perceive the experience as beneficial (Cohen et al., 2002; Cohen et al., 1994; Pinquart & Sorensen, 2003). Further, my analyses suggest that caregivers caring for recipients who exhibit symptoms of depression, caregivers who are themselves at risk for depression and anxiety, co-resident caregivers, and caregivers who have been providing care for more than five years are groups that may benefit most from assistance. My findings in this area add to previous research suggesting that these groups of caregivers are at risk of impaired immune responses, high rates of depression and anxiety, inflammation, chronic disease, and high mortality (Gouin et al., 2012; Ho et al., 2009; Lovell & Wetherell, 2011; Ohaeri, 2003; Piquart & Sorensen, 2003; Schulz & Beach, 1999; Vitaliano, Zhang, & Scanlan, 2003). Given the increasing reliance of the US long-term care system for older adults on informal caregivers (Federal Interagency Forum on Aging-Related Statistics, 2004), it is important to address the needs of these groups, facilitating a more beneficial caregiving experience.

Tables

Table 2. 1. Weighted sample descriptive statistics. (N=2,202)

Variable	%	Mean	Std	Min	Max
Primary stressors					
CR self-rated health (Range: 0 – 4)		1.60	1.04	0	4
CR depressive symptoms (PHQ-2)		1.61	1.62	0	6
CR anxiety symptoms (GAD-2)		1.43	1.65	0	6
CR 3+ medical diagnoses (reference=<3)	74.29				
Primary appraisal					
CG tercile of hours helped in past month					
0 to 20 (reference)	39.76				
21 to 63	33.75				
64 or more	26.48				
CG frequency of ADL help (mean)		1.34	1.19	0	4
CG frequency of IADL help (mean)		1.55	0.81	0	4
CG number of medical tasks		2.35	1.94	0	6
Key structural/contextual factors					
CG race					
White (reference)	67.38				
Black	12.49				
Hispanic	9.22				
Other	10.91				
CG education					
Less than high school (reference)	10.34				
High school	26.84				
Some college	35.51				
Bachelor's degree or higher	27.31				
CG work status					
Employed (reference)	41.41				
Unemployed	26.87				
Retired	31.72				
CG female (reference = male)	62.37				
CG age					
Young adult, 18-39 (reference)	11.77				
Middle-aged, 40-60	40.59				
Mature adult, 61-74	31.65				
Older adult, 75+	15.99				
CG depression symptoms (PHQ-2)		0.97	1.36	0	6
CG anxiety symptoms (GAD-2)		1.04	1.40	0	6
Confounding factors					
CG relation to care recipient					
Spouse (reference)	21.29				

Adult child	45.50				
Other relative	22.21				
Other nonrelative	10.99				
CG in household (reference = no)	41.86				
CG caregiving more than 5 years (reference = no)	50.32				
CG number of helpers		1.92	0.95	1	5
CR female (reference = male)	68.57				
CR different race than CG (reference = no)	9.29				
CR age					
Young old, 65-74 (reference)	31.71				
Old old, 75-84	36.56				
Oldest old, 85+	31.73				
CR education					
Less than high school (reference)	28.91				
High school	29.64				
Some college	25.00				
Bachelor's degree or higher	16.45				
CR homeowner (reference = no)	54.11				
CR receives social assistance (reference = no)	20.56				

Notes: CG denotes caregiver. CR denotes care recipient.

Table 2. 2. Weighted sample percentage of caregivers experiencing a particular caregiving burden or benefit (N=2,202).

	Item	%
Caregiving burden	*Emotional*	
	Emotionally difficult	40.34
	No time for self	45.57
	Too much to handle	39.16
	As soon as routine, need change	29.93
	Interpersonal	
	Care recipient argues with you	59.32
	Care recipient gets on your nerves	63.83
	Physical	
	Exhausted when you go to sleep	45.71
	Physically difficult	20.28
	Financial	
	Financially difficult	17.86
	Kept from work	7.96
	Social	
	Kept from visiting friends/family	13.65
	Kept from religious services	8.26
	Kept from going out for enjoyment	11.08
	Kept from volunteering	5.80
	Kept from caring for others	3.55
	Kept from meetings groups	7.33
Caregiving benefits	*Emotional*	
	Gives you satisfaction	86.06
	Interpersonal	
	Brought closer to care recipient	70.30
	Enjoy being with care recipient	83.85
	Care recipient appreciates you	86.72
	Behavioral/cognitive	
	More confident in abilities	46.88
	Taught you how to deal	53.35

Source: NSOC 2015.

Table 2. 3. Model fit statistics for caregiving experience weighted two to six-latent class solutions.

Classes	LL	Df	AIC	aBIC	Entropy	LMR test	BLR test	Matrix condition #
2	-21445.39	45	42980.77	43094.17	0.84	4464.45 (0.0000)	4923.48 (0.0000)	0.000900
3	-20710.87	68	41557.74	41729.10	0.82	1460.78 (0.0144)	1515.07 (0.0000)	0.000641
4	-20322.44	91	40826.87	41056.19	0.82	772.50 (0.3751)	786.24 (0.0000)	0.001290
5	-20029.69	114	40287.38	40574.65	0.82	582.21 (0.6016)	651.53 (0.0000)	0.001090
6	-19851.55	137	39975.78	40321.01	0.83	355.59 (0.5484)	325.68 (0.0000)	0.000336

Notes: LL = maximum loglikelihood. Df = Degrees of freedom. AIC = Akaike information criterion. aBIC = Adjusted Bayesian information criterion. LMR = Lo-Mendell-Rubin. BLR = bootstrap likelihood ratio. # = number.

Table 2. 4. Five latent classes of the subjective experiences of informal caregiving to older adults. (N=2,202)

		Latent class				
		Intensive Caregivers	Balanced Caregivers	Dissatisfied Caregivers	Relationship Caregivers	Satisfied Caregivers
	Predicted class membership	10%	18%	15%	26%	32%
	Items	*Probability of endorsing item*				
Caregiving burden	*Emotional*					
	Emotionally difficult	**0.82**	**0.61**	**0.79**	0.16	0.17
	No time for self	**0.90**	**0.77**	**0.57**	0.24	0.25
	Too much to handle	**0.82**	**0.73**	**0.54**	0.19	0.15
	Establish routine, then change	**0.69**	**0.54**	0.48	0.09	0.12
	Interpersonal					
	Recipient argues with you	**0.79**	**0.79**	**0.79**	**0.52**	0.38
	Recipient gets on your nerves	**0.87**	**0.84**	**0.93**	**0.58**	0.36
	Physical					
	Exhausted when go to sleep	**0.85**	**0.81**	**0.54**	0.25	0.26
	Physically difficult	**0.57**	0.39	0.28	0.09	0.04
	Financial					
	Financially difficult	0.45	0.34	0.24	0.07	0.06
	Kept from work	0.39	0.09	0.08	0.02	0.03
	Social					
	Kept from visiting friends/family	**0.80**	0.16	0.15	0.01	0.02
	Kept from religious services	**0.59**	0.06	0.05	0.02	0.01
	Kept from going out for enjoyment	**0.84**	0.07	0.10	0.00	0.00
	Kept from meetings, groups	**0.62**	0.04	0.02	0.00	0.00
	Kept from caring for others	0.28	0.01	0.03	0.00	0.01
	Kept from volunteering	0.40	0.06	0.04	0.00	0.01
Caregiving	*Emotional*					
	Gives you satisfaction	**0.84**	**0.95**	**0.60**	**0.80**	**0.98**

Interpersonal					
Brought closer to recipient	**0.57**	**0.95**	0.21	**0.54**	**0.96**
Enjoy being with recipient	**0.68**	**0.96**	0.39	**0.89**	**0.98**
Care recipient appreciates you	**0.68**	**0.91**	**0.56**	**0.95**	**0.98**
Behavioral/cognitive					
More confident in abilities	0.45	**0.62**	0.11	0.06	**0.88**
Taught you how to deal	**0.56**	**0.82**	0.30	0.04	**0.87**

Notes: Item response probabilities higher than 0.50 are highlighted to facilitate interpretation. The conditional probability of not endorsing the item can be obtained by subtracting the probability of endorsing it from 1.

Table 2. 5. Predictors of five types of the subjective experience of informal caregiving to older adults.

	Class 1: Intensive Caregivers			Class 2: Balanced Caregivers			Class 3: Dissatisfied Caregivers	Class 4: Relationship Caregivers			Class 5: Satisfied Caregivers		
	rr	*ci*	*p*	*rr*	*ci*	*p*	*reference*	*rr*	*ci*	*p*	*rr*	*ci*	*p*
Primary stressors													
CR self-rated health score	0.77	0.51-1.16		0.93	0.69-1.25			0.94	0.69-1.29		0.87	0.65-1.17	
CR depression symptoms (PHQ-2)	0.76	0.49-1.20		0.50	0.34-0.72	***		0.48	0.33-0.71	***	0.47	0.32-0.70	***
CR anxiety symptoms (GAD-2)	1.08	0.70-1.67		1.49	0.95-2.34			1.07	0.68-1.68		1.19	0.77-1.82	
CR 3+ diagnoses (ref=<3)	0.58	0.22-1.54		0.45	0.22-0.93	*		0.51	0.25-1.03		0.49	0.24-1.00	
Primary appraisal													
Hours/month caregiving (ref=0-20)													
21 to 63	3.82	1.35-10.79	*	2.86	1.33-6.14	**		1.67	0.86-3.24		1.95	0.95-4.04	
64 or more	3.67	0.95-14.19		1.68	0.77-3.68			0.76	0.30-1.92		1.60	0.73-3.50	
Frequency of ADL help	1.75	1.30-2.35	***	1.55	1.20-2.00	**		0.90	0.66-1.24		1.23	0.94-1.62	
Frequency of IADL help	1.88	0.82-4.28		1.00	0.60-1.66			0.90	0.53-1.54		1.27	0.75-2.16	
Number of medical tasks	1.43	1.16-1.78	**	1.12	0.92-1.36			0.76	0.63-0.93	**	0.88	0.72-1.07	
Key structural/contextual factors													
CG race (ref=white)													
Black	1.07	0.38-3.03		2.86	1.25-6.51	*		2.34	0.90-6.11		3.32	1.49-7.42	**
Hispanic	1.57	0.48-5.08		2.46	0.85-7.09			0.45	0.07-2.89		2.20	0.76-6.35	
Other race	0.42	0.11-1.60		0.73	0.26-2.01			0.53	0.20-1.42		0.95	0.44-2.04	
CG education (ref=less than HS)													
High school	0.54	0.17-1.76		0.86	0.31-2.39			1.02	0.30-3.44		0.98	0.33-2.88	
Some college	0.84	0.25-2.82		0.97	0.34-2.80			1.07	0.34-3.34		0.90	0.33-2.46	
BA+	1.11	0.31-3.95		0.60	0.19-1.95			0.97	0.29-3.21		0.33	0.10-1.09	
CG employment (ref=employed)													
Unemployed	1.11	0.51-2.37		1.15	0.50-2.62			1.38	0.68-2.79		1.31	0.74-2.31	

Retired	1.07	0.51-2.26	1.48	0.64-3.43	1.54	0.79-2.99	1.92	1.00-3.66
CG female (ref=male)	1.70	0.86-3.37	1.43	0.72-2.85	0.90	0.51-1.58	1.31	0.76-2.27
CG age (ref=young adult, 18-39)								
Middle-aged (40-60)	1.08	0.24-4.90	1.01	0.32-3.21	0.30	0.11-0.88 *	0.47	0.17-1.28
Mature adult (61-74)	0.90	0.18-4.43	0.55	0.13-2.36	0.23	0.07-0.76 *	0.27	0.09-0.81 *
Older adult (75+)	2.12	0.28-15.94	0.82	0.10-6.41	0.46	0.09-2.38	0.59	0.12-2.91
CG depression symptoms (PHQ-2)	1.11	0.61-1.99	0.77	0.45-1.33	0.55	0.34-0.90 *	0.49	0.32-0.76 **
CG anxiety symptoms (GAD-2)	1.35	0.81-2.25 *	1.45	0.96-2.18	0.48	0.28-0.83 **	0.50	0.29-0.84 *
Confounding factors								
CG recipient relation (ref=spouse)								
Adult child	1.52	0.44-5.23	0.54	0.16-1.87	0.73	0.24-2.24	0.90	0.30-2.71
Other relative	1.11	0.24-0.50	0.37	0.09-1.52	0.76	0.22-2.55	1.31	0.37-4.68
Nonrelative	0.19	0.01-3.08	0.54	0.11-2.58	1.90	0.51-7.05	4.76	1.28-17.69 *
CG coresident (ref=no)	0.40	0.16-0.99 *	0.44	0.21-0.92 *	0.47	0.20-1.12	0.38	0.19-0.78 **
CG caregiving 5+ years (ref=no)	0.51	0.29-0.90 *	0.73	0.41-1.32	0.78	0.46-1.32	0.82	0.51-1.31
CG number of other helpers	0.91	0.59-1.41	1.06	0.75-1.51	0.95	0.66-1.38	1.15	0.82-1.61
CR female	0.89	0.46-1.73	1.30	0.78-2.16	1.09	0.56-2.13	2.18	1.31-3.63 **
CR different race than caregiver	1.43	0.32-6.48	1.20	0.33-4.36	1.65	0.58-4.66	0.86	0.42-1.78
CR age (ref=young old, 65-74)								
Old old, 75-84	0.99	0.41-2.39	0.68	0.32-1.43	0.49	0.21-1.13	0.51	0.25-1.06
Oldest old, 85+	0.64	0.28-1.47	0.51	0.20-1.27	0.45	0.18-1.13	0.43	0.20-0.94 *
CR education (ref=less than HS)								
High school	1.05	0.40-2.75	0.44	0.18-1.07	0.68	0.29-1.62	0.56	0.23-1.35
Some college	0.67	0.21-2.13	0.44	0.16-1.16	0.55	0.21-1.48	0.56	0.22-1.41
BA+	1.03	0.36-2.91	0.51	0.18-1.45	0.85	0.29-2.50	0.54	0.20-1.43
CR homeowner (ref=no)	0.87	0.46-1.63	0.87	0.46-1.63	1.49	0.78-2.85	1.79	0.99-3.22
CR social assistance (ref=no)	1.15	0.50-2.62	1.12	0.48-2.59	0.93	0.34-2.53	1.27	0.59-2.73

Notes: N=2,202. *p<0.05, **p<0.01, ***p<0.001. rr = relative risk. ci = confidence interval. CR = care recipient. CG = caregiver.

Table 2. 6. Model fit statistics following block additions of auxiliary variables.

Model	Adjustment	AIC	aBIC	df	maxLL	Entropy
Model 0	baseline	40287.38	40574.65	114	-20029.69	0.818
Model 1	+ primary stressors	39753.71	40080.12	130	-19746.85	0.819
Model 2	+ primary appraisal	36753.10	37120.08	150	-18227.49	0.822
Model 3	+ key contextual factors	35018.25	35514.14	206	-17317.32	0.837
Model 4	+ caregiver confounds	34925.29	35478.60	230	-17246.63	0.840
Model 5	+ care recipient confounds	32949.46	33573.34	266	-16231.07	0.855

Notes: Fit statistics obtained using non-imputed data and a one-step auxiliary variable inclusion procedure. AIC = Akaike information criterion. aBIC = Adjusted Bayesian information criterion. df = Degrees of freedom. maxLL = maximum loglikelihood.

Appendix

Table 2. 7. Variable correlation matrix (N=2,202).

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25
Primary stressors																									
1CR SR health	1.00																								
2CR # dep symp.	**-0.32**	1.00																							
3CR # anx symp.	**-0.27**	**0.54**	1.00																						
4CR # of diagnoses	**0.20**	-0.15	-0.13	1.00																					
Primary appraisal																									
5CG # of hours	-0.10	0.10	0.07	-0.07	1.00																				
6CG ADL freq.	-0.16	0.15	0.09	-0.11	**0.44**	1.00																			
7CG IADL freq.	-0.11	0.04	0.03	-0.05	**0.43**	**0.47**	1.00																		
8CG # med. tasks	-0.03	0.10	0.05	-0.06	**0.31**	**0.36**	**0.40**	1.00																	
Contextual factors																									
9CG gender	-0.02	0.01	-0.01	-0.02	0.08	0.02	0.01	0.14	1.00																
10CG age	0.08	-0.07	-0.09	0.02	0.00	-0.08	0.01	-0.01	-0.04	1.00															
11CG race	-0.09	0.08	0.02	-0.05	0.10	0.11	0.18	0.09	0.00	-0.19	1.00														
12CG education	0.17	-0.09	-0.06	0.00	-0.08	-0.08	-0.18	0.09	0.04	-0.04	-0.11	1.00													
13CG work status	0.03	-0.02	0.00	0.02	-0.10	-0.03	-0.12	0.01	-0.02	**-0.43**	0.06	0.19	1.00												
14CG relation	0.00	-0.01	-0.01	0.03	-0.14	-0.07	**-0.27**	-0.18	0.10	**-0.37**	**0.21**	0.02	0.15	1.00											
15CG # dep. symp.	-0.08	0.12	0.11	-0.04	0.13	0.16	0.13	0.08	0.01	0.01	0.06	-0.15	-0.12	-0.09	1.00										
16CG # anx.symp.	-0.06	0.12	0.13	-0.04	0.12	0.11	0.07	0.10	0.12	-0.04	-0.04	-0.07	-0.06	-0.07	**0.54**	1.00									
17CG coresident	-0.03	-0.02	-0.02	-0.01	**0.32**	**0.23**	**0.51**	0.17	-0.14	0.17	0.02	-0.14	-0.19	**-0.44**	0.14	0.08	1.00								
18CG long term	-0.01	0.00	-0.01	-0.04	0.03	-0.03	0.00	-0.01	0.00	0.12	0.01	-0.03	-0.04	-0.16	0.03	0.03	0.06	1.00							
19CG # of helpers	0.00	-0.01	0.04	-0.03	-0.06	0.05	-0.13	-0.15	-0.01	**-0.20**	0.04	-0.04	0.11	**0.23**	-0.05	-0.02	**-0.20**	-0.06	1.00						
20CR gender	0.00	0.04	0.12	-0.08	-0.06	0.02	-0.06	-0.05	-0.14	-0.06	0.00	0.04	0.05	0.17	0.01	-0.01	-0.15	-0.03	0.07	1.00					
21CR different race	0.02	0.05	0.00	-0.03	0.03	0.00	0.03	0.00	0.02	-0.05	**0.57**	-0.03	0.03	0.17	0.00	-0.01	-0.04	0.00	0.02	0.00	1.00				
22CR age	0.16	-0.06	-0.04	0.08	0.03	0.00	-0.19	0.06	0.08	0.19	-0.09	0.17	-0.02	0.16	-0.08	-0.04	-0.19	0.00	0.12	0.15	-0.03	1.00			
23CR education	**0.21**	-0.12	-0.13	0.07	-0.06	-0.09	-0.13	-0.13	-0.05	0.13	**-0.21**	**0.35**	0.01	-0.12	-0.06	0.00	0.05	-0.03	-0.06	-0.04	-0.01	-0.03	1.00		
24CR homeowner	-0.04	-0.05	-0.08	0.03	0.05	-0.02	0.08	-0.04	-0.05	0.10	-0.09	-0.01	-0.07	**-0.20**	0.03	0.03	0.12	0.06	-0.05	-0.10	0.02	-0.17	0.11	1.00	
CR receives 25assist.	-0.12	0.06	0.07	-0.05	0.03	0.04	0.10	0.05	0.00	-0.14	0.18	-0.14	0.03	0.06	0.07	0.03	-0.05	0.04	-0.02	0.09	0.02	-0.08	**-0.25**	-0.08	1.00

Notes: CG = caregiver. CR = care recipient. # = Number. ADL = Activities of daily living. IADL = Instrumental activities with daily living. Correlations ≥|0.20| are bolded to facilitate interpretation.

Table 2. 8. Correlation matrix for latent class measurement model indicators (N=2,202).

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
	Caregiving burden																					
1	Emotionally difficult	1.00																				
2	No time for self	**0.26**	1.00																			
3	Too much to handle	**0.33**	**0.47**	1.00																		
4	As soon as routine, need change	**0.29**	**0.30**	**0.30**	1.00																	
5	Care recipient argues with you	**0.25**	0.14	0.17	**0.25**	1.00																
6	Care recipient gets on your nerves	**0.31**	**0.20**	**0.22**	**0.24**	**0.51**	1.00															
7	Exhausted when you go to sleep	**0.30**	**0.37**	**0.49**	**0.32**	0.17	**0.23**	1.00														
8	Physically difficult	**0.36**	**0.21**	**0.30**	**0.26**	0.17	0.19	**0.30**	1.00													
9	Financially difficult	**0.25**	**0.20**	**0.24**	**0.22**	0.14	0.13	**0.21**	**0.29**	1.00												
10	Kept from work	**0.21**	0.19	**0.20**	**0.20**	0.07	0.09	0.17	0.12	**0.22**	1.00											
11	Kept from visiting friends/family	**0.29**	**0.29**	**0.31**	**0.30**	0.12	**0.21**	**0.27**	**0.32**	**0.24**	**0.29**	1.00										
12	Kept from religious services	**0.20**	0.19	0.18	**0.23**	0.11	0.13	**0.21**	**0.20**	0.18	**0.25**	**0.40**	1.00									
13	Kept from going out for enjoyment	**0.27**	**0.26**	**0.28**	**0.29**	0.13	0.17	**0.28**	**0.25**	**0.23**	**0.35**	**0.60**	**0.45**	1.00								
14	Kept from meetings, groups	**0.22**	**0.24**	**0.20**	**0.23**	0.08	0.13	**0.24**	**0.23**	0.18	**0.34**	**0.48**	**0.47**	**0.58**	1.00							
15	Kept from caring for others	0.14	0.13	0.16	0.15	0.05	0.07	0.12	0.17	0.14	**0.27**	**0.30**	**0.29**	**0.34**	**0.36**	1.00						
16	Kept from volunteering	**0.20**	0.17	0.17	**0.22**	0.09	0.12	0.16	0.19	**0.20**	**0.33**	**0.36**	**0.37**	**0.39**	**0.42**	**0.39**	1.00					
	Caregiving benefits																					
17	Gives you satisfaction	-0.09	-0.01	-0.03	-0.03	-0.07	-0.12	0.02	-0.04	-0.04	0.02	-0.03	0.00	-0.03	-0.01	-0.03	0.02	1.00				
18	Brought closer to care recipient	-0.18	-0.05	-0.06	-0.06	-0.15	**-0.20**	-0.01	-0.05	-0.01	-0.02	-0.04	-0.02	-0.08	-0.05	-0.05	-0.02	**0.39**	1.00			
19	Enjoy being with care recipient	**-0.28**	-0.09	-0.12	-0.12	-0.16	**-0.25**	-0.07	-0.10	-0.10	-0.06	-0.13	-0.08	-0.17	-0.08	-0.07	-0.04	**0.30**	**0.39**	1.00		
20	Care recipient appreciates you	**-0.25**	-0.10	-0.14	-0.17	**-0.21**	**-0.22**	-0.09	-0.17	-0.15	-0.09	-0.18	-0.12	-0.18	-0.14	-0.08	-0.13	**0.21**	**0.31**	**0.41**	1.00	
21	More confident in abilities	-0.11	0.01	-0.04	-0.02	-0.10	-0.18	0.01	-0.07	0.01	-0.01	-0.04	0.03	-0.05	-0.02	0.01	0.00	**0.26**	**0.41**	**0.25**	0.15	1.00

Notes: Correlations ≥|0.20| are bolded to facilitate interpretation.

Table 2. 9. Sample descriptive statistics by caregiving experience latent class.

		Latent class					
	Sample	Class 1: Intensive Caregivers	Class 2: Balanced Caregivers	Class 3: Dissatisfied Caregivers	Class 4: Relationship Caregivers	Class 5: Satisfied Caregivers	Diff. Sig.
Predicted class membership	N = 2,202	10%	18%	15%	26%	32%	
Caregiver characteristics							
Female (yes)	62.35	74.24	65.27	59.86	56.07	63.31	*
Age (years)	58.72 (0.78)	59.28 (1.15)	58.24 (1.10)	60.34 (1.01)	59.80 (0.61)	57.21 (1.06)	
Race							***
White	67.37	67.02	62.94	75.71	77.97	57.69	
Black	12.5	11.79	14.27	6.04	9.67	16.93	
Hispanic	9.22	13.02	12.7	4.98	3.08	12.99	
Other	10.91	8.18	10.09	13.26	9.28	12.39	
In household (yes)	41.83	58.87	49.27	44.7	35.83	36.11	***
Relationship type							***
Spouse	21.25	27.61	26.04	23.37	21.1	15.87	
Adult child	45.53	58.8	52.55	52.36	41.33	37.93	
Other relative	22.23	13.11	16.34	18.78	23.38	28.85	
Other nonrelative	10.99	0.48	5.07	5.5	14.19	17.35	
Marital status							**
Married/partnered	64.29	64.72	65.43	70.1	69.69	56.58	
Separated/divorced	13.13	19.53	12.04	12.92	10.48	14.2	
Widowed	6.66	4.6	3.69	3.34	8.1	9.29	
Never married	15.92	11.16	18.84	13.64	11.72	20.1	
Education							***
Less than HS	10.34	12.13	12.23	7.14	6.97	12.93	
High school	26.86	20.26	28.97	26.11	23.99	30.31	
Some college	35.53	35.38	35.16	29.48	32.43	31.04	
BA or higher	27.27	32.23	23.64	37.27	36.61	15.73	
Work status							
Employed	41.41	38.15	43.15	45.62	42.6	38.53	
Unemployed	26.87	32.17	26.71	24.75	26.87	27.24	
Retired	31.72	29.68	30.14	29.63	31.66	34.23	
Health							
Self-rated (0 to 4)	2.47 (0.04)	2.11 (0.11)	2.31 (0.09)	2.41 (0.08)	2.52 (0.08)	2.66 (0.06)	***

Depr. symp. (0 to 6)	0.97 (0.05)	1.77 (0.13)	1.28 (0.11)	1.26 (0.13)	0.65 (0.05)	0.69 (0.07)***
Anx. symp. (0 to 6)	1.04 (0.05)	1.89 (0.16)	1.51 (0.11)	1.30 (0.10)	0.65 (0.06)	0.71 (0.07)***
Care recipient characteristics	N=1,458					
Female (yes)	68.63	61.32	67.8	65.07	68.11	74.85
Age (years)	79.42 (0.34)	79.90 (0.74)	78.14 (0.75)	81.47 (0.76)	79.83 (0.77)	78.63 (0.61)*
Race						*
White	70.52	70.44	69.48	76.58	77.22	62.07
Black	12.08	9.4	13.85	5.67	9.98	17.45
Hispanic	8.72	13.07	12.28	5.4	4.38	9.87
Other	8.68	7.09	4.39	12.35	8.41	10.61
Marital status						
Married/partnered	45.82	51.94	44.94	44.21	49.58	41.62
Separated/divorced	10.05	7.27	12.78	9.76	10.5	9.01
Widowed	40.8	39.41	39.22	43.8	36.72	44.26
Never married	3.33	1.39	3.07	2.23	3.2	5.11
Number in HH	2.22 (0.07)	2.37 (0.13)	2.45 (0.17)	2.21 (0.16)	1.99 (0.07)	2.20 (0.08)*
Number of children	3.21 (0.07)	3.48 (0.28)	3.14 (0.11)	3.21 (0.15)	2.96 (0.14)	3.38 (0.15)
Education						*
Less than HS	28.94	27.81	35.12	23.13	22.24	33.88
High school	29.67	35.67	25.28	36.99	27.52	27.95
Some college	29.92	21.35	23.57	26.25	24.77	26.9
BA or higher	16.46	15.16	16.03	13.64	25.46	11.27
Longest-held occupation						
Upper-white collar	27.42	24.71	26.81	28.42	31.79	24.76
Lower-white collar	33.95	37.09	33.3	28.4	32.27	38
Blue collar	26.04	26.86	31.27	28.31	23.06	24.15
Other	12.23	11.34	8.62	15.23	12.88	13.08
Received social assistance (yes)	20.58	23.49	19.6	17.25	14.11	27.51*
Homeowner	54.07	50.89	50.48	49.99	57.57	57.47
Health						
Self-rated health (0 to 4)	1.60 (0.04)	1.36 (0.09)	1.45 (0.10)	1.62 (0.11)	1.84 (0.08)	1.58 (0.07)**
Depr. symp. (0 to 6)	1.61 (0.07)	2.08 (0.17)	1.65 (0.11)	2.04 (0.18)	1.28 (0.14)	1.43 (0.11)**
Anx. symp.(0 to 6)	1.43 (0.08)	1.70 (0.19)	1.74 (0.23)	1.54 (0.16)	1.07 (0.11)	1.34 (0.11)**
ADL disabilities (0 to 4)	3.16 (0.06)	4.04 (0.18)	3.27 (0.16)	3.30 (0.13)	2.72 (0.11)	3.01 (0.09)***
Diagnoses (0 to 11)	2.21 (0.08)	2.51 (0.21)	2.50 (0.25)	2.20 (0.15)	1.84 (0.16)	2.20 (0.14)

Care characteristics	N = 2,202					
Hours helped in past month	67.28 (3.15)	153.78 (11.93)	80.65 (6.18)	52.90 (7.17)	34.93 (3.05)	66.13 (4.93)***
Years caregiving to SP	7.38 (0.30)	6.91 (0.59)	8.27 (0.64)	8.78 (0.88)	7.16 (0.58)	6.57) (0.30)*
Freq. ADL help (0 to 4)	1.34 (0.03)	2.33 (0.13)	1.68 (0.07)	1.13 (0.08)	0.86 (0.06)	1.34 (0.06)***
Freq. IADL help (0 to 4)	1.56 (0.03)	2.11 (0.05)	1.74 (0.05)	1.41 (0.06)	1.26 (0.04)	1.60 (0.04)***
Number medical tasks (0 to 6)	2.36 (0.08)	4.01 (0.11)	3.05 (0.13)	2.54 (0.13)	1.52 (0.12)	2.07 (0.12)***
Tasks						
Freq. helps laundry/cleaning/meals (0 to 4)	2.15 (0.04)	3.06 (0.09)	2.47 (0.11)	2.03 (0.11)	1.64 (0.08)	2.17 (0.07)***
Freq.helps with shopping (0 to 4)	1.98 (0.04)	2.65 (0.09)	2.17 (0.07)	1.86 (0.08)	1.57 (0.07)	2.06 (0.06)***
Helps order medicines (% yes)	42.69	72.82	57.57	41.39	22.62	42.03***
Helps with bills/banking	54.71	73.58	66.78	58.89	44	49.02***
Freq. helps with personal care (0 to 4)	1.15 (0.04)	2.29 (0.14)	1.51 (0.09)	0.93 (0.10)	0.62 (0.06)	1.12 (0.07)***
Freq. helps with getting around (0 to 4)	1.54 (0.03)	2.37 (0.14)	1.86 (0.07)	1.32 (0.08)	1.11 (0.07)	1.57 (0.06)***
Freq. helps drive (0 to 4)	1.72 (0.04)	2.15 (0.10)	1.84 (0.09)	1.50 (0.11)	1.54 (0.06)	1.76 (0.07)***
Freq. accompanies on transit (0 to 4)	0.39 (0.03)	0.60 (0.11)	0.47 (0.07)	0.24 (0.04)	0.28 (0.04)	0.43 (0.05)**
Helps track medicines (% yes)	43.66	79.33	57.26	40.46	25.35	41.54***
Helps take shots (% yes)	8.15	16.76	14.94	4.16	2.88	7.84***
Helps manage medical tasks (% yes)	9.07	18.8	13.08	7.92	3.79	8.69***
Helps with medical exercises (% yes)	24.96	48.74	34.17	18.71	12.89	25.22***
Helps with special diet (% yes)	25.7	42.56	39.37	18.37	12.52	26.96***
Helps care for teeth (% yes)	13.11	32.33	16.92	10.02	3.43	14.39***
Helps care for feet (% yes)	25.19	49.61	37.21	20.04	11.76	24.31***
Helps care for skin (% yes)	21.26	49.98	29.15	16.94	11.92	17.75***
Helps make medical appointments (% yes)	54.43	81.67	68.76	65.5	36.99	47.19***
Speaks to medical doctor (% yes)	46.31	76.52	60.92	58.79	33.64	33.63***
Helps change insurance (% yes)	20.47	37.82	26.85	17.78	12.23	19.56***
Helps with insurance matters (% yes)	28.11	52.85	34.08	30.03	20.81	22.37***
Caregivers' caregiving support (% yes)						
Has friends/family to talk to	86.64	78.26	85.85	82.86	86.78	91.17**
Has friends/family to help them	55.06	50.57	54.77	52.88	55.71	57.04
Has friends/family to help with SP	69.35	65.93	70.57	66.81	70.37	70.06
Went to carer support group	3.88	6.77	5.43	4.31	2.32	3.19
Used respite care	15.26	28.2	15.81	31.93	8.55	8.81***
Received care training	6.9	15.38	6.91	7.11	4.21	6.41**
Looked for information	8.28	24.45	8.87	10.58	2.77	6.44***

Notes: Percentages by column provided for categorical variables. Means and standard errors provided for continuous variables. $p<0.05$*, $p<0.01$**, $p<0.001$***.

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Chapter 3

Receiving Support and Caregiving Experiences: How do Informal and Formal Support for Caregivers Shape Their Burden and Benefit Perceptions?

Abstract

Caring for older adults can be an ambivalent experience, generating both benefits and burden for caregivers. Informal (i.e., unpaid) caregivers may be able to access informal assistance from family and friends, and formal assistance like training, or respite care; this support may shape caregiving experiences. I extend previous studies that focus on the role of social support only in shaping only burden perceptions to also include benefit perceptions. Further, I modify and extend the caregiving appraisal framework to examine how receiving informal and formal support is associated with distinguishable caregiving experience types that include negative as well as positive appraisals. I merge National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC) data to obtain caregivers' and recipients' own reports. I conduct latent class regression analysis on a nationally representative sample of US informal caregivers for older adults. I examine: 1) how receiving informal and formal support is associated with caregiving experience types (each characterized by an unique combination of caregivers' perceived burden and benefits), controlling for conceptually relevant factors (care recipient health factors as primary stressors, caregiving intensity and tasks as primary appraisal factors, and contextual or structural factors); and 2) whether receiving support buffers the association between primary stressors and primary appraisal with caregiving experience types. The results show that receiving informal support is associated with perceiving high

benefits, and that receiving such support may reduce burden perceptions. In contrast, receiving formal assistance does not appreciably alleviate perceived burden, suggesting that caregivers may be reluctant to use such services, or that only caregivers with high levels of burden seek out formal help. Finally, social support may affect perceived burden and benefits independently of stress levels. Given these findings, it may be important to introduce formal support options to caregivers early after they assume their role, and to de-stigmatize and encourage formal service use.

Keywords

Informal caregiving, NHATS, NSOC, social support.

Introduction

Informal caregivers are integral to the US long-term care system. Over 34 million Americans provided informal (i.e., unpaid) care to an older individual in 2015, and informal caregivers are often older adults' only source of assistance outside residential and nursing facilities (AARP, 2015; Centers for Disease Control and Prevention, 2011; Doty, 2015). Caregivers are a heterogeneous group of family and non-kin individuals who help with a range of tasks, from instrumental activities like shopping to more intensive personal care like bathing (Wolff & Kasper, 2006). Given population aging, an increasing number of individuals living with chronic and degenerative illnesses, and a changing landscape of family demography, the demand for informal caregivers will become increasingly pressing in the coming decades (US Census Bureau, 2016; US Department of Health and Human Services, 2003).

Ensuring that caregivers have positive and beneficial caregiving experiences allows them to stay in better health, to provide higher quality care, and to continue on in their roles for a longer period of time (Cohen et al., 2002). However, caring for older adults can be an ambivalent experience—it can generate benefits, but also burden for the caregiver (Chen & Greenberg, 2004; Walker, Pratt, & Eddy, 1995). Caregiving benefits, also referred to as satisfaction, gains, rewards, or uplifts, encompass the objective and perceived positive consequences resulting from caregiving (Braithwaite, 1996; Cohen, Colantonio, & Vernich, 2002; Kramer, 1997; Pearlin, Mullan, Semple, & Skaff, 1990; Tarlow et al., 2004;). Conversely, caregiving burden, also conceptualized as strain, stress, or costs, refers to the objective and perceived negative consequences of providing care (Hunt, 2003; Vitaliano, Russo, Young, Becker, & Maiuro, 1991; Zarit, Reever, & Bach-

Peterson, 1980). Theoretical efforts like the two-factor caregiving appraisal model have integrated the two facets of the caregiving experience, arguing that both types of appraisal can result from the same objective situation (Lawton, Kleban, Dean, Rajagopal, & Parmelee, 1992; Pruchno, Peters, & Burant, 1995).

Receiving support is an essential factor that can shape caregivers' experiences (Pearlin et al., 1990; Verbakel, Metzelthin, & Kempen, 2016). For example, confiding in friends may alleviate caregivers' emotional burden and help them to recognize more personal benefits, and using respite care may reduce physical burden. Those who can leverage social ties to receive support may be better able to adjust and cope; in this way, social support may shape perceived caregiving experiences. Support refers to the "exchange of resources between two individuals perceived by the provider or the receiver as intended to enhance the receiver's well-being" (Shumaker & Brownell, 1984).). Informal support (like assistance from family and friends) and formal support (like institutional training and respite programs) may shape the behavioral and psychological actions that caregivers take to manage stressful events and circumstances (Lazarus & Folkman, 1984; Taylor & Stanton, 2007). The caregiving appraisal model provides a useful framework for conceptualizing the process: In this framework, primary appraisal refers to care given in response to recipient's needs (like the type and intensity of care that a caregiver provides), and it results from primary stressors, or factors engendering the need for caregiving (such as care recipient health status). According to the direct effects hypothesis, caregivers' informal and formal support receipt are in turn associated with primary stressors and caregiving experiences (labeled secondary appraisal). According to the buffering effects hypothesis, they may also moderate the association.

Despite theoretical reason for considering caregiving burden and benefits simultaneously, caregiving experiences (or secondary appraisal) are typically operationalized only as caregiver burden (or negative appraisal). This conceptualization fails to recognize potential ambivalence, and burden and benefits as two co-existing appraisals arising from the same situation (Andren & Elstahl, 2005; Boerner, Schulz, & Horwitz, 2004; Brown & Brown, 2014; Kramer, 1997; Lawton, et al., 1992; Pruchno et al., 1995). Caregiving experience frameworks and research exploring the importance of support resources within it focus heavily on negative appraisals (Goldsworthy & Knowles, 2008; van den Wijngaart, Vernooj-Dassen, & Felling, 2007; Verbakel et al., 2016; Yates, Tennstedt. & Chang, 1999). Building on conceptual models interested in explaining burden, these frameworks overlook the importance of informal and formal support as factors simultaneously facilitating the perception of benefits (Pearlin et al., 1990). When research does consider the link between support resources and both positive and negative appraisals, burden and benefits are studied in isolation rather than together, and rarely within one individual (Brand, Barry, & Gallagher, 2016; van den Wijngaart et al., 2007).

Given that burden and benefits co-exist, examining support in relation to positive and negative appraisals separately cannot explain how possessing particular support resources may alter both types of appraisal at the same time and for the same caregiver (Andren & Elstahl, 2005; Boerner et al., 2004; Brown & Brown, 2014; Kramer, 1997). Thus, although studies have examined the importance of informal and formal support for caregivers, they have typically only captured changes in one appraisal type (Sorensen, Pinquart, & Duberstein, 2002). A second limitation of prior work on caregiving

appraisals is that studies are frequently carried out in non-representative samples of caregivers to older adults with particular illnesses (Acton & Kang, 2001; Brodaty, Green, & Koschera, 2003; Parker, Mills, & Abbey, 2008; Sorensen et al., 2002).

To address these two limitations and capture how perceptions of burden and benefits co-exist, in previous work using a nationally representative sample of informal caregivers to US older adults, I develop the following typology of five distinct caregiving experiences (see chapter 1 of dissertation). The presence or absence, level, and burden and benefit domain uniquely characterize the experience types. "Intensive Caregivers" experience high burden and moderate benefits across all domains and are the only group reporting burden in the social domain; "Balanced Caregivers" report moderate burden and high benefits; "Dissatisfied Caregivers" report predominantly burden and low to absent benefits; "Relationship Caregivers" report high interpersonal benefits and low burden limited to the same domain; and "Satisfied Caregivers" report high benefits and no burden. In the current analysis, I employ this typology to operationalize caregiving experience types, or secondary appraisal (Figure 1).

There are several benefits to examining the relationship between informal and formal support and caregivers' simultaneous perceptions of burden and benefits. First, such an inquiry expands our understanding of how support resources matter for both negative and positive caregiving experiences (Lawton et al., 1992; Pruchno et al., 1995). It recognizes the co-existence of burden and benefits from caregiving, and revises past portrayals of caregiving as an overwhelmingly negative and stressful experience (Kramer, 1997). Relatedly, it addresses the imbalance in evaluating the potential of informal and formal support for only reducing caregiver burden.

Second, it is useful to study the association between support for caregivers and perceptions of benefits and burdens because informal and formal support are potentially malleable, and may be opportunities for targeted interventions aimed at improving both caregivers' and care recipients' outcomes (Roberts, Walton, & Viechtbauer, 2006). Although studies of caregiver services and interventions typically examine changes in burden, it may not always be possible for support resources to reduce perceived or objective burden. In such situations, it may be preferable to instead design interventions to increase perceptions of benefits from caregiving (Folkman et al., 1991; Toohey, Muralidharan, Medoff, Lucksted, & Dixon, 2016).

Finally, objective and perceived beneficial experiences matter for caregivers' quality of life. The World Health Organization (WHO) defines health not only as the absence of disease, but also the presence of overall well-being (WHO, 2017). A quarter of all caregivers report that it is difficult to get affordable and helpful support, which may affect their own health and ability to provide care (AARP, 2015). It is crucial to ensure caregivers get the support they want and need to meet their own needs; maintaining caregivers' own health and well-being his may facilitate good caregiving experiences and the provision of higher quality care (Cohen et al., 2002). It is therefore also important to evaluate different support types for their associations with co-occurring benefit and burden perceptions to inform services that can facilitate good caregiving experiences. Given the above, understanding associations between informal and formal support, and burden and benefits simultaneously—while recognizing the diversity in the nature of care that individuals provide—is both theoretically and practically relevant.

In this study, I modify the caregiving appraisal framework that focuses only on negative appraisals and use a caregiving experience typology that includes caregivers' both burden and benefits perceptions (see Chapter 1 of dissertation). I examine whether and how receiving different types and levels of social support is associated with distinguishable caregiving experience types, each uniquely characterized by caregivers' perceived benefits and burden (Collins & Lanza, 2010). I combine National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC) data to gather caregivers' as well as recipients' own reports; doing so avoids potential single-informant bias resulting from caregivers reporting on recipient factors, and it allows me to better capture how caregiver-reported experiences respond to recipient-reported stressors. I use a nationally-representative sample of US caregivers to older adults and conduct latent class analysis to address the following research questions:

1) To what extent are informal and formal support receipt associated with distinct caregiving experience types? (See previous description of caregiver appraisal types developed in Chapter 1.) Are particular support types associated with qualitatively different experiences that include perceiving high benefits only, low burden only, or perceiving high benefits and low burden at the same time?
2) Do the effects evaluated in (1) persist after controlling for primary stressors (recipient health status), primary appraisal (type and frequency of care provided), and contextual (structural) factors?

3) Does receiving informal or formal support buffer the association between primary stressors and caregiving experience types, or primary appraisal and caregiving experience types?

Conceptual framework

I use a modified stress appraisal conceptual model to examine the associations between informal and formal social support and caregiving experience types, where the latter are uniquely characterized by both perceived burden and benefits (Verbakel et al., 2016). This framework follows the caregiving stress process model and draws on the two-factor caregiving appraisal model to recognize the subjective nature of stress responses (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Pearlin et al., 1990). It conceptualizes informal and formal support as potentially buffering stress process factors (Morano, 2003; Verbakel et al., 2016).

The framework posits that contextual factors, primary stressors, primary appraisal, and support and contextual factors shape subjective caregiving experiences (Figure 1). In the framework, contextual factors refer to demographic (caregiver gender, age, race), socioeconomic (caregiver education level, employment status), and health factors that shape caregivers' exposure and responses to stressors (Pinquart & Sorensen, 2003; 2005; 2006). For example, women are more likely to be primary caregivers and to provide intensive care, and are less likely to ask for help; this may shape their experiences negatively (Pinquart & Sorensen, 2006). Similarly, middle-aged and older caregivers may be balancing multiple competing demands with caregiving (Stone &

Short, 1990). Due to lack of resources or access to services, low SES and minority caregivers may be providing more hours of care and more intensive care, and may be offering assistance to individuals in poorer health, which may result in negative caregiving perceptions (Evercare and National Alliance for Caregiving, 2008; Pinquart & Sorensen, 2005). Further, caregivers experiencing symptoms of anxiety or depression—caregivers frequently develop poor mental health (Pinquart & Sorensen, 2003) —may negatively evaluate their caregiving experiences.

Primary stressors refer to factors giving rise to the need for caregiving. For example, recipients in poorer health may need more frequent assistance or assistance with intensive tasks such as personal care, which may be taxing for the caregiver and increase caregiving hours; recipients in good health may require less physically or otherwise demanding care, which may facilitate bonding rather than engender burden. To capture primary stressors, I include measures of care recipient self-rated health, number of medical diagnoses, and depression and anxiety symptoms. Primary stressors are frequently reported by proxy through the caregiver; linking caregiver and recipient data allows me to use care recipients' own reports about their health status, thus avoiding potential bias in the caregivers' rating due to underlying mood or viewpoint. It further helps address concerns about caregivers' mental health status biasing reports of primary stressors.

Primary stressors are linked to caregiving experiences through a primary appraisal pathway. Primary appraisal refers to care given in response to primary stressors. In addressing stressors that give rise to the need for care (recipient health), caregivers provide a lower or higher number of hours of assistance to the recipient, different

frequency of help with basic activities of daily living (ADL), frequency of help with instrumental activities of daily living (IADL), and frequency of help with medical tasks. I measure primary appraisal using these care characteristics as reported by caregivers themselves. In this way, I am able to capture how caregivers report on primary appraisal (care intensity and type) in response to care recipient-reported primary stressors (recipient health). As individuals who provide a high number of hours of care and more intense assistance are also likely to be the recipient's spouse or partner and to cohabit, I also account for these potentially confounding factors in my analyses (AARP, 2015).

The framework further posits that informal and formal social support shape caregiving experiences and may buffer the effect of primary stressors (recipient health status) and appraisal (care provided) on caregiving experiences, or secondary appraisals. As such, it follows the stress buffering effects hypothesis about support processes, which suggests that receiving social support may be particularly important at high burden levels. Research indicates that support may not be uniformly protective against stress, and that it may instead only be relevant with acute exposure to stressors, and when stress levels are high (Cohen & Wills, 1985; Gerin, Milner, Chawla, & Pickering, 1995; Krause, 1986; Wheaton, 1985). Alternatively, following the social support direct effects hypothesis, informal and formal support may improve caregiving experiences regardless of burden level (Bell, LeRoy, & Stephenson, 1982; Williams, Ware, & Donald, 1981).

Although the modified stress appraisal model incorporates appraisal into the stress process, it does not integrate insights on caregiving appraisals' ambivalence: it focuses on negative perceptions and operationalizes secondary appraisal, or subjective caregiver experience, only as caregiver burden. It fails to recognize that positive appraisals, or

benefits, can arise from the same caregiving situation (Lazarus & Folkman, 1984; Chen & Greenberg, 2004). Negative (burden) and positive appraisals (benefits) represent two separate dimensions of the same experience (Lawton et al., 1992; Pruchno et al., 1995). Subjective burden is a multidimensional construct that reflects negative appraisal and encompasses the perceived negative caregiving consequences. Conversely, subjective benefits are a multidimensional construct that reflects a caregiver's positive appraisal, and encompasses the perceived positive consequences of caregiving (Brown & Brown, 2014; Zarit, 2012). The two types can co-exist: for example, a caregiver may experience physical or financial burden, but she or he may simultaneously draw emotional benefits from their relationship with the recipient. Given the heterogeneity of kin and non-kin relationships, socioeconomic backgrounds, and task profiles among US informal caregivers, it is important to recognize these factors can also facilitate varied—negative, positive, or ambivalent—experiences (Wolff & Kasper, 2006).

Rather than understanding caregiving as primarily burdensome, I thus modify the conceptual model to include benefits as well as burden in operationalizing secondary caregiving appraisal (Lawton et al., 1992; Kramer, 1997). In prior work, I extend research focusing on burden only and develop an informal caregiving experience typology that acknowledges the ambivalence of perceptions: it integrates caregivers' burden and benefit appraisal, as well as considers each appraisal type as multidimensional. Using latent class analysis on NHATS and NSOC data from a nationally representative sample of US informal caregivers to older adults, I identify five distinguishable informal caregiving experience subtypes. Each group is unique in the type and intensity of reported burden and benefits.

In two types (labeled “Intensive Caregivers” and “Balanced Caregivers”), burdens and benefits co-occur. Intensive Caregivers report experiencing high burden and moderate benefits across all emotional, interpersonal, physical, and social domains. Compared to other caregivers, their perceived burden is the highest, but their perceived benefits are comparable to those who report little to no burden. Balanced Caregivers report moderate burden—with an absence of social burden—coexisting with high benefits, also at levels comparable to those of caregivers reporting no burden. In the third type (“Dissatisfied Caregivers”), caregivers report experiencing only burden, at levels comparable to that of Intensive or Balanced Caregivers. Finally, in two types (“Relationship Caregivers” and “Satisfied Caregivers”), caregivers indicate predominantly experiencing benefits. Relationship Caregivers experience these benefits in the interpersonal domain and also report some low burden in this domain; Satisfied Caregivers do not indicate experiencing any burden, and their benefits perception is higher than that of any other group.

To recognize the multiplicity and ambivalence of caregivers’ perceptions and to consider caregivers’ positive and negative perceptions simultaneously, I use these five types of caregiving experiences in operationalizing secondary appraisal in my analyses. I consider the association between receiving informal and formal social support and having a particular experience type (that is, experiencing one of the five representative and distinguishable types of burden and benefit combinations). Figure 1 shows the resulting conceptual framework.

Informal and formal social support and their association with caregiving appraisal

Social support refers to the perceived or actual resources (such as emotional, behavioral, physical, financial, or other resources) that caregivers may receive and that they may use in order to address challenges related to caregiving (Chappell & Funk, 2011; Taylor & Stanton, 2007; Verbakel et al., 2016). Social isolation can be detrimental to health and well-being, and given the often demanding nature of tasks like personal care and ADL assistance, caregivers without social support may be at elevated risk of having poor experiences (Lilly, Richards, & Buckwaiter, 2003). Those who can draw on their social ties and institutions to receive support may be able to better cope with stressors, adjust more easily, and obtain assistance that alleviates their burden. Caregivers may receive two main types of social support (formal and informal) that could shape their experiences; both informal and formal support may reduce caregivers' objective or perceived burden, or increase their objective or perceived benefits (Lazarus & Folkman, 1984; Taylor & Stanton, 2007). Informal and formal social support may thus shape caregiving appraisals (Morano, 2003; Pearlin et al., 1990; Verbakel et al., 2016; Yates et al., 1999).

Informal support. Informal support refers to the subjective and objective interpersonal resources available to caregivers that they can mobilize to address stressors (Barrera, 1986; House, Umberson, & Landis, 1988). It entails practical and material assistance, as well as the perception of being loved, cared for, valued, and included in a network of mutual assistance, with some studies suggesting that the perception of support may matter even more than objectively received support for caregiver well-being (O'Rourke & Tuokko, 2000; Taylor & Stanton, 2007). Informal support is typically provided without financial compensation and received from family and friends (Close,

Estes, & Linkins, 2001). A Canadian study shows that family caregivers commonly receive support from spouses, siblings, in-laws, and friends, as well as from their adult children (Sims-Gould & Martin-Matthews, 2007). Especially in caring for parents, spouses and siblings often share caregiving responsibilities; primary caregivers may have the support of secondary ones, and about half of US caregivers report having such help (Gaugler, Mendiondo, Smith, & Schmitt, 2003; Matthews & Rosner, 1988; Wolff & Kasper, 2006). Caregivers may receive instrumental (support directly to the caregiver and support in caring for the recipient) as well as emotional assistance (Sims-Gould & Martin-Matthews, 2007). Over 70% of caregivers look to family, friends, and to fellow caregivers to get both information and support, and they seek informal help at higher rates than non-caregivers (Pew Research Center, 2013).

Individuals who perceive high informal support may be able to better manage stress, adjust to a stressful caregiving situation more quickly, experience lower objective burden and higher benefits, or benefit in other life domains from good social integration (Lilly et al., 2003). For example, among Dutch informal caregivers, those receiving help from friends and family report spending fewer hours on caregiving and experience lower perceived burden (Verbakel et al., 2016). In a Chinese sample, caregivers reporting low levels of informal support also report higher perceived burden than their counterparts with more social capital (Wang, Zhong, Ji, & Chen, 2016). Similarly, caregivers who perceive having higher informal social support are more likely to report benefits than those with low informal support (Brand, Barry, & Gallagher, 2016).

Several intervention studies providing informal social support and resources to caregivers find no differences in perceived burden between caregivers who receive the

intervention versus those who do not (Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016; Pinquart & Sorensen, 2006). However, the inconsistency may be due to differences in social support definitions, the measurement of burden and stress, in the caregivers who were part of the intervention or the type of care they were providing (for example, studies frequently focus on dementia caregivers only), and in whether the provision of informal support was part of a multi- or single-component intervention. Quantitative analyses using a nationally representative sample of informal caregivers allow me to examine the importance of informal support receipt among the general population of caregivers without regard to experimental settings.

Formal support. Formal support refers to formally or institutionally organized services, programs, and resources like information and skills training relevant to the care recipient's disease, disease management, and caregiving (Chappell & Funk, 2011; Verbakel et al., 2016). Contrary to informal support, formal assistance is typically tied to institutions and organizations, and either privately or publicly financed (Coward & Dwyer, 1991; Penrod, Harris, & Kane, 1994). Caregivers can access formal support like lectures or organized groups, where participants share experiences and knowledge (Chien et al., 2011; Corbett et al., 2011; Elvish, Lever, Johnstone, Cawley, & Keady, 2013; Greenwood, Pelone, & Rassenkamp, 2016; Thompson et al., 2007). Formal support also includes other institutionally-provided assistance like transportation services and respite programs, which provide temporary time away from the care recipient and care activities; such respite can include in-home care, adult day care, group care, and overnight care (Feinberg & Kelly, 1995; Sorensen et al., 2002). About 28% of US caregivers use transportation services, 19% use training, and 15% use respite care (AARP, 2015).

Caregivers' formal support receipt is associated with their burden perceptions (although the causal direction may be reverse, further discussed below and in Discussion) (van den Wijngaart et al., 2007). For example, family caregivers of older individuals with Alzheimer's disease who participate in programs educating them on disease management report lower distress levels than non-participants (Marriott, Donaldson, Tarrier, & Burns, 2000). Participants in formal support groups for caregivers of older adults with dementia report lower distress levels than family caregivers in control groups (Fung & Chien, 2002). Caregivers to individuals with mental illness report higher benefits after an intervention providing information and training, compared to non-intervention controls (Toohey et al., 2016). Further, caregivers to recipients with Alzheimer's disease express higher satisfaction after using formal respite care (Powell Lawton, Brody, & Saperstein, 1989). However, some studies report no change in perceived burden between caregivers taking advantage of formal support and those not using such resources (Fortinsky et al., 2014; Nichols, Martingale-Adams, Burns, Graney, & Zuber, 2011; Rodriguez-Sanchez et al., 2013). For example, information provision and institutional support group participation do not reduce perceived burden in experimental versus control groups of informal caregivers in some studies (Acton & Kang, 2001; Brodaty, Mittelman, Gibson, Seehar, & Burns, 2009; Dias et al., 2008; Parker, Mills, & Abbey, 2008; Winter and Gitlin, 2007). Similarly to informal support, experimental studies differ with respect to which groups of caregivers they target and are not representative of informal caregivers. Additionally, the causal direction between formal support and burden perceptions may be reverse, as some studies show that caregivers are reluctant to use formal support and do not seek such assistance until burden is high (Braithwaite, 1998; McGhan & Penrod,

2015; Powell Lawton et al., 1989; Verbakel et al., 2016). Although cross-sectional data preclude me from inferring causality and distinguishing whether formal assistance reduces burden levels or increases benefits (or, further, whether it is only highly burdened caregivers who seek out formal support), I am able to examine what kind of caregiving experiences are associated with formal support receipt for a nationally representative sample of US informal caregivers.

Overall, for caregivers, receiving informal and formal support may thus give rise to more positive appraisals and reduce negative appraisals (Bandura, 2006; Scheier et al., 1989). Alternatively, caregivers may not be able to reduce the intensity of primary stressors and appraisal (number of hours and intensity of care provided) and continue experiencing burden (negative secondary appraisal), but access to informal and formal support may still increase their perception of benefits (positive secondary appraisals). For example, receiving emotional support from a close friend may not help with physically taxing caregiving tasks, but may encourage cognitive reappraisal and more effective problem-solving; for example, the caregiver may recognize that caregiving can nurture their relationship with the recipient, and help them develop emotion-focused coping skills. Caregivers' support receipt and perception may therefore be associated with both positive and negative caregiving appraisals, but existing studies overlook this potential ambivalence and offer mixed results about how informal and formal support operate due to small or non-representative samples of caregivers to older adults with particular illnesses.

I examine how receiving informal and formal support is linked with both burden and benefits perceptions simultaneously for a single caregiver. In examining this

association, I expect that compared to those not receiving support, caregivers receiving informal or formal support are more likely to have experiences that include benefits or benefits alongside burden than to experience only burden. Further, following the stress appraisal conceptual framework, I posit and expect that receiving support will buffer the association between primary stressors (recipient health status) and primary appraisal (care provided) with secondary appraisal (the five caregiving experience types).

Data and methods

Data

To examine the importance of informal and formal support for informal caregivers' experiences, I link two datasets. I first use the 2015 wave of the longitudinal US National Health and Aging Trends Study (NHATS) (Kasper & Freedman, 2014). NHATS is a nationally representative survey designed to monitor aging changes and explore social implications of aging transitions. It uses computer-assisted personal interviewing to collect information on a stratified three-stage sample of Medicare recipients over the age of 65, who are either living in residential care or at home (Montaquila et al., 2012); 96% of all U.S. older adults are enrolled in Medicare. The survey oversamples black older adults and older adults over the age of 85. At baseline, the response rate was 71%.

I link NHATS data with its 2015 National Study of Caregiving (NSOC) supplement (Kasper, Freedman, & Spillman, 2013). NSOC is a nationally representative study of individuals from whom NHATS sample persons indicated receiving help with self-care, mobility, or household activities. NSOC uses telephone interviews to collect

data about family members and friends' roles in providing care to older adults, including care provision activities, assistance duration and intensity, effects of caregiving on helpers, and caregivers' support service use. Interviews were conducted with 2,007 caregivers, for a response rate of 59.7%.

Data are cross-sectional due to insufficient caregiver sample size across the two available interviews. For this reason, my analyses cannot definitively ascertain causal ordering. However, the data compensate for this limitation with three important strengths. First, by linking two datasets, I obtain both caregivers' and care recipients' reports. In this way, I avoid potential single-reporter bias introduced when caregivers report on recipients' health status, and can better capture how caregiver-reported perceptions respond to recipient-reported stressors. Second, NSOC includes a wide array of caregiving experience indicators that cover both caregivers' burden and benefits, allowing me to examine experiences comprehensively (rather than focusing on burden only). Finally, contrary to intervention studies using clinical samples, using nationally representative data allows me to better establish the importance of receiving formal or informal support for US informal caregivers broadly.

Sample

The study sample consists of 2,007 informal caregivers, matched to their US older adult care recipients to obtain first-person reports of health and other relevant recipient factors that are otherwise often reported by caregiver proxy. Informal caregivers are typically unpaid family members, friends, or other individuals providing care to an older

person with whom they have a personal relationship (i.e. not volunteers, part of the paid caregiver workforce, or otherwise associated with an institutional care system).

Because I examine caregiving experience types as a caregiver-level outcome, I use NSOC analytic weights to account for differential selection probabilities and nonresponse bias, making the sample representative of US informal caregivers to older adults over 65 years old.[1]

I retain cases with missing data on latent class measurement items after performing sensitivity analyses to ensure the final latent class solution remains robust. I use multiple imputation for cases with missing data on latent class covariates (described in detail in the Methods section). Table 3.1 shows weighted sample descriptive statistics.

Measures

Dependent (latent) variable: Caregiving experience types

Caregiving experience type is a categorical variable based on caregivers' reports about burdens and benefits they experienced. Based on their item response pattern, I use most likely class membership to assign each caregiver to one of five categories developed in prior latent class analyses (please see Chapter 1 of dissertation): 1) Intensive Caregiver (reporting high caregiving burden and moderate benefits across all emotional, interpersonal, physical, and social domains); 2) Balanced Caregiver (reporting moderate burden with an absence of social burden, and high benefits); 3) Dissatisfied Caregiver

[1] I initially conduct all analyses only for a sample of caregivers providing care for community-dwelling older adults. However, including informal caregivers providing assistance to recipients in residential care such as retirement community (n=275) and nursing home (n=58), who may be receiving additional care, does not change the results obtained. Further, control variables for care recipient residential status are not statistically significantly associated with caregiver experience types. I therefore show analyses and results using the full sample of NSOC caregivers.

(reference category; reporting burden only); 4) Relationship Caregiver (reporting interpersonal burden only, and interpersonal benefits); or 5) Satisfied Caregiver (reporting benefits only).

Key predictor variables: Support resources

I use six items from the NSOC support environment (SE) module to operationalize caregiver informal and formal support receipt. The SE module specifies that the questions it includes refer to caregiving and are "about support [the caregiver] may be getting." Factor analysis of the SE module items yields a two-factor solution describing caregiver informal and formal support resources. Table 3.2 shows the item correlation matrix.

Informal support receipt is a total score composed of a caregiver's responses to three SE items (alpha=0.53), asking: "Do you have friends or family that you talk to about important things in your life?;" "Do you have friends or family that help you with your daily activities, such as running errands, or helping you with things around the house?;" and "Do you have friends or family that help you care for [NHATS sample person]?." The original response categories for each item are "yes" (measured as 1) and "no" (measured as 0). Responses to the three items were summed, with the composite variable values ranging from 0 (indicating no informal support receipt) to 3 (indicating high informal support receipt).

Formal support receipt is a total score composed of a caregiver's responses to three SE items (alpha=0.34), asking: "In the last year, have you gone to a support group for people who give care?;" "In the last year, have you used any service that took care of

[NHATS sample person] so that you could take some time away from helping?;" and "In the last year, have you received any training to help you take care of [NHATS sample person]?." The original response categories for each item are "yes" (measured as 1) and "no" (measured as 0). Responses to the three items were summed, with the composite variable values ranging from 0 (indicating no formal support receipt) to 3 (indicating high formal support receipt).

Other predictor variables

In line with the caregiving stress appraisal theoretical framework, I include primary stressors, primary appraisal, and structural/contextual factors as predictors of caregivers' caregiving experience latent class membership.

Primary stressors.

Care recipient self-rated health is a continuous measure of the care recipient's self-reported health, ranging from poor (0) to excellent (4).

Care recipient depression symptoms (measured using PHQ-2) and anxiety symptoms (measured using GAD-2) are continuous measures of care recipient-reported depressive and anxious symptomatology, with higher scores indicating greater risk for depression or anxiety, respectively. I construct the measures and scores using validated two-item depression and anxiety screeners that consist of two questions reflecting DSM-V core diagnostic criteria (Lowe et al., 2010). Care recipient depression symptoms and care recipient anxiety symptoms are correlated at 0.43. I include each measure separately.

I measure care recipient's medical diagnoses with a dichotomous variable indicating whether the care recipient reported zero to two medical diagnoses (=0) or

whether the recipient reported three or more health conditions diagnosed by a physician (=1). The dichotomization is based on the expected number of comorbidities in older adults aged 65 and above (Divo, Martinez, & Mannino, 2014). The measure is based on individual items asking the care recipient whether they were ever diagnosed with a heart attack, heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, Dementia or Alzheimer's, cancer, or broken or fractured hip or other bones.

Primary appraisal.[2]

Hours per month spent in caregiving is a categorical variable indicating whether the caregiver reported spending fewer than 20 hours (reference), 21 to 63 hours, or 64 hours or more providing informal care to the recipient in the past month. Cut-off points are based on terciles of the response distribution.[3]

Frequency of help with activities of daily living (ADL) is a continuous measure of how often the caregiver reported assisting the care recipient with activities of daily life. It is a mean score composed of two items (alpha = 0.77) asking the caregiver how frequently they help the recipient with "personal care such as eating, showering or bathing, dressing or grooming, or using the toilet," and how often they help the recipient with "getting around, that is, getting in and out of bed, getting around inside their home, or leaving their home to go outside." The original five-category response scale ranges from "never" to "every day."

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[2] The four primary appraisal measures are correlated at $p<0.05$ level, with the Pearson correlation coefficient ranging from 0.36 (medical and ADL assistance) to 0.58 (number of hours spent and IADL assistance).

[3] Sensitivity analyses including hours per month caregiving as a continuous variable suggest that the measure does not have a linear association with the dependent variable. I therefore include the variable as categorical.

Frequency of help with instrumental activities of daily living (IADL) is a continuous measure of how often the caregiver reports assisting the care recipient with instrumental activities of daily life. It is a mean score composed of four items (alpha = 0.66) asking the caregiver how frequently they help the recipient with "laundry, cleaning, or making hot meals," "shopping for groceries or personal items," "driving places," and how often they go with the recipient "in a van, shuttle or cab, or take public transportation with them." The original five-category response scale ranges from "never" to "every day."

Number of medical tasks assistance is a continuous measure of the number of medical tasks the caregiver reports performing for the care recipient. It is a count of six items (alpha = 0.76) asking the caregiver whether they help the care recipient: "order their prescribed medicines;" "keep track of medications;" "make appointments with a medical provider;" "speak to or email medical provider about their care;" "change or add a health insurance plan or prescription drug plan;" or "handle any other health insurance matters related to their medical care." The original response categories for each item are "yes" (counted as 1) and "no" (counted as 0).

Key structural/contextual factors.

Caregiver race is a categorical variable indicating whether the caregiver self-identifies their race as non-Hispanic white (reference), non-Hispanic Black, Hispanic, or other.

Caregiver education is a categorical variable indicating whether the caregiver's self-reported highest level of education is less than high school (reference), high school or equivalent, some college or technical school, or college degree or above.

Caregiver employment status is a categorical measure indicating whether the caregiver reports being employed (reference), unemployed, or retired.

Caregiver gender is a dichotomous variable indicating whether the caregiver reports their gender as female (=1) or male (=0).

Caregiver age is a categorical measure of the caregiver's self-reported age, indicating whether the caregiver is a young adult (reference; aged 18-39), middle-aged (40-60), a mature adult (61-74), or an older adult (75 or over).[4]

Caregiver depressive symptoms (measured using PHQ-2) and caregiver anxiety symptoms (measured using GAD-2) are continuous indicators of caregiver-reported depressive and anxious symptomatology, constructed and measured in the same way as described for care recipient mental health (see primary stressors). Caregiver depressive symptoms and caregiver anxiety symptoms are correlated at 0.32, indicating that each construct represents a separate set of mental health symptoms, and that it is statistically not problematic to include each measure separately.

Confounding factors

[4] Sensitivity analyses including caregiver age as a continuous variable suggest that the measure has a non-linear association with the dependent variable. I therefore include the variable as categorical to examine the experience of caregiving by life stage.

Caregiver relation type is a categorical variable indicating whether the caregiver reports that they are the care recipient's spouse (reference), adult child, other relative, or nonrelative.[5]

Coresidence is a dichotomous variable indicating whether the caregiver reports residing with the care recipient (=1) or not (=0).

Long-term caregiver is a dichotomous measure indicating whether the caregiver reported providing care for the recipient for fewer than five years (=0) or for five years or more (=1). I include the variable as categorical to account for the possibility of adaptation to caregiving.[6]

Number of other helpers is a continuous measure indicating the number of persons other than the caregiver from whom the care recipient reports receiving assistance.[7]

Care recipient gender is a dichotomous variable indicating whether the care recipient reports their gender as female (=1) or male (=0).

Care recipient race is a dichotomous variable indicating whether the care recipient reports their race is different than the caregiver's race (=1) or whether they identify as being of the same race (=0).[8]

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[5] Because caregiver relation type includes information about caregiver marital status for spouses, caregiver and care recipient marital status are not included in final models due to collinearity. Neither caregiver nor care recipient marital status variables was statistically significant in any models, and sensitivity analyses including and excluding particular combinations and recodes of caregiver relation type, caregiver marital status, and care recipient marital status did not change the magnitude, direction, or significance of coefficients obtained. I therefore drop marital status variables from analyses.

[6] Sensitivity analyses including the number of years spent caregiving as a continuous variable suggest that the measure does not have a linear association with the latent variable.

[7] Sensitivity analyses in which I include the number of other helpers as a categorical variable (coded as zero, one, and two or more other caregivers) do not suggest a non-linear association with the dependent variable. I therefore include the measure as continuous in the interest of model parsimony.

[8] The variable is dummy-coded and based on differences from the caregiver's race to avoid collinearity due to the high correlation between caregiver and care recipient race. Sensitivity analyses including and excluding the full information available about recipient race suggest no changes in the magnitude,

Care recipient age is a categorical measure of the recipient's self-reported age, indicating whether the care recipient belongs to the "young old" (reference; 65-74), the "old old" (75-84), or the "oldest old" (85 and over) age group.[9]

Care recipient education is a categorical variable indicating whether the care recipient's self-reported highest level of education is less than high school (reference), high school or equivalent, some college or technical school, or college degree or above.

Homeowner is a dichotomous variable indicating whether the care recipient reports owning a home (=1) or not owning a home (=0).

Social assistance is a dichotomous variable indicating whether the care recipient reported receiving any type of social assistance in the past year (food stamps, other types of food assistance, or gas and electricity assistance) (=1) or not (=0).

Methods

I employ latent class analysis (LCA) in prior work to identify distinguishable subtypes of informal caregivers' experiences of caregiving to US older adults. I enumerate caregiving experience classes, characterized by particular patterns of burden and benefits perceptions, in Chapter 1 of dissertation. The methodological details of class enumeration are described in the aforementioned chapter.

In the present study, I use latent class regression analysis to examine the association between informal and formal social support and caregiving experience latent

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direction, or significance of coefficients ultimately obtained. I therefore show results from the more parsimonious model.

[9] Sensitivity analyses in which I include care recipient age as a continuous variable measured in years suggests that the measure has a non-linear association with the latent variable. I therefore include the variable as categorical to examine caregivers' experience of caregiving by recipient age group.

classes, with classes distinguishable based on the pattern of burden and benefit item response probabilities. In conducting latent class regression analysis and evaluating the importance of social support types for class membership, I follow the three-step approach of including covariates (Asparouhov & Muthen, 2014). This approach first re-estimates the latent class measurement model without predictors, and assigns each observation to its most likely class based on latent class posterior distribution (Kim et al., 2016; Nylund-Gibson & Masyn, 2016). It then uses class membership as an additional latent class indicator variable while preserving classification uncertainty. In this way, it avoids the difficulties of discarding measurement error information common to one-step approaches (Vermunt, 2010). To ensure model stability, I first examine changes in model fit, item response probabilities, and class prevalence after the inclusion of each predictor variable separately in the estimation of the final solution (Miche, Huxhold, & Stevens, 2013). I then proceed with including blocks of predictor variables (key independent variables, primary stressor factors, primary appraisal factors, key structural/contextual factors, confounding factors) before including the full array.

I conduct multiple imputation to impute data missing on covariates. Due to nonresponse, 15% of cases had values missing on at least one covariate included in the final covariate models. The variables with the highest percent of missing values were care recipient education (5.53%) and number of hours spent caregiving in the past month (5.49%); missingness did not exceed 1.5% on other covariates. With the assumption of data missing at random, I generate 20 imputed datasets using the variance covariance analysis algorithm recommended for models with a large number of categorical variables (Asparouhov & Muthen, 2010). I use all variables included in the final models, including

analytic weights, strata, and the sampling unit variables to account for complex survey design. The imputation procedure did not produce any implausible values. Sensitivity analyses show that parameters obtained through complete case analysis do not differ in direction, magnitude, or pattern of significance from parameters obtained using multiply imputed data. I present results using the latter.

I perform data cleaning and preparation in Stata 14.1 and conduct multiple imputation and analyses in Mplus 7.4.

Results

Descriptive statistics

Table 3.1 shows weighted sample descriptive statistics. On average, caregivers in the sample have high informal support (M=2.11, SD=0.93, Min=0, Max=3) but low formal support (M=0.26, SD=0.54, Min=0, Max=3): while the majority have family and friends to talk to (87%), to help them with daily activities (55%), and to help them care for the recipient (69%), few have gone to a caregiver support group (4%), used respite care (15%), or received caregiving training (10%). Caregivers provide assistance to recipients who report fair self-rated health (M=1.60, SD=1.04) and few depression symptoms (M=1.61, SD=1.62) and anxiety symptoms (M=1.43, SD=1.65) on average, but the majority of whom are likely to have three or more medical diagnoses (74%).

Most caregivers (40%) provide no more than 20 hours of caregiving per month; about a third (34%) provides between 21 and 63 hours, and 26% provide 64 or more hours of care. They assist with ADL (M=1.34, SD=1.19) about as frequently as they do

with IADL (M=1.55, SD=0.81). On average, they provide assistance with two medical or nursing tasks (M=2.35, SD=1.94).

The majority of caregivers are female (62%), and self-identify as white (67%). Slightly more than a third (35%) have some college education, and 41% are employed. The highest proportion is middle-aged (40%). They report good mental health, with few depression symptoms (M=0.97, SD=1.36) and anxiety symptoms (M=1.04, SD=1.40). They are likely to be an adult child caregiver, providing assistance to an aging parent (46%), but most do not reside with the care recipient (58%). About half (50%) have been providing assistance for over 5 years, and many are sole caregivers; on average, NHATS care recipients have just under two helpers (M=1.92, SD=0.95).

Latent class regression analysis

Table 3.3 shows the results of latent class regression analysis examining cross-sectional associations between receiving informal or formal support and having a particular caregiving experience type (each uniquely characterized by a particular type of burden and benefit combination). Latent class regression analysis predicts membership in the five caregiving experience types, estimating relative risk ratios and the associated confidence intervals. The reference class for comparison in all models is Dissatisfied Caregivers (Class 3), the class in which caregivers report experiencing predominantly caregiving burden, with lowest caregiving benefits.

In analyses not shown here, I included conceptually relevant variables in blocks to explore whether and how the association between receiving support and caregiving experience types changes with the addition of primary stressors, primary appraisal, key

structural/contextual, and confounding factors. Here, I show the full model with all factors included, as the coefficients obtained did not change appreciably after block additions of these variables, and the pattern of statistical significance remained constant. Table 3.4 shows the relative risk ratios and associated confidence intervals on key independent variables following the addition of each block of variables. I tested a total of eight two-way interactions between four primary stressors and four primary appraisal factors, respectively, with the formal support variable; and eight two-way interactions between primary stressors and primary appraisal factors with the informal support variable. No interaction terms were significant after covariate adjustments at the $p<0.05$ level (and, by extension, at the lowered p value when applying the Bonferroni correction for multiple comparisons); the interaction terms were accordingly excluded from final models.

Since the choice of reference class in latent class regression analysis is arbitrary, I offer three additional tables to provide fuller information in support of study findings. The three tables show the relative risk of having a particular caregiving experience type versus every other experience type, based on informal and formal use receipt. Specifically, Table 3.5 shows alternative parametrizations on both key independent variables from fully adjusted models using other latent classes as the reference for comparisons. For clarity, Table 3.6 further shows these parametrizations for informal support only, and Table 3.7 shows them for formal support only.

Informal support

Caregivers whose experiences are largely positive report higher informal support levels. In the unadjusted model (Table 3.4), compared to those experiencing predominantly burden, caregivers who receive high levels of informal social support are more likely to have experiences characterized predominantly by benefits than burden. Although cross-sectional data preclude me from disentangling temporal ordering and caregiving experiences can also give rise to the need for informal support, the association remains robust and does not change in direction, magnitude, or level of significance following the inclusion of primary stressor variables, primary appraisal variables, contextual factors, and control factors. In the fully adjusted model (Table 3.3), with each additional reported type of informal support, caregivers have a 36% higher relative probability of being Relationship Caregivers and experiencing high interpersonal benefits with some interpersonal burden (Class 4; rr=1.36, $p<0.05$) than of being Dissatisfied Caregivers and experiencing predominantly burden. Compared to the same group, caregivers receiving informal support also have a 42% higher relative probability of being Satisfied Caregivers and experiencing benefits only (Class 5; rr=1.42, $p<0.01$). Caregivers who receive more informal support are no more or less likely to experience a combination of burden and benefits than to report burden only.

Alternative parameterizations using other latent classes as the reference group for comparison further suggest that receiving informal support is associated with higher benefits and lower burden (Table 3.5, Table 3.6). For example, those reporting more informal support are more likely to be Relationship Caregivers or Satisfied Caregivers (reporting absent or limited burden and the highest benefits) than Intensive Caregivers experiencing high burden and moderate benefits. Additionally, compared to being

Relationship Caregivers or Satisfied Caregivers, those reporting high informal support are less likely to be Intensive Caregivers or Dissatisfied Caregivers, two groups with the highest burden level.

Moderation analyses suggest that informal support does not buffer the association between primary stressors or primary appraisal with caregiving experiences. I tested eight two-way interactions between four primary stressor and four primary appraisal factors, respectively, with the informal support variable. Although the interaction term between informal support and recipient depression was significant in the model adjusted for primary stressors only ($p<0.05$), it was not significant after applying the Bonferroni correction for multiple comparisons, or in final fully adjusted models. Supplementary analyses using individual informal support items in examining the likelihood of having a particular caregiving experience type suggest that in separate and unadjusted models, having friends and family to help with daily activities, and having friends and family to help care for the recipient may facilitate a more beneficial versus burdensome experience for those offering high levels of IADL and medical task assistance (not shown). However, small cell sizes do not allow for drawing conclusions on these associations after adjusting for conceptually relevant and confounding factors.

In sum, caregivers who receive higher informal social support are likely to be Relationship Caregivers or Satisfied Caregivers, reporting experience types with high benefits and absent burden (or low burden limited to the interpersonal domain). However, they are not more likely to report benefits alongside burden, compared to reporting burden only.

Formal support

Formal support receipt is associated with more caregivers' more negative characterizations of their experiences. In the unadjusted model (Table 3.4), compared to experiencing predominantly burden, caregivers are less likely to report experience types characterized by either a combination of burden and benefits (except at the highest levels of burden) or by benefits alone, when they receive high formal social support. Although I cannot ascertain causal ordering (and consider this issue further in the Discussion section), the association remains robust and does not change in direction, magnitude, or level of significance following the inclusion of primary stressor variables, primary appraisal variables, contextual factors, and control factors. In the fully adjusted model (Table 3.3), compared to being Dissatisfied Caregivers who experience burden only (Class 3), with each additional reported type of formal support, caregivers have a 41% lower relative likelihood of being Balanced Caregivers and experiencing moderate burden and high benefits (Class 2; rr=0.59, $p<0.01$). Compared to the same group, they further have a 63% lower relative likelihood of reporting high interpersonal benefits with some interpersonal burden (Class 4; rr=0.37, $p<0.001$), and a 60% lower relative likelihood of being Satisfied Caregivers who experience benefits only (Class 5; rr=0.40, $p<0.001$). However, they are no more or less likely to be Intensive Caregivers reporting high burden and moderate benefits than to be Dissatisfied Caregivers experiencing predominantly burden.

Contrasts with other latent classes as reference groups and other parametrizations similarly suggest that formal support receipt is associated with higher burden (Table 3.5, Table 3.7). Compared to being Intensive Caregivers and reporting high burden and

moderate benefits, caregivers reporting high formal assistance are less likely to be Balanced Caregivers reporting moderate burden and high benefits, Relationship Caregivers reporting interpersonal benefits and some interpersonal burden, and Satisfied Caregivers reporting high benefits only. Compared to being Balanced Caregivers, they are more likely to be Intensive Caregivers or Dissatisfied Caregivers—groups reporting the highest burden levels—the more formal support they receive. In contrast to Relationship Caregivers or Satisfied Caregivers, who report the highest level of benefits with no or limited (interpersonal) burden, those receiving more formal support are also more likely to be either Intensive Caregivers reporting high burden alongside moderate benefits, or Dissatisfied Caregivers reporting only high burden.

Moderation analyses indicate that formal support does not buffer the association between primary stressors or primary appraisal with caregiving experience types. I tested eight two-way interactions between four primary stressor and four primary appraisal factors, respectively, with the formal support variable. The interaction term between formal support and the primary appraisal factors of medical tasks performed was statistically significant in the model adjusted for primary appraisal only ($p<0.05$), but it was not significant after applying the Bonferroni correction for multiple comparisons, or in fully adjusted final models. Sensitivity analyses examining primary stressor and primary appraisal buffering using individual formal support items suggest that in separate and unadjusted models, support group participation and receiving training may be associated with more beneficial experiences versus burdensome ones for those providing more hours of care and more IADL assistance; including the full set of covariates and

interactions by item resulted in unstable models and precludes conclusive analyses by support item.

Thus, results suggest that caregivers receiving more formal support are unlikely to be Balanced Caregivers, Relationship Caregivers, or Satisfied Caregivers; that is, to report high benefits or benefits with limited to moderate burden. However, they are as likely to be Intensive Caregivers and to report high benefits alongside high burden as they are to be Dissatisfied Caregivers who report burden only. As in the case of informal support, however, I am unable to examine causal effects in this study, and I acknowledge and address the possibility of reverse causation and low benefits prompting support-seeking when interpreting findings in the Discussion section.

Other factors

Although not the primary focus of the present analyses, I also examine other factors relevant to the caregiving stress appraisal model for associations with poor caregiving experiences. I thoroughly motivate and explore the role of primary stressors, primary appraisal, and contextual/structural factors for caregiving experiences in the first analytic chapter of the dissertation (Chapter 2). Findings from this analytic chapter (Chapter 3) corroborate previous analyses and suggest that poor recipient health, a high number of hours of care provided, assistance with ADL and medical tasks, coresidence, long-term caregiving, and poor caregiver mental health put caregivers at risk of having experience types characterized by burden only. A write-up of these findings is available in the appendix. An in-depth discussion of the findings is the main focus of, and available in, Chapter 2.

Discussion

The US long-term care system for older adults increasingly relies on informal caregivers, and these caregivers report both negative and positive perceptions of their experiences. To facilitate their continued provision of informal assistance to older persons, it is important to understand who is experiencing burden, how to minimize these caregivers' objective and perceived burden, and how to maximize objective and perceived benefits. In this study, following the caregiving appraisal framework, I used NHATS and NSOC data and a nationally representative sample of informal caregivers to US older adults to examine how informal and formal social support are linked to distinguishable subtypes of caregiving experiences that reflect both burden and benefit perceptions. Although cross-sectional data preclude me from identifying causal effects or direction, my results show that caregivers receiving informal support are more likely to have experiences characterized predominantly by benefits than by burden. In contrast, those receiving formal support are less likely to experience benefits or a combination of burden and benefits (except at highest burden levels) than to experience only burden. These associations remain robust to the inclusion of other conceptually relevant factors. Neither informal nor formal support buffers the association between primary stressors and appraisal with caregiving experiences. I also find that primary appraisal, primary stressors, and contextual factors shape caregiving experiences; I motivate and discuss the findings regarding these factors in detail in Chapter 1 of this dissertation. Below, I focus on the interpretation and implications of my key findings related to informal and formal social support.

First, I find that caregivers in this study who receive high informal social support—those who have family or friends to confide in, to assist them, and to assist with the care recipient—are more likely to report care experiences characterized by high benefits, both in contrast to experiencing predominantly high burden, and in contrast to experiencing high burden alongside benefits. This finding suggests that informal support receipt is associated with high positive appraisal; I am unable to ascertain causality in this study, but it is possible that receiving such support may reduce negative appraisal. Caregivers seek informal assistance from family and friends at higher rates than non-caregivers (Pew Research Center, 2013); access to and use of interpersonal resources may help caregivers manage stress or improve their mental health, resulting in a better caregiving experience (Brand et al., 2016; Wang et al., 2016). Family and friends may temporarily substitute for the caregiver or assist them with care and other tasks, reducing their workload and giving them the opportunity to address their own social, emotional, and other needs; caregivers who receive support from family and friends report that they perform fewer hours of care work—controlling for the recipient's health—and improved well-being (Verbakel et al., 2016). The finding that those receiving informal assistance report predominantly beneficial experiences is encouraging, given that over 70% of caregivers report having support from friends and family, and that such support is often enduring and stable (Close, Estes, & Linkins, 2001; Pew Research Center, 2013; Sims-Gould & Martin-Matthews, 2007). Caregivers who perceive benefits have better mental and physical health, and continue assisting longer than those who do not perceive benefits (Cohen et al., 2002; Cohen, Gold, Shulman, & Zucchero, 1994; Pinquart & Sorensen, 2003). Alternatively, caregivers who perceive their experience positively may also be the

ones more likely to have time and emotional energy to maintain social relationships; I discuss this possibility in the study limitations section.

Second, caregivers who receive higher formal support are more likely to have experience types characterized by high burden, and less likely to have experience types that include high benefits or benefits alongside burden (unless these benefits appear alongside burden at the highest levels). This finding may indicate that formal assistance does not appreciably alleviate objective or perceived caregiver burden. This is unexpected, given that caregivers generally report multiple positive outcomes from using formal assistance, including higher caregiving satisfaction, increased confidence, better mental health, lower stress, and improved interpersonal relationships, all of which may function similarly to informal assistance in reducing burden and increasing positive appraisal (Dulcy & Goldman, 1989; Hepburn, Tornatore, Center, & Ostwald, 2001; Kosloski & Montgomery, 1993; Ostwald, Helpburn, Caron, Burns, & Mantell, 1999; Powell Lawton et al., 1989; Scharlach & Fenzel, 1986; Zarit, Stephens, Townsend, & Greene, 1998). However, participating in formal assistance programs such as respite care and psycho-education also typically delays the care recipient's nursing home placement (Brodaty, McGilchrist, Harris, & Peters, 1993; Kosloski, Rhonda, & Montgomery, 1995; Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Powell Lawton et al., 1989; Schulz et al., 2002). This extends the duration of the caregiver's role while the recipient's health may further deteriorate, which may result in poorer rather than more beneficial experiences. Similarly as for individuals coping with bereavement, interventions at later stages of caregiving may have to be tailored individually to be effective (Lund, Caserta, Utz, & de Vries, 2010)

Alternatively, as I cannot establish causal direction in this study, it is possible that caregivers do not turn to formal assistance until they are already facing significant burden that is difficult to mitigate. Several studies find that caregivers do not seek respite care unless caregiving demands are high or they encounter a crisis (Braithwaite, 1998; McGhan & Penrod, 2015; Powell Lawton et al., 1989; Verbakel et al., 2016). In studies where caregivers are experimentally provided free respite care, between one third and one half of them do not use the service (Powell Lawton, Brody, & Saperstein, 1991; Montgomery & Borgatta, 1989). Estimates using nationally representative data show that only about 5% of caregivers attend support groups, and although the use of respite care programs is increasing, only about 16% of caregivers used them in 2015 (Wolff et al., in press). One barrier to early formal assistance use is the relationship between the caregiver and the recipient; caregivers reporting a poor interpersonal relationship with the recipient are more likely to use respite care than those with close relationships, and family caregivers such as spouses and adult children may be especially reluctant to place their partner or parent in others' care (Braithwaite, 1998). Although caregivers often request respite care services in surveys asking about their needs, financial concerns or feeling guilt or failure for relying on others in caring for loved ones—especially if they place a high value on being able to do so themselves—and may make it difficult to accept formal assistance and consider partial institutionalization or similar options (Crossman, London, & Barry, 1981; Rabins, Mace, & Lucas, 1982; Scharlach & Fenzel, 1986). Bureaucratic difficulties may further complicate receiving formal assistance, and these potential negative factors may also outweigh its positive aspects.

To encourage service utilization and participation in formal programs that may improve caregivers' experiences, it is important to destigmatize and make accessible the use of such assistance. Caregivers who become familiar with formal services early in their role and have better knowledge about them may be more likely to use them; intervention studies focused on problem-solving, skills development, and counseling show that caregivers who complete training are subsequently less reluctant to use formal care (Ducharme et al., 2011; Gendron, Poitras, Dastoor, & Perodeau, 1996; Moniz-Cook, Agar, Gibson, Win, & Wang, 1998).

A further reason why formal support receipt is not associated with lower burden experience types is that formal assistance may not effectively increase caregivers' benefits perceptions, even though it may address objective burden. Caregivers using respite programs also often report lower stress and anxiety, but no decreases in depression symptoms, which may negatively bias evaluations of their experiences (Guttman, 1991). Further, factors that give rise to benefit perceptions may differ from those related to burden appraisals, and they may not be present or focal in caregiver intervention programs (Lawton et al., 1991). For example, medication and care recipient behavior management trainings may ease caregiving tasks, but may not offer caregivers the tools to manage stress and maintain their own psychological and physical well-being (Gaugler, Davey, Pearlin, & Zarit, 2000). Providing nursing care may have particular challenges, as caregivers providing nursing care report significantly higher burden than others, including those who provide relatively complex personal care (Moorman & Macdonald, 2012). Studies examining caregivers' quality of life suggest that caregivers can experience high well-being despite feeling burdened, and to this end, policy and

practitioners may focus on extending interventions that aim to increase positive appraisals (Chappell & Dujela, 2010). Several stress management and psychosocial interventions were successful in improving caregivers' feelings about their role, life satisfaction, positive mood, and their social participation (Bourgeois, Schulz, Burgio, & Beach, 2002; Cox, 1998; Millan-Calenti et al., 2000; Zanetti, Metitieri, Bianchetti, & Trabucchi, 1998).

I do not find that either informal or formal social support buffers the association between other conceptually relevant factors (primary stressors and appraisal) with caregiving experiences. The finding that informal and formal social support are associated with caregiving experiences, but do not depend on levels of primary stressors or appraisal, therefore does not lend support to the buffering effects model of support processes (Cohen & Wills, 1985; Gerin et al., 1995; Krause, 1986). Instead, it indicates that social support may operate independently of stress levels, in line with the direct effects model (Bell et al., 1982; Williams et al., 1981). In other words, especially in the case of informal assistance, support may be beneficial to caregivers regardless of workload or the recipient's level of impairment. In the case of formal assistance, it is possible that buffering effects were not detected due to lack of measurement detail; the content of formal programs and interventions often has to be flexible and tailored to the variety of caregivers' contexts and needs in order to successfully mitigate stressors (Gitlin, Marx, Stanley, & Hodgson, 2015; Sorensen et al., 2002). Given support for the direct effects model, it is important to note that the link between support and experience types remains robust to the inclusion of other factors. Primary stressors (poor recipient mental and physical health), primary appraisal (high number of hours of care, frequent

ADL assistance, and assistance with medical tasks), and contextual factors (caregiver race, employment status, mental health, co-residence, and caregiving duration) independently predict caregiving appraisals, but they do not reduce the magnitude of the association between receiving support and experience types (see Chapter 1 of the dissertation for a detailed discussion). Although I do not find that social support acts as a buffer, it is possible that these effects have gone undetected. It may be relevant to know who provides support—for example, caregivers may respond differently to, or receive different type of support from a spouse than from a nonrelative—but this detail is absent in NSOC data. Similarly, support needs and the type of support received may differ for men and women. I discuss this and further study limitations below.

This study has two main limitations. The data are cross-sectional and do not allow for an examination of caregiving experiences and support receipt over time (Verbakel et al., 2016). Although caregivers were asked about receiving formal support "in the past year," questions regarding informal support from family and friends were not framed in this way, and the present analysis thus cannot temporally disentangle the association between social support and caregiving experiences. Two waves of NSOC are currently available, but caregiver and recipient attrition between the 2011 and 2015 time points results in a sample size with insufficient statistical power. I control for caregiving duration and contrast all caregiving experience types to better understand changing perceptions given the constraints, but as subsequent waves of NSOC become available, future research may use latent class transition analysis techniques to longitudinally and more fully examine caregiving experience changes.

A further limitation is the absence of detail about the informal and formal support caregivers receive. In the case of informal support, it is not known whether the caregiver is reporting assistance from a sibling, spouse, friend, or someone else. Caregivers can have varied help networks, and helpers can provide different types of resources. For example, siblings often provide instrumental assistance, while friends are a source of emotional support (Clipp & George, 1990; Suitor & Pillemer, 1993). In the case of formal support, the lack of nuance in measures further precludes determining whether support was predominantly emotional or instrumental; for example, "training to help you take care of /the recipient/" may entail both recipient behavior and health management, as well as psychosocial and coping training. Buffering effects may also not be uniform across gender. Women and men who are caregivers may need, desire, or respond to different types of support, and the potentially alleviating function of informal and formal assistance could be masked in pooled analyses (Kramer & Thompson, 2005). Further, I am unable to distinguish between caregivers who chose not to use formal support services that were available to them, and those who were unable to use such assistance due to geographic unavailability or financial constrains. Data with more granular information on formal assistance may provide an opportunity to further explore its relation with caregiving appraisals.

Despite limitations, this study provides insight into how different types of social support operate with respect to caregivers' experiences. It examines changes in burden and benefit perceptions simultaneously, offering preliminary evidence that: 1) informal support may decrease burden *and* increase benefits, altering both types of appraisals at the same time and for the same caregiver; and that 2) formal support may not be well-

suited for increasing benefits perceptions, and that caregivers may be using such support as a last option. It also shows that support receipt may have direct effects on caregivers' experiences and may be beneficial regardless of stress levels, in line with the direct effects of social support processes hypothesis (Bell et al., 1982; Williams et al., 1981). These findings are notable given that they take into account care recipient's own reports of their physical, mental, and self-rated health, rather than relying on potentially biased information obtained from the caregiver, and that they reflect the experiences of a nationally representative sample of informal caregivers to US older adults, rather than those of caregivers to older adults with particular illnesses (Acton & Kang, 2001; Brodaty, Green, & Koschera, 2003; Parker et al., 2008; Sorensen et al., 2002).

With new trends in family demography, increased geographic mobility, and women's labor force participation, older adults' support needs and caregiver availability will continue to change (Chappell & Funk, 2011). The oldest old are one of the fastest growing population segments, and an increasing number of older adults will live with disabilities and impairments that require long-term assistance (He, Goodkind, & Kowal, 2016; National Center on Caregiving, 2015). The need for care services will increase accordingly in the coming decade. Over 34 million Americans currently provide informal care to older adults, but the US is projected to experience a shortage of almost 4 million informal caregivers by 2030 (Osterman, 2017; US Census Bureau, 2016; US Department of Health and Human Services, 2003). The homecare workforce will have to be expanded to meet rising demand, as well as offered better working conditions and incentives than these workers currently receive (Poo & Whitlach, 2016). Good caregiving experiences could facilitate continued caregiving with both formal and informal caregivers.

Caregivers with positive experiences continue in their role longer than peers who experience burden; to ensure caregivers have the necessary resources themselves to maintain their own health and well-being, and that they are able to offer quality assistance to older persons, researchers and decision-makers will need to better understand how and when to intervene in providing caregivers with support (Pinquart & Sorensen, 2003; Sorensen et al., 2002). With frequent changes in family caregiver networks, as fewer close family members take on the caregiving role due to work conflicts or physical distance, and as they themselves have a smaller pool of available helpers, formal support to caregivers may gain importance (Jette, Tennstedt, & Branch, 1992; Szinovacz & Davey, 2007). Given the study findings, it may be important to introduce formal support options to caregivers early after they assume their role, to design such services with sensitivity to the caregiver-recipient relationship, and to incorporate into these programs a focus on increasing caregivers' perceptions of benefits.

Tables

Table 3. 1. Weighted sample descriptive statistics (N=2,202).

Variable	%	M	SD
Support			
CG informal support (range: 0-3)		2.11	0.93
CG has family/friends to talk to (=yes)	86.58		
CG has family/friends to help with daily activities (=yes)	55.03		
CG has family/friends to help care for recipient (=yes)	69.31		
CG formal support (range: 0-3)		0.26	0.54
CG gone to support group (=yes)	3.88		
CG used respite care (=yes)	15.26		
CG received training (=yes)	6.90		
Primary stressors			
CR self-rated health (range: 0-4)		1.60	1.04
CR # depression symptoms (range: 0-6)		1.61	1.62
CR # anxiety symptoms (range: 0-6)		1.43	1.65
CR 3+ medical diagnoses (reference=<3)	74.29		
Primary appraisal			
CG tercile of hours helped in past month			
1 to 20 (reference)	39.76		
21 to 63	33.75		
64 or more	26.48		
CG mean frequency of ADL help (range: 0-4)		1.34	1.19
CG mean frequency of IADL help (range: 0-4)		1.55	0.81
CG # medical tasks (range: 0-6)		2.35	1.94
Key structural/contextual factors			
CG female (reference = male)	62.37		
CG race			
White (reference)	67.38		
Black	12.49		
Hispanic	9.22		
Other	10.91		
CG education			
Less than high school (reference)	10.34		
High school	26.84		
Some college	35.51		
Bachelor's degree or higher	27.31		
CG work status			
Employed (reference)	41.41		
Unemployed	26.87		
Retired	31.72		
CG age			

Young adult, 18-39 (reference)	11.77		
Middle-aged, 40-60	40.59		
Mature adult, 61-74	31.65		
Older adult, 75+	15.99		
CG # depression symptoms (range: 0-6)		0.97	1.36
CG # anxiety symptoms (range: 0-6)		1.04	1.40
Confounding factors			
CG relation to care recipient			
Spouse (reference)	21.29		
Adult child	45.50		
Other relative	22.21		
Other nonrelative	10.99		
CG in household (reference = no)	41.86		
CG caregiving more than 5 years (reference = no)	50.32		
CG # helpers (range: 1-5)		1.92	0.95
CR female (reference = male)	68.57		
CR different race than CG (reference = no)	9.29		
CR age			
Young old, 65-74 (reference)	31.71		
Old old, 75-84	36.56		
Oldest old, 85+	31.73		
CR education			
Less than high school (reference)	28.91		
High school	29.64		
Some college	25.00		
Bachelor's degree or higher	16.45		
CR homeowner (reference = no)	54.11		
CR receives social assistance (reference = no)	20.56		

Notes: CG = caregiver. CR = care recipient. # = number.

Table 3. 2. Correlation matrix for caregiver informal and formal support items.

		1	2	3	4	5	6
	Informal support						
1	Has family/friends to talk to (=yes)	1.00					
2	Has family/friends to help with daily activities (=yes)	0.23***	1.00				
3	Has family/friends to help care for recipient (=yes)	0.22***	0.41***	1.00			
	Formal support						
4	Gone to support group (=yes)	0.01	0.03	-0.01	1.00		
5	Used respite care (=yes)	0.06**	0.07**	0.08**	0.03***	1.00	
6	Received training (=yes)	0.05*	0.07**	0.02	0.20***	0.13***	1.00

Notes: N=2,202.

Table 3. 3. Relative risk ratios and 95% confidence intervals on predictors for five types informal caregiving experiences.

	Class 1 (10%) Intensive Caregivers			**Class 2 (18%)** Balanced Caregivers			**Class 3 (15%)** Dissatisfied Caregivers	**Class 4 (26%)** Relationship Caregivers			**Class 5 (32%)** Satisfied Caregivers		
Support	RRR	CI-	CI+	RRR	CI-	CI+		RRR	CI-	CI+	RRR	CI-	CI+
Informal support	0.90	0.63	1.27	1.12	0.87	1.44	reference	1.36	1.06	1.76*	1.42	1.10	1.83**
Formal support	0.90	0.60	1.37	0.59	0.41	0.84**		0.37	0.22	0.62***	0.40	0.27	0.61***
Primary stressors													
CR self-rated health score	0.79	0.52	1.19	0.93	0.68	1.28		0.95	0.70	1.30	0.88	0.64	1.20
CR # depression symptoms (PHQ-2)	0.79	0.52	1.22	0.50	0.34	0.74**		0.51	0.33	0.78**	0.49	0.33	0.72***
CR # anxiety symptoms (GAD-2)	1.12	0.71	1.75	1.48	0.94	2.32		1.11	0.69	1.77	1.22	0.79	1.88
CR 3+ diagnoses (ref=<3)	0.56	0.19	1.65	0.45	0.21	0.97*		0.51	0.25	1.03	0.49	0.24	1.00
Primary appraisal													
Hours/month caregiving (ref=0-20)													
21 to 63	3.71	1.19	11.55*	2.66	1.27	5.61*		1.65	0.86	3.15	1.95	0.97	3.96
64 or more	3.86	0.89	16.78	1.68	0.75	3.76		0.87	0.35	2.14	1.77	0.82	3.80
Frequency of ADL help (mean)	1.73	1.27	2.37**	1.57	1.19	2.06**		0.90	0.65	1.26	1.23	0.96	1.59
Frequency of IADL help (mean)	1.77	0.79	3.95	1.03	0.62	1.72		0.93	0.53	1.65	1.31	0.76	2.27
Medical tasks #	1.45	1.14	1.83**	1.13	0.91	1.40		0.77	0.63	0.94*	0.88	0.72	1.07
Contextual factors - Caregiver													
CG female (ref=male)	1.67	0.82	3.37	1.34	0.67	2.65		0.83	0.46	1.49	1.16	0.66	2.05
CG race (ref=white)													
Black	1.16	0.40	3.41	3.10	1.28	7.48*		2.56	0.85	7.67	3.60	1.49	8.69**
Hispanic	1.60	0.49	5.19	2.34	0.81	6.74		0.44	0.07	2.65	2.10	0.74	5.92
Other race	0.48	0.10	2.20	0.79	0.28	2.22		0.62	0.23	1.65	1.01	0.42	2.44
CG age (ref=young adult, 18-39)													
Midlife (40-60)	1.49	0.30	7.30	1.39	0.45	4.34		0.50	0.17	1.46	0.76	0.29	1.99

Mature adult (61-74)	1.22	0.24	6.09		0.84	0.22	3.23		0.38	0.12	1.22	
Older adult (75+)	2.83	0.38	21.30		1.17	0.18	7.86		0.75	0.14	4.04	
CG education (ref=less than HS)												
High school	0.55	0.16	1.85		0.80	0.28	2.31		1.03	0.31	3.47	
Some college	0.93	0.28	3.14		0.99	0.34	2.85		1.11	0.38	3.25	
BA+	1.25	0.34	4.54		0.61	0.18	2.00		1.02	0.33	3.12	
CG employment (ref=employed)												
Unemployed	1.20	0.55	2.62		1.20	0.53	2.73		1.46	0.67	3.20	
Retired	1.06	0.49	2.28		1.46	0.63	3.40		1.57	0.77	3.18	
CG # depression symptoms (PHQ-2)	1.12	0.63	1.97		0.78	0.45	1.35		0.59	0.36	0.99	*
CG # anxiety symptoms (GAD-2)	1.70	1.00	2.88	*	1.42	0.92	2.18		0.47	0.26	0.84	*
Contextual factors - Arrangement												
CG recipient relation (ref=spouse)												
Adult child	1.49	0.40	5.55		0.60	0.17	2.11		0.77	0.25	2.40	
Other relative	1.16	0.23	5.91		0.43	0.11	1.74		0.93	0.27	3.21	
Nonrelative	0.18	0.01	3.88		0.64	0.12	3.41		2.46	0.60	10.09	
CG coresident (ref=no)	0.40	0.16	1.03		0.44	0.20	0.97	*	0.49	0.20	1.24	
CG caregiving 5+ years (ref=no)	0.51	0.28	0.92	*	0.74	0.41	1.33		0.79	0.45	1.36	
CG # other helpers	0.95	0.62	1.46		1.02	0.72	1.45		0.90	0.62	1.30	
Control factors												
CR female (ref=male)	0.89	0.43	1.83		1.19	0.67	2.09		1.02	0.49	2.11	
CR different race than CG (ref=no)	1.39	0.19	10.27		1.20	0.30	4.72		1.54	0.53	4.43	
CR age (ref=young old, 65-74)												
Old old (75-84)	0.95	0.38	2.39		0.63	0.30	1.33		0.44	0.19	1.01	
Oldest old (85+)	0.62	0.26	1.47		0.48	0.20	1.19		0.44	0.17	1.13	
CR education (ref=less than HS)												
High school	1.01	0.37	2.74		0.46	0.18	1.15		0.71	0.30	1.69	
Some college	0.59	0.19	1.89		0.39	0.16	0.93	*	0.54	0.21	1.35	
BA+	0.91	0.31	2.69		0.50	0.18	1.35		0.86	0.32	2.34	

Mature adult (61-74)	0.45	0.15	1.32									
Older adult (75+)	1.03	0.19	5.56									
CG education (ref=less than HS)												
High school	1.02	0.33	3.12									
Some college	1.01	0.39	2.64									
BA+	0.36	0.11	1.18									
CG employment (ref=employed)												
Unemployed	1.40	0.77	2.58									
Retired	2.05	1.06	4.00	*								
CG # depression symptoms (PHQ-2)	0.52	0.33	0.82	**								
CG # anxiety symptoms (GAD-2)	0.50	0.28	0.89	*								
Contextual factors - Arrangement												
CG recipient relation (ref=spouse)												
Adult child	0.95	0.31	2.96									
Other relative	1.63	0.43	6.19									
Nonrelative	4.06	1.01	16.40	*								
CG coresident (ref=no)	0.38	0.18	0.82	*								
CG caregiving 5+ years (ref=no)	0.86	0.54	1.38									
CG # other helpers	1.13	0.84	1.51									
Control factors												
CR female (ref=male)	1.97	1.10	3.55	*								
CR different race than CG (ref=no)	0.84	0.38	1.88									
CR age (ref=young old, 65-74)												
Old old (75-84)	0.47	0.23	0.97	*								
Oldest old (85+)	0.40	0.18	0.90	*								
CR education (ref=less than HS)												
High school	0.58	0.23	1.49									
Some college	0.57	0.24	1.38									
BA+	0.58	0.22	1.55									

CR homeowner (ref=no)	0.89	0.45	1.76		0.84	0.44	1.61		1.45	0.74	2.82		1.72	0.93	3.15
CR social assistance (ref=no)	1.14	0.50	2.59		1.15	0.50	2.62		0.91	0.33	2.53		1.28	0.60	2.76

Note: N=2,202. Multiply imputed data. # = number. CG = caregiver. CR = care recipient. p<0.05*, p<0.01**, p<0.001***

Table 3. 4. Relative risk ratios and 95% confidence intervals on key independent variables after block additions of predictors for five types informal caregiving experiences.

	Class 1: Intensive caregivers (10%)														
Key variable	*Model 1 (unadjusted)*			*Model 2 (+prim.str.)*			*Model 3 (+prim.app.)*			*Model 4 (+contex.)*			*Model 5 (+control)*		
	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+
Informal support	0.90	0.66	1.24	0.90	0.67	1.21	0.89	0.66	1.19	0.88	0.63	1.23	0.90	0.63	1.27
Formal support	1.13	0.81	1.57	1.14	0.80	1.62	0.91	0.64	1.30	0.88	0.59	1.30	0.90	0.60	1.37
	Class 2: Balanced caregivers (18%)														
	Model 1			*Model 2*			*Model 3*			*Model 4*			*Model 5*		
	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+
Informal support	1.17	0.96	1.43	1.19	0.97	1.44	1.17	0.96	1.43	1.11	0.86	1.43	1.12	0.87	1.44
Formal support	0.59	0.42	0.82**	0.62	0.44	0.86**	0.54	0.38	0.77**	0.55	0.39	0.78**	0.59	0.41	0.84**
	Class 3: Dissatisfied caregivers (15%)														
							reference								
	Class 4: Relationship caregivers (26%)														
	Model 1			*Model 2*			*Model 3*			*Model 4*			*Model 5*		
	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+
Informal support	1.25	0.98	1.58	1.25	1.00	1.55	1.30	1.03	1.64*	1.30	1.01	1.67*	1.36	1.06	1.76*
Formal support	0.76	0.49	1.20***	0.29	0.18	0.47***	0.40	0.25	0.63***	0.35	0.21	0.59***	0.37	0.22	0.62***
	Class 5: Satisfied caregivers (32%)														
	Model 1			*Model 2*			*Model 3*			*Model 4*			*Model 5*		
	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+
Informal support	1.31	1.04	1.66*	1.32	1.07	1.64*	1.39	1.12	1.73**	1.38	1.09	1.74**	1.42	1.10	1.83**
Formal support	0.38	0.28	0.51***	0.39	0.28	0.55***	0.42	0.32	0.57***	0.38	0.25	0.56***	0.40	0.27	0.61***

Notes: N=2,202. Multiply imputed data. p<0.05*, p<0.01**, p<0.001***

Model 1 unadjusted; Model 2 + primary stressors; Model 3 + primary appraisal; Model 4 + contextual factors; Model 5 + control factors.

Table 3. 5. Relative risk ratios and 95% confidence intervals on key independent variables by latent class reference category.

	Class 1 (10%) Intensive Caregivers			**Class 2 (18%)** Balanced Caregivers			**Class 3 (15%)** Dissatisfied Caregivers			**Class 4 (26%)** Relationship Caregivers			**Class 5 (32%)** Satisfied Caregivers		
	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+	RRR	CI-	CI+
Reference: Intensive CGs															
Informal support	reference			1.25	0.98	1.59	1.12	0.79	1.58	1.52	1.10	2.11**	1.58	1.19	2.08**
Formal support				0.65	0.44	0.97*	1.11	0.73	1.68	0.41	0.21	0.79**	0.45	0.27	0.74**
Reference: Balanced CGs															
Informal support	0.80	0.63	1.02	reference			0.90	0.69	1.16	1.22	0.90	1.66	1.27	0.98	1.63
Formal support	1.53	1.03	2.28*				1.69	1.18	2.43**	0.63	0.37	1.07	0.69	0.42	1.13
Reference: Dissatisfied CGs															
Informal support	0.90	0.63	1.26	1.12	0.86	1.45	reference			1.36	1.05	1.77*	1.41	1.10	1.82**
Formal support	0.90	0.59	1.37	0.59	0.41	0.85**				0.37	0.22	0.62***	0.40	0.27	0.61***
Reference: Relationship CGs															
Informal support	0.66	0.47	0.91**	0.82	0.60	1.11	0.73	0.57	0.95*	reference			1.04	0.81	1.32
Formal support	2.43	1.27	4.67**	1.59	0.93	2.72	2.69	1.62	4.48***				1.09	0.67	1.78
Reference: Satisfied CGs															
Informal support	0.63	0.48	0.84**	0.79	0.61	1.02	0.71	0.55	0.91**	0.96	0.76	1.23	reference		
Formal support	2.23	1.36	3.67**	1.46	0.89	2.41	2.47	1.65	3.71***	0.92	0.56	1.50			

Notes: Results from the same fully adjusted model using imputed data, showing parametrization using each of the latent classes as the reference group. CG = Caregiver. RRR = Relative risk ratio. CI-/CI+ = 95% confidence interval. p<0.05*, p<0.01**, p<0.001***

Table 3. 6. Class membership likelihood by informal support receipt using different reference classes.

	Class 1 (10%) Intensive Caregivers	Class 2 (18%) Balanced Caregivers	Class 3 (15%) Dissatisfied Caregivers	Class 4 (26%) Relationship Caregivers	Class 5 (32%) Satisfied Caregivers
Intensive CGs as reference					
Informal support	*reference*			more likely	more likely
Balanced CGs as reference					
Informal support		*reference*			
Dissatisfied CGs as reference					
Informal support			*reference*	more likely	more likely
Relationship CGs as reference					
Informal support	less likely		less likely	*reference*	
Satisfied CGs as reference					
Informal support	less likely		less likely		*reference*

Notes: Results from the same fully adjusted model using imputed data, showing parametrization using each of the latent classes as the reference group. Only significant results highlighted. CG = Caregiver.

Table 3. 7. Class membership likelihood by formal support receipt using different reference classes.

	Class 1 (10%) Intensive Caregivers	Class 2 (18%) Balanced Caregivers	Class 3 (15%) Dissatisfied Caregivers	Class 4 (26%) Relationship Caregivers	Class 5 (32%) Satisfied Caregivers
Intensive CGs as reference					
Formal support	*reference*	less likely		less likely	less likely
Balanced CGs as reference					
Formal support	more likely	*reference*	more likely		
Dissatisfied CGs as reference					
Formal support		less likely	*reference*	less likely	less likely
Relationship CGs as reference					
Formal support	more likely		more likely	*reference*	
Satisfied CGs as reference					
Formal support	more likely		more likely		*reference*

Notes: Results from the same fully adjusted model using imputed data, showing parametrization using each of the latent classes as the reference group. Only significant results highlighted. CG = Caregiver.

Table 3. 8. Likelihood of informal and formal support use by caregiver group.

	Has family/friends to talk to (=yes)	Has family/friends to help with daily activities (=yes)	Has family/friends to help care for recipient (=yes)	Gone to support group (=yes)	Used respite care (=yes)	Received training (=yes)
Intensive CGs as reference group						
Intensive CGs	ref	ref	ref	ref	ref	ref
Balanced CGs	>	>			<	
Dissatisfied CGs		>				<
Relationship CGs	>			<	<	<
Satisfied CGs	>		>		<	<
Balanced CGs as reference group						
Intensive CGs	<	<			>	
Balanced CGs	ref	ref	ref	ref	ref	ref
Dissatisfied CGs					>	<
Relationship CGs				<	<	<
Satisfied CGs					<	
Dissatisfied CGs as reference group						
Intensive CGs						>
Balanced CGs					<	>
Dissatisfied CGs	ref	ref	ref	ref	ref	ref
Relationship CGs	>			<	<	
Satisfied CGs			>		<	
Relationship CGs as reference group						
Intensive CGs	<			>	>	>
Balanced CGs				>	>	>
Dissatisfied CGs				>	>	
Relationship CGs	ref	ref	ref	ref	ref	ref
Satisfied CGs	>		>			>

Satisfied CGs as reference group						
Intensive CGs	<	<	<		>	>
Balanced CGs					>	
Dissatisfied CGs	<		<		>	
Relationship CGs	<		<			<
Satisfied CGs	ref	ref	ref	ref	ref	ref

Note: N=2,202. CG = caregiver. Ref = reference. > = more likely to report than reference group. < = less likely to report than reference group. Contrasts obtained using binary logistic regression predicting the likelihood of each support type reported. Models are unadjusted. Differences significant at $p<0.05$ or smaller.

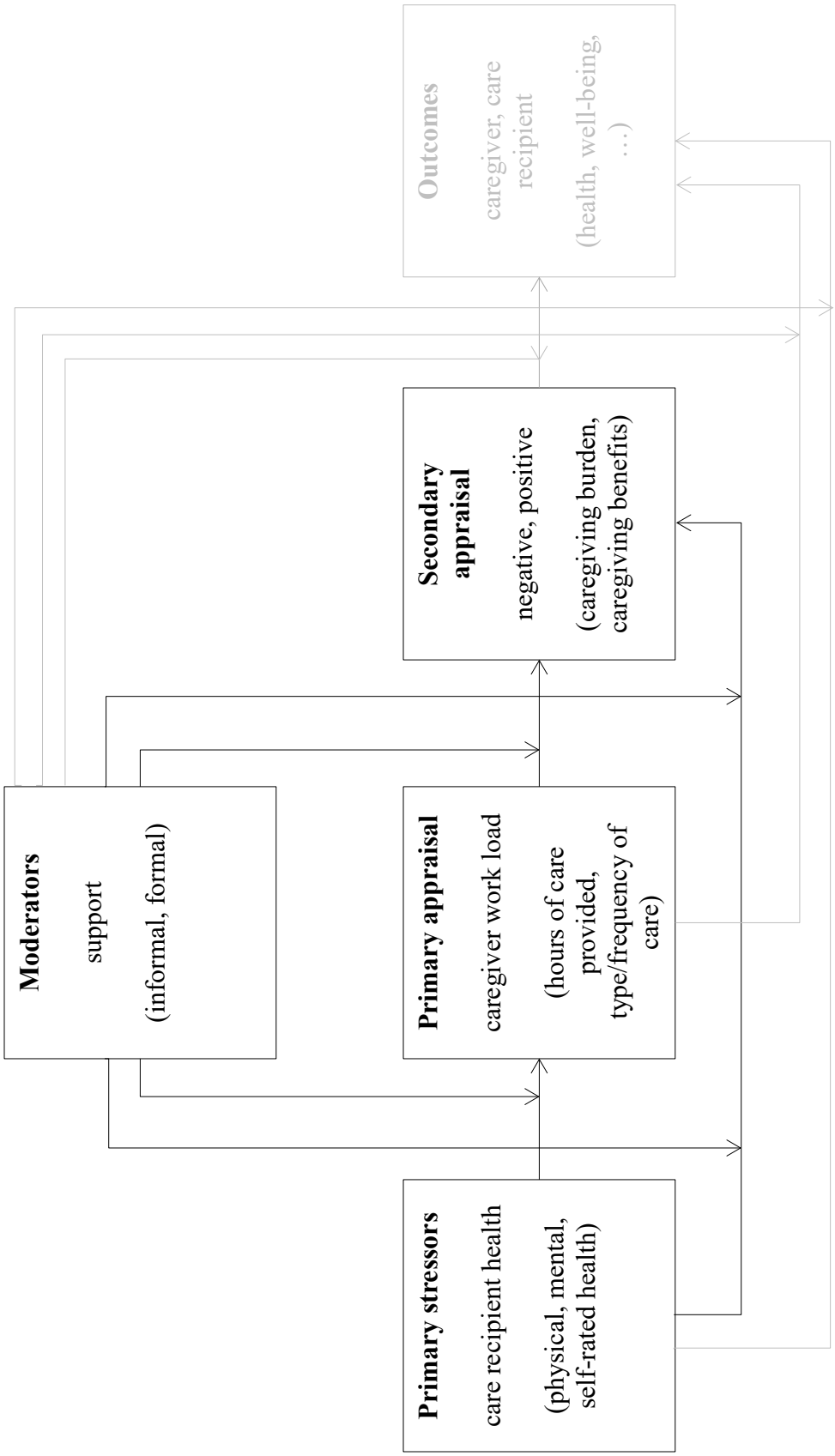

Figure 1. Study conceptual framework.

Appendix

Other study results

Primary stressors. Results from fully adjusted models (Table 3.3) suggest that poorer recipient mental and physical health are associated with caregivers' greater risk of being Dissatisfied Caregivers and experiencing caregiving as primarily burdensome and not beneficial. Caregivers whose recipients report more depressive symptoms have a 50% lower relative likelihood of being Balanced Caregivers and reporting moderate burden and high benefits (Class 2; rrr=0.50, $p<0.01$), a 49% lower relative likelihood of being Relationship Caregivers and reporting high interpersonal benefits with some burden (Class 4; rr=0.51, $p<0.01$), and a 51% lower relative likelihood of being Satisfied Caregivers and reporting benefits only (Class 5; rr=0.49, $p<0.001$), compared to being Dissatisfied Caregivers and experiencing predominantly burden. Similarly, compared to caregivers whose recipients have fewer than three medical diagnoses, those assisting recipients with three or more medically diagnosed conditions have a 55% lower relative risk of being Balanced Caregivers and experiencing moderate burden and high benefits (Class 2; rr=0.45, $p<0.05$), compared to being Dissatisfied Caregivers reporting predominantly burden. Thus, recipients' depressive symptoms and diagnosed medical conditions are associated with caregivers' greater chances of being Dissatisfied Caregivers, who do not report perceiving caregiving benefits.

Primary appraisal. Caregivers with high care levels—those providing a high number of hours of care, frequent ADL assistance, and assistance with medical tasks—are likely to be Intensive or Balanced Caregivers and to experience both caregiving

benefits and burden, rather than burden only. Relative to those who provide fewer than 20 hours of care per month, caregivers who provide 21 to 63 hours of care have almost three times the risk of being Intensive Caregivers experiencing high burden and moderate benefits (Class 1; rr=3.71, $p<0.05$) , and almost double the risk of being Balanced Caregivers reporting moderate burden and high benefits (Class 2; rr=2.66, $p<0.05$), compared to being Dissatisfied Caregivers who experience predominantly burden (Class 3),

In terms of ADL assistance, with each increase in their ADL help frequency, caregivers have a 73% higher relative risk of being Intensive Caregivers reporting high burden and moderate benefits (Class 1; rr=1.73, $p<0.01$), and a 57% higher relative risk of being Balanced Caregivers reporting moderate burden and high benefits (Class 2; rr=1.57, $p<0.01$) rather than being Dissatisfied Caregivers who experience predominantly burden. Further, with each additional medical or nursing task they assist with, caregivers have a 45% higher relative risk of being Intensive Caregivers experiencing high burden and moderate benefits (Class 1; rr=1.45, $p<0.01$) than being Dissatisfied Caregivers experiencing predominantly burden. Conversely, they have a 23% lower relative risk of being Relationship Caregivers and experiencing high interpersonal benefits with some interpersonal burden (Class 4; rr=0.77, $p<0.05$). The number of hours of care provided, ADL assistance, and assistance with medical tasks are thus associated with experience types involving benefits and burden, relative to experiencing only burden.

Contextual and control factors. In terms of caregiver characteristics, results indicate that Black and retired caregivers are more likely than white or employed caregivers to perceive benefits compared to burden; conversely, those experiencing

depression or anxiety symptoms are likely Dissatisfied Caregivers, perceiving caregiving as primarily burdensome and reporting the lowest benefits. Relative to white caregivers, Black caregivers have a relative risk 2.10 times higher of being Balanced Caregivers and experiencing moderate burden with high benefits (Class 2; rr=3.10, $p<0.05$), and relative risk 2.60 times higher of being Satisfied Caregivers experiencing benefits only (Class 5; rr=3.60, $p<0.01$), than of being Dissatisfied Caregivers reporting predominantly burden. Compared to employed caregivers, those who are retired have relative risk 1.05 times higher of being Satisfied Caregivers reporting high benefits only (Class 5; rr=2.05, $p<0.05$) than of being Dissatisfied Caregivers and reporting predominantly burden.

In terms of care arrangement characteristics, co-resident caregivers and long-term caregivers are at risk of being Dissatisfied Caregivers, perceiving caregiving as primarily burdensome and reporting the lowest benefits. Co-resident caregivers have a 55% lower relative risk of being Balanced Caregivers and reporting moderate burden with high benefits (Class 2; rr=0.44, $p<0.05$) and a 62% lower relative risk of being Satisfied Caregivers experiencing benefits only (Class 5; rr=0.38, $p<0.05$), than of being Dissatisfied Caregivers reporting predominantly burden, compared to caregivers who do not reside with their recipient. Compared to those who have been providing care to their recipient for fewer than five years, long-term caregivers have 49% lower relative risk of being Intensive Caregivers and experiencing high burden and moderate benefits (Class 1; rr=0.51, $p<0.05$) than of being Dissatisfied Caregivers reporting predominantly burden.

In sum, coresidence, long-term caregiving, and poor mental health may put caregivers at greater risk of experiencing caregiving as primarily burdensome. These

caregivers are more likely to be in the Dissatisfied Caregiver experience type, reporting the lowest amount of benefits from caregiving.

In terms of recipient characteristics, caregivers assisting female recipients are likely to report primarily beneficial caregiving experiences, but the opposite is the case for those assisting the oldest old, and for those with some college education. Compared to those providing assistance to male recipients, caregivers assisting women have 97% higher relative risk of being Satisfied Caregivers experiencing benefits only (Class 5; $rr=1.97$, $p<0.05$) than of being Dissatisfied Caregivers and experiencing predominantly burden. Caregivers assisting the old old have a 53% lower relative risk of being Satisfied Caregivers experiencing only benefits (Class 5; $rr=0.47$, $p<0.05$) than of being Dissatisfied Caregivers reporting predominantly burden. Relative to Dissatisfied Caregivers, those assisting the oldest old similarly have a 60% lower risk of being Satisfied Caregivers and reporting only benefits (Class 5; $rr=0.40$, $p<0.05$). Caregivers whose recipients have some college education, compared to those with less than high school education, have a 61% lower relative risk of being Balanced Caregivers and reporting moderate burden with high benefits (Class 2; $rr=0.39$, $p<0.05$) than of being Dissatisfied Caregivers reporting predominantly burden.

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Chapter 4

The Caregiving Dyad: Do Caregivers' Appraisals of Caregiving Matter for Care Recipients' Health?

Abstract

The implications of perceived caregiving burdens and benefits for caregivers' own well-being are well understood. Less is known about the ways in which caregivers' experiences affect the health and well-being of older adults for whom they provide care. Prior studies focus on burden alone, and overlook its coexistence with perceived benefits, offering an incomplete account of caregiving experiences and their associations with recipient outcomes. In this study, guided by the stress process framework and role theory, I prospectively explore the association between caregivers' experiences and recipients' mental health. I link National Health and Aging Trends Study (NHATS) and National Study of Caregivers (NSOC) data, yielding a sample of older adults receiving care from a nationally representative sample of informal caregivers. I employ binary logistic regression analysis to assess the role of caregivers' appraisals in recipients' risk of depression and anxiety, and examine caregiver mental health and recipient unmet care need as potential mediating factors. Controlling for sociodemographic, socioeconomic, and social support factors, older adults receiving care from persons who perceive caregiving to be entirely beneficial are less likely to experience depression three years post-baseline than counterparts receiving care from caregivers reporting exclusively burden. Similarly, older adults receiving care from persons reporting benefits even alongside low to moderate burden are less likely to experience anxiety. Recipient unmet

care need and caregiver mental health account for 17% of the association between caregivers' experiences and recipients' depression, and 37% of the association with recipients' anxiety. Informal caregivers' experiences have implications for recipients' mental health beyond the provision of care itself. Rather than viewing the caregiving experience as solely an individual phenomenon, researchers and practitioners should consider caregiving as a dyadic process. Caregivers' experiences matter for recipient outcomes, indicating that improving conditions for caregivers may have benefits for both members of the caregiving dyad.

Keywords: Caregiving, mental health, NHATS, NSOC, stress process, unmet need.

Introduction

Informal caregiving is a key part of the US long-term care system. In 2015, approximately 34.2 million, or 14% of all Americans, provided informal care to an individual aged 50 or older (AARP, 2015a). Informal caregivers' unpaid service was valued at approximately $470 billion and provided aging adults with 90% of care outside long-term care facilities, enabling older individuals to remain in their homes and communities (AARP, 2015b). For more than two-thirds of older adults, family caregivers are their only source of assistance (Centers for Disease Control and Prevention, 2011; Doty, 2015). With those aged 85 years and older being one of the fastest growing segments of the population, and an increasing prevalence of degenerative and chronic illness, the number of individuals living at home with impairments and disabilities who will require assistance from informal caregivers is expected to rise further in the coming decades (He, Goodkind, & Kowal, 2016; US Census Bureau, 2016; US Department of Health and Human Services, 2003).

Informal caregivers are therefore a key component of the US long-term care system, but caring for older adults can be a difficult experience (Feinberg, Newman, Gray, & Kolb, 2004). For many, the intensive nature of providing informal care to family members or friends is physically, psychologically, and financially draining, and may result in caregivers experiencing physical and emotional burden (Zarit, Todd, & Zarit, 1986). At the same time, researchers increasingly recognize that caregiving can also generate benefits as a potentially positive emotional and practical experience (Kramer, 1997). The caregiving experience is therefore multi-faceted, including both negative appraisals (burden) and positive appraisals (benefits), and the implications of these

burdens and benefits for caregivers' well-being have been well-established (Pinquart & Sorensen 2003; 2007). Little is known, however, about whether caregivers' experiences of benefit and burden have implications for their recipients' health and wellbeing (Lyons, Zarit, Sayer, & Whitlatch, 2002; Roberto, Blieszner, & Allen, 2006). A dyadic approach and reports obtained from both caregivers and their recipients avoid the difficulties of confounding due to one informant's underlying affect, and can improve our understanding of caregiving as an interpersonal process.

Several studies that examine the association between other caregiver characteristics and recipient outcomes offer initial support for the assertion that caregivers' experiences and recipients' health may be linked. Caregiver well-being is generally associated with better quality care, better care recipient adjustment, and later and more successful transitions to facility living. For example, caregiver-reported quality of life is associated with recipient-reported quality of life (Jolly, Thakkar, Mikolaitis, & Block, 2015). When caregivers experience anxiety, depression, or high levels of stress, recipients are more likely to report lower self-efficacy, poor treatment adherence, and poor symptom monitoring (Buck et al., 2015; Ejem, Drentea, & Clay, 2014; Trivedi, Piette, Fihn, & Edelman, 2012). Older adults whose caregivers report burden are also more likely to be placed in a nursing home (Gaugler et al., 2000; Gaugler, Kane, Kane, Clay, & Newcomer, 2003; McClendon & Smyth, 2015; Spillman & Long, 2009). Conversely, positive caregiver-recipient interactions, caregiver commitment, and better caregiver health are associated with delayed nursing home placement for the recipient (Wright, 1994). Recipients in dyads with a close relationship adjust to nursing homes better and experience slower cognitive decline (Burgener & Twigg, 2002; Norton et al.,

2009). When caregivers are confident in recipients' capabilities, recipients are also more likely to experience improvements in performing abilities of daily life (ADL; Li & McLaughlin, 2012).

Although these studies examine the association between certain caregiver characteristics and recipient well-being, they suffer from two main limitations. First, prior research frequently relies on measures obtained from a single reporter, introducing potential bias due to one informant's underlying affect or viewpoint (Bradford et al., 2013). Burdened caregivers may give negatively biased reports about their recipients' well-being. Using dyadic data with caregivers' and recipients' self-reports avoids this bias. Second, past studies do not comprehensively evaluate the importance of caregivers' experiences as a whole for recipients' overall well-being, and health outcomes in particular. They focus predominantly on caregivers' burden perceptions, and do not account for the co-existence and different levels of both positive and negative appraisals that each individual caregiver may experience (Lawton et al., 1989; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991).

In addition, most studies examining caregiver experiences and recipient outcomes are cross-sectional, and cannot establish causal ordering; that is, whether a strained caregiver contributes to negative recipient outcomes, or whether recipient health conditions add to greater caregiver burden (Braun et al., 2009; Chiao, Wu, & Hsiao, 2015; Ejem, Drentea, & Clay, 2014; Iecovich, 2015; Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2016). Most research also relies on convenience or clinical samples, often of care recipients from a single disease group (Abbate et al., 2011; Iecovich, 2011; Jennings et al., 2015; Norton et al., 2009). These samples are not representative of

population experiences, and often focus on caregivers of older persons with particular types of impairment. For example, although research frequently examines caregiving in dementia and Alzheimer's disease, only 9% of older individuals' caregivers cite it as the primary reason their recipients need care; many older adults have comorbidities or are receiving care due to other conditions (AARP, 2015a; Cuijpers, 2005; Ory, 1999). Small sample sizes also preclude these studies from distinguishing between groups of caregivers, such as between close family and nonrelative caregivers (Penning & Wu, 2015; Robison et al., 2009).

I use longitudinal data from the National Health and Aging Trends Study (NHATS) and link it with its companion study, the National Study of Caregivers (NSOC) survey, to address these gaps and evaluate the importance of caregivers' self-reported burdens and benefits for care recipients' self-reported mental health. Dyadic data allow me to avoid potential single-reporter bias and capture how recipient-reported mental health responds to caregiver-reported experiences, rather than confounding the two due to an individual informant's underlying affect or viewpoint. I assess the role of caregivers' appraisals of their burdens and benefits for recipients' depression and anxiety symptoms using a sample of adults over 65 years old who are receiving care from a nationally-representative group of informal caregivers. I developed and use a population-derived caregiving experience typology that accounts for both negative and positive appraisals, and focus on care recipients broadly, rather than on a clinically select sample of caregiver and recipient dyads (Norton et al., 2009). Arguing that the stress of negative caregiver appraisals (burden) may spill over to the recipient when unaccompanied with positive appraisals (benefits) through processes of objective (quality of care) or emotional

transmission (caregiver mental health), I use baseline reports of subjective caregiver burden and benefits to predict recipient mental health three years later. These prospective data allows me to ascertain causal ordering (considering caregiver experiences as a cause rather than consequence of recipient mental health) and to examine associations between caregiving experiences and recipient health that may take time to develop (Bolger, DeLongis, Kessler, & Schilling, 1989; Krause & Shaw, 2002). Stress process models posit that health outcomes develop with continuous and cumulative exposure to stressors, and using two waves of data avoids capturing the effects of only the initial stress of becoming a caregiver.

I address two research questions. First, I ask whether and how caregivers' experiences of caregiving are prospectively associated with recipients' mental health (depression and anxiety). Relatedly, I explore the relative importance of caregivers' experiences of burden versus benefits for recipients' mental health. Second, I examine whether secondary stressors arising from caregiving (caregiver mental health and recipient unmet need) mediate the association between caregivers' experiences and recipients' mental health, and whether the association persists after controlling for conceptually and practically relevant contextual factors.

Informal caregivers' experiences and caregiving appraisals

Many caregivers experience burden, or the "overall physical, psychological, emotional and financial toll of providing care" (Zarit, Todd, & Zarit, 1986). Almost 65% of older adults' caregivers assist persons with a physical impairment, 29% assist individuals with a memory problem, and 16% attend to individuals with "old age issues"

(AARP, 2015a). On average, they spend 24 hours per week providing help: they assist with personal care and ADL, coordinate care with medical professionals, manage medications, and increasingly carry out tasks that health care providers have traditionally performed (AARP, 2015a; Gillespie, Mullan, & Harrison, 2013). Attending to an older individual with a difficult personality may make caregiving more demanding, particularly in the case of dementia and Alzheimer's disease caregivers (Lockenhoff, Duberstein, Friedman, & Costa, 2011; Roberts, Smith, Jackson, & Edmonds, 2009; Riffin, Lockenhoff, Pillemer, Friedman, & Costa, 2013). Half of all caregivers to older persons report not having a choice in adopting the caregiving role (AARP, 2015a; Schulz et al., 2012).

As a result of these factors, older adults' informal caregivers report high rates of stress, depression and anxiety, social isolation, and more sleep troubles than their non-caregiving counterparts (Ho, Chan, Woo, Chong, & Sham, 2009; Ohaeri, 2003; Piquart & Sorensen, 2003; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009; Savla, Almeida, Davey, & Zarit, 2008). As most informal care providers to older adults are working-age adults, many struggle with competing demands of work and care roles (Chari, Engberg, Ray, & Mehrotra, 2014; Scharlach, 1994; Stephens, Townsend, Martire, & Drule, 2001). They may miss work due to caregiving responsibilities, and earn less income after reducing work hours to accommodate caregiving (Evandrou, Glaser, & Henz, 2002; Lilly, Laporte, & Coyle, 2007; Moen, Robison, & Fields, 1994; Robison et al., 2009). Further, older adult caregivers—likely to be spouses or partners—may be in poor health or require care themselves (Wharton & Zivin, 2017).

At the same time, researchers increasingly recognize that caregiving can also engender benefits, or the "positive affective or practical return that is experienced as a direct result of becoming a caregiver" (Kramer, 1997: 219). In one nationally-representative study, 80% of Canadian caregivers identified at least one positive outcome from their experience (Cohen, Colantonio, & Vernich, 2002). Caregivers report developing close relationships with care recipients, feeling companionship, and feeling appreciated (Andren & Elmstahl, 2005; Cohen et al., 2002; Kinney & Stephens, 1989; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Peacock et al., 2010). They indicate that caregiving provides them with the pleasure of seeing a loved one being cared for, gives them meaning, and feelings of accomplishment, personal fulfillment, and growth (Andren & Elmstahl, 2005; Cohen et al., 2002; Kinney & Stephens, 1989; Netto, Goh, & Yap, 2009; Quinn, Clare, & Woods, 2012).

The caregiving experience can thus include both negative (burden) and positive appraisals (benefits). Previous research focuses predominantly on how caregivers' appraisals of their experiences shape their own health and well-being (Ohaeri, 2003; Piquart & Sorensen, 2003). Few studies explicitly acknowledge that the caregiving relationship is by definition dyadic, and that the actions and experiences of caregivers and recipients are inextricably linked and mutually influential. Studies that do examine the role of caregiver appraisals for recipient outcomes take a narrow view of the caregiving experience, examining its facets—burden and benefits—in isolation (Buck et al., 2015; Ejem, Drentea, & Clay, 2014; Gaugler et al., 2000; Gaugler, Kane, Kane, Clay, & Newcomer, 2003; McClendon & Smyth, 2015; Spillman & Long, 2009; Trivedi, Piette, Fihn, & Edelman, 2012). Recurrent negative daily events may be particularly

consequential for older adults'; older persons tend to avoid negative exchanges and to attend to positive stimuli, making negative interactions more salient and typically more strongly associated with well-being than positive ones (Kraaij, Arensman, & Spinhoven, 2002; Proulx, Helms, & Buehler, 2007). However, caregivers' both positive and negative appraisals may ultimately affect recipients (Ingersoll-Dayton, Morgan, & Antonucci, 1997). Considering burden alongside benefit appraisals acknowledges the multiplicity and ambivalence of caregivers' perceptions, and allows for a better understanding of how caregivers experience their role.

To integrate caregivers' burden and benefit appraisal, in prior work, I develop an informal caregiving experience typology. Using latent class analysis on NHATS and NSOC data from a nationally-representative sample of US informal caregivers to older adults, I identify five distinguishable informal caregiving experience subtypes. Each group is unique in the type and intensity of reported burden and benefits. In two types (labeled "Intensive Caregivers" and "Balanced Caregivers"), burdens and benefits co-occur. Intensive Caregivers report experiencing high burden and moderate benefits across all emotional, interpersonal, physical, and social domains. Compared to other caregivers, their perceived burden is the highest, but their perceived benefits are comparable to those who report little to no burden. Balanced Caregivers report moderate burden—with an absence of social burden—coexisting with high benefits, also at levels comparable to those of caregivers reporting no burden. In the third type ("Dissatisfied Caregivers"), caregivers report experiencing only burden, at levels comparable to that of Intensive or Balanced Caregivers. Finally, in two types ("Relationship Caregivers" and "Satisfied Caregivers"), caregivers indicate predominantly experiencing benefits. Relationship

Caregivers experience these benefits in the interpersonal domain and also report some low burden in this domain; Satisfied Caregivers do not indicate experiencing any burden, and their perception of benefits is higher than that of any other group. I use these five informal caregiving experience types to examine the importance of caregivers' overall experiences for care recipient health.[1]

Role sets and the caregiving stress process

Role theory suggests that the experiences of caregivers and recipients are linked (Merton, 1957). In the caregiving relationship, the recipient's role is entangled with the caregiver's role as part of an enduring role set, or an interpersonal relationship structured around a common context and the frequent interactions that arise from it. Social interactionism perspectives on role-making processes suggest that individuals develop and commit to identities through such consistent behaviors; in turn, the former shape interchanges, as role performance is consistent with role expectations associated with that identity (Stryker, 1968).

The caregiving arrangement is one such structured context, with recurring interactions between the caregiver and recipient that include regular help with essential and instrumental ADL, personal care, and medical assistance (AARP, 2015a). The recipient's role in the caregiving relationship is relatively persistent and stable over time, as are daily experiences and encounters with the caregiver. Further, caregivers and

[1] As opposed to variable interactions, the latent class-derived typology reflects underlying groupings of caregiving experiences in the population of US informal caregivers; variable interactions project hypothetical combinations of burden and benefits and are not indicative of the population experience. Further, latent classes are better able to account for both the level and types of burden and benefits that caregivers experience, a task that would be complex and require multiple comparisons in the case of interactions.

recipients influence each other through continued interactions (Stryker, 1968). In this way, the lives of the caregiver and recipient are "linked" (Elder, George, & Shanahan, 1996). Caregivers' subjective experiences, caregiving interactions, and quality of received care become regular and important to recipients, and may shape their well-being (Pearlin, 2010; Stryker, 1968).

Role theory thus suggests that caregiver and care recipient experiences are linked; the stress process model helps explain how they are connected (Pearlin, 2010). I employ the stress process framework to examine potential links between caregivers' experiences and recipients' mental health and use conceptual insights from role theory to move the focus from caregiver to recipient outcomes in the theoretical model, accounting for the dyadic nature of the caregiving relationship. The resulting framework suggests that daily stress (or absence thereof) of interacting with a caregiver who experiences caregiving as more burdensome than beneficial may worsen recipient mental health (Figure 2).

In the conceptual model guiding my analyses, primary stressors (caregiver appraisals) can impact recipient outcomes (mental health) directly, and/or through secondary stressors that develop in the process of stress proliferation (caregiver mental health, recipient unmet need). Further, this model posits that outcomes depend on structural and contextual background (demographic, socioeconomic factors), and that coping resources (social support) moderate the stress process. In the following section, I discuss the elements of the framework in turn.

Caregiver experiences as a primary stressor shaping recipient mental health

Caregivers' experiences are a potential stressor that may shape care recipient mental health. In the stress process framework, primary and chronic stressors—the "relatively enduring problems, conflicts, and threats that people face in their daily lives" (Pearlin, 1989: 245)—represent negative experiences that recur due to the structured arrangements of an individual's life (Pearlin, 1989). Through a process that Pearlin (2010) labels a "contagion of stressors within [a] role set" (212), "the stressors one person faces can become sources of stress for her or his interacting partners within the role set" (Pearlin, 2010: 212). Caregiving issues often concern members of a broader family system, and other members of the caregiver's network—noncaregiving family and friends—often experience stress contagion (Amirkhanyan & Wolf, 2003). Similarly, receiving care from a caregiver who perceives high burden and/or few benefits may be a primary stressor for the recipient her- or himself, and experiencing this stress may worsen the recipient's health (Pearlin, 1989). Stressed caregivers may interact in a negative way with the recipient, voicing criticism, discouragement, showing a lack of respect, or providing poor emotional support to care recipients. Such exchanges may be consequential for the recipient, degrading their sense of confidence and control, or engendering feelings of sadness and worry. Prior research suggests that stressful interpersonal events and daily hassles are consistent and strong predictors of poor mental health in old age (Hammen, 2005; Kraaij et al., 2002). Such stressful events predict an increase in depressive symptoms over a 10-year period for older adults, and the association remains robust after accounting for illness history (Moos, Brennan, Schutte, & Moos, 2005); conversely, positive social interactions are associated with older adults reporting fewer depression symptoms, and such interactions appear to benefit the

psychological wellbeing of both partners in studies of couples (Han, Kim, & Burr, 2017; Robles, Slatcher, Trombello, & McGinn, 2014).

Pathways between caregiver experiences and recipient mental health

In addition to acting as a primary stressor, encounters with a burdened caregiver may give rise to secondary stressors for the recipient (Pearlin, 1989). Secondary stressors develop over time as a result of primary stressors through stress proliferation (Pearlin, Schieman, Fazio, & Meersman, 2005). Caregivers' appraisals may affect care recipients through two main pathways: care quality and emotional transmission.

Care quality. Caregivers' experiences—the burden and benefits they perceive—may affect the recipient indirectly through the quality of caregiving. Caregivers experiencing burden may feel overwhelmed and have fewer psychological, temporal, or physical resources to attend to the recipients' needs well. They may not take into account the recipient's wishes, exclude them from decisions, become neglectful, or may otherwise enact and "take out" their stress in performing caregiving tasks. Burdened caregivers may thus provide lower quality care. Accordingly, their recipients may report unmet need in assistance with ADL and instrumental ADL (IADL) (Beach & Schulz, 2017). Unmet ADL and IADL needs are distinct indicators of recipient quality of life that rarely overlap, but both are associated with health declines (Allen & Mor, 1997; LaPlante, Kaye, Kang, & Harrington, 2004; Tennstedt, McKinlay, & Kasten, 1994). Conversely, caregivers who perceive benefits may interact in a more positive way with recipients or provide better quality care. Caregivers' positive appraisals are generally associated with better caregiver mental health, physical health, and coping (Kim, Baker, & Spillers, 2007;

van der Lee, Bakker, Duivenvoorden, & Droes, 2014); thus, satisfied caregivers may be better equipped to attend to the recipient and offer good care.

Emotional transmission. Besides working through caregiving quality, primary stressors may also operate through a psychosocial pathway and proliferate to the recipient through emotional transmission. Caregivers are likely to develop poor mental health; caregivers may manifest depression or anxiety symptoms with negative mood and resigned behavior, and recipients may respond to perceiving their caregiver's mental health issues with their own feelings of fear, worry, sadness, or helplessness. Studies of cross-partner effects in marital and other relationships do suggest that the experiences and mental health of one partner are frequently associated with the mental health of the other partner in the dyad (Beach et al., 2005; Butterworth & Rodgers, 2006; Ohaeri, 2003; Pearlin, 2010; Pinquart & Sorensen, 2003; Tower & Kasl, 1995; Townsend, Miller, & Guo, 2001). Similarly to partners in close relationships who frequently show concordance in disorders like depression and anxiety, affective concordance with the caregiver (denoting close partners' shared emotional states) may thus shape recipient mental health (Hippisley-Cox, Coupland, Pringle, Crown, & Hammersley, 2002; Goodman & Shippy, 2002; Joutsenniemi, Moustgaard, Koskinen, Ripati, & Martikainen, 2011; Meyler, Stimpson, & Peek, 2007).

In sum, the stress process framework suggests that the experience of chronic stress ultimately results in adverse recipient health outcomes. Caregiver appraisals may act as a primary stressor, or through unmet recipient care need and poor caregiver mental health as secondary stressors (Pearlin, 1989). As adapted for this study, the framework also recognizes that interactions with a caregiver who perceives caregiving as primarily

beneficial may be less stressful for the recipient, resulting in better recipient mental health.

Stress-buffering factors

The stress process model suggests that coping resources like social support moderate the stress process, with higher perceived social support buffering from stress. Meta-analyses find that lower perceived social support and contact frequency are consistently associated with older adults' poor mental health (Almeida, Draper, & Pirkis, 2012; Beekman et al., 2000; Creighton, Davison, & Kissane, 2016). Receiving social support may give care recipients a greater sense of control, dignity, and self-worth; they may receive emotional or instrumental resources from family and friends that allow them to mitigate potentially stressful interactions and exchanges with the caregiver. For example, married and cohabiting older adults may have their partner as a supportive confidante who provides validation, and may report better psychological wellbeing despite stress (Wright & Brown, 2017). An extensive social network may provide a similar buffer, allowing older adults to draw on more interpersonal connections for support. Emotional support is a key psychosocial protective factor against poor mental health, but individuals' social networks shrink as they age (Fiori, Antonucci, & Cortina, 2006; Carstensen, Isaacowitz, & Charles, 1999). Additional instrumental support beyond that of the primary caregiver may also be beneficial for recipients and offset stressful experiences with the main caregiver; alternatively, it may engender feelings of dependency and worsen their mental health (Hansen & Aranda, 2012; Gur-Yaish, Zisberg, Sinoff, & Shadmi, 2013).

Mental health outcomes of the stress process

The stress appraisal framework recommends examining multiple health outcomes because individuals react to stress differently, and there are multiple pathways through which stress may affect health (Pearlin, 2010; Pearlin, Menaghan, Lieberman, & Mullan, 1981). Further, although stress can have immediate consequences for health, some effects take longer to appear (Pearlin, 2010). The delay is likely shorter for psychological than physical consequences, and I consider recipient mental health outcomes (Bolger et al., 1989; Krause & Shaw, 2002).

Depression and anxiety are the two most common poor mental health conditions in old age (Gonçalves, Pachana, & Byrne, 2011; Stallones, Marx, & Garrity, 1990). Studies of dyads in close relationships showing that one's psychological wellbeing depends on both unique stressors and the stress that their partner experiences suggest that the mental health status of one partner is frequently associated with the other partner's depression and anxiety (Birditt, Newton, Cranford, & Ryan, 2016; Butterworth & Rodgers, 2006; Monin et al., 2010; Neff & Kearney, 2007; Tower & Kasl, 1995; Townsend, Miller, & Guo, 2001). I thus evaluate the importance of caregiver experiences for the recipient's likelihood of experiencing depression and anxiety symptoms.

Depression and anxiety are related but distinct conditions. Anxiety can be a personality trait-like condition that is frequently associated with neuroticism and describes general susceptibility to anxiety disorders (McCrae & Costa, 1995). It is a "stable tendency to attend to, experience, and report negative emotions such as fears, worries, and anxiety across many situations" (Gidron, 2013). Between 42% and 63% of

older adults' differences in anxiety experiences are due to genetic factors (Lee, Gatz, Pedersen, & Prescott, 2016). Conversely, depressed mood, including sadness and helplessness, may be a more temporary response to stressors from particular situations or events. For example, older adults admitted to a hospital show significant changes in depression symptoms over time. They experience more symptoms while in hospital care—where they may lose privacy and experience more dependency and vulnerability—and a decrease after discharge, when they likely regain a sense of social integration and connectedness (Chen, Huang, & Chen, 2014). Similarly, older adults report decreases in depression symptoms following good interactions with nurses; positive exchanges and being treated with attention and respect may facilitate care recipients' greater sense of self-worth, dignity, and agency (Haugan, Innstrand, & Moksnes, 2013).

Thus, it is possible that recipient depression responds differently from anxiety to stressors proliferating from the caregiver's experiences of caregiving. Caregiver appraisals may more strongly predict differences in recipient depression over time; conversely, caregiver appraisals may not affect the more trait-like recipient anxiety.

Confounding factors in caregivers' experiences and recipient mental health

The conceptual model suggests that the stress process unfolds in the context of background and structural factors that may be associated with both caregivers' experiences and recipient mental health. Care recipient characteristics may affect responses to stressors, and gender, race, age, socioeconomic status, and health status all shape older adults' likelihood of anxiety and depression (Beattie, Pachana, & Franklin, 2010; Berkman et al., 1986; Blazer, Hybels, Simonsick, & Hanlon, 2000; Creighton,

Davison, & Kissane, 2016; Gonçalves, Pachana, & Byrne, 2011; Meller, Fichter, & Schroppel, 1996; Ried & Planas, 2002; Schoevers, Beekman, Deeg, Jonker, & van Tilburg, 2003; Stallones, Marx, & Garrity, 1990; Vink, Aartsen, & Schoevers, 2008). Caregiver characteristics like gender, socioeconomic status, relationship to recipient, and caregiving duration may also in part explain the relationship between caregivers' experiences and caregivers' mental health and quality of care (the two factors potentially mediating the caregiver appraisals-recipient mental health association) (Pinquart & Sorensen, 2003; 2005; 2006).

Data

To examine the relationship between caregiver experiences and recipient health, I link two datasets. First, I use the 2011 and 2013 waves of the longitudinal US National Health and Aging Trends Study (NHATS) to obtain reports from care recipients (Kasper & Freedman, 2014). NHATS is a nationally-representative survey designed to monitor aging changes and to explore the social implications of aging transitions. Using computer-assisted personal interviewing (CAPI), it collects information on a stratified three-stage sample of Medicare recipients over 65 years old living in residential care or at home; 96% of all U.S. older adults are enrolled in Medicare (Montaquila et al., 2012). NHATS oversamples black older adults and older adults over 85 years old. The baseline response rate was 71%.

I link NHATS data with its 2011 National Study of Caregiving (NSOC) supplement to obtain reports from caregivers (Kasper, Freedman, & Spillman, 2013). NSOC is a NHATS companion study of informal caregivers (that is, individuals not

associated with the formal care system) from whom NHATS sample persons indicated receiving help with self-care, mobility, or household activities. NSOC uses telephone interviews to collect data on family members and friends' roles in providing care to older adults, including activities for which help was provided, help duration and intensity, effects of caregiving on helpers, and the kinds of support services helpers use. NHATS sample persons could identify multiple helpers, and NSOC interviews were conducted with 2,007 caregivers (a response rate of 59.7%) of 1,369 older persons. As described below, I focus on dyads that include the NHATS sample person and their primary caregiver.

Analytic sample

The analytic sample consists of dyads that include a NHATS sample person and their primary caregiver. If the NHATS sample person was associated with multiple caregivers (38.4%), primary caregiver refers to the individual providing the highest number of hours of assistance to the older adult in the month prior to NSOC interview.

Of the 1,369 NHATS participants with caregivers in the NSOC companion study at Wave 1, 155 (11.3%) died and 380 (27.8%) attrited by Wave 3. Attrition analysis using chi-square tests and multinomial logistic regression predicting attrition and deceased status odds suggests no unexpected demographic differences between the final analytic sample and those who attrited. Those who died between Wave 1 and 3 differ from the final sample on factors commonly associated with old-age mortality, including advanced age, poor health, and being black.[2]

[2] Deceased status. Males relative to females (rr=1.40, se=0.20, $p<0.05$), persons at older ages relative to younger individuals (rr=1.06, se=0.01, $p<0.001$), and widowed persons relative to those married or

Of the remaining 834 older persons with caregivers in the Wave 3 sample, 27 dyads (3.2%) had missing data on at least one variable included in analyses. Because of the low level of missing data, I use listwise deletion for cases without information on factors included in final models. The analytic sample thus includes 781 pairs of older adults and their primary caregivers. Although no individuals in the sample were living in nursing care facilities at baseline, some portion (4.0%) had moved into nursing care facilities between the baseline and subsequent interview.

Measures

Dependent variables: Care recipient mental health at Wave 3.

Recipient depression symptoms is a dichotomous measure of recipient-reported likely depression (based on the Patient Health Questionnaire-2 (PHQ-2) depression screener), and recipient anxiety symptoms is a dichotomous measure of recipient-reported likely anxiety (based on the Generalized Anxiety Disorder Scale (GAD-2) anxiety screener). PHQ-2 and GAD-2 are widely used, validated two-item screeners reflecting DSM-V core diagnostic criteria for depression and anxiety, respectively. PHQ-2 asks whether the respondent had little interest or pleasure in doing things; and whether they felt down, depressed, or hopeless, over the past month. GAD-2 asks whether the

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partnered (rr=1.41, se=0.21, p<0.01), had higher risk ratios for deceased status relative to being in the sample. Black persons relative to whites (rr=0.67, se=0.11, p<0.01), and older adults in good health relative to those in poorer health (rr=0.71, se=0.05, p<0.001) had lower risk ratios for deceased status relative to being in the sample. There were no education level differences in individuals' likelihood of attrition versus being in the sample.

Attrition. Males relative to females (rr=1.41, se=0.23, p<0.05), and Hispanic persons relative to whites (rr=2.04, se=0.56, p<0.01) had higher risk ratios for attrition relative to being in the sample. Individuals in better health relative to those in poorer health (rr=0.75, se=0.56, p<0.001), and widowed older adults relative to their married or partnered counterparts (rr=0.61, se=0.10, p<0.01) had lower risk ratios for attrition relative to being in the sample. There were no age or education level differences in individuals' likelihood of attrition versus being in the sample.

respondent felt nervous, anxious, or on edge; and whether they felt unable to stop or control worrying over the past month.

For items constituting each screener, the original response categories (not at all, several days, more than half the days, and nearly every day) are scored with values 0 to 3, respectively, with a total score range from 0 to 6 (Lowe et al. 2010). A score greater or equal to 3 is considered the cutoff point for a respondent's likelihood of suffering from depression, or the likelihood of suffering from anxiety. I recode the variables accordingly to indicate whether the respondent likely meets diagnostic criteria for depression (=1) versus does not (=0), and whether the respondent likely meets diagnostic criteria for anxiety (=1) versus does no (=0). I control for the lagged dependent variables using the same indicators measured at Wave 1.

Primary stressors (caregivers' experience of caregiving) at Wave 1.

Caregivers' experience type is a categorical variable based on caregivers' reports about the caregiving burdens and benefits they experienced. Based on their item response pattern, I use most likely class membership to assign each caregiver to one of five categories developed in prior latent class analyses (LCA; Author, 2017, Chapter 1 of dissertation): 1) Intensive Caregiver (reporting high caregiving burden and moderate benefits across all emotional, interpersonal, physical, and social domains); 2) Balanced Caregiver (reporting moderate burden with an absence of social burden, and high benefits); 3) Dissatisfied Caregiver (reference category; reporting burden only); 4) Relationship Caregiver (reporting interpersonal burden only, and interpersonal benefits); or 5) Satisfied Caregiver (reporting benefits only). The analytic sample is smaller in this

study (compared to Chapter 1) due to attrition, but measurement model construction on the present analytic sample confirms the existence of the same latent classes (see Appendix Tables 4.5, 4.6).

Secondary stressors / Pathways (caregiver mental health, recipient unmet need) at Wave 1.

Caregiver mental health.

Caregiver depression and anxiety symptoms are dichotomous measures of caregiver-reported depression and anxiety symptoms, measured using the same items and procedure described above for recipients.[3] Caregiver depressive symptoms and caregiver anxiety symptoms are correlated at 0.32, and I therefore include each measure separately.

Care recipient unmet need for care.[4]

Unmet ADL need is a dichotomous measure indicating whether the recipient reported (at Wave 1) being unable in the past month to perform any basic ADL (eating, bathing, toileting, dressing, moving around inside, getting out of bed) because there was no one there to help (=1), or whether the recipient had no difficulty performing ADL due to lack of help.

Unmet IADL need is a dichotomous measure indicating whether the recipient reported (at Wave 1) being unable in the past month to perform any IADL (doing

[3] I conducted sensitivity analyses in which I include the number of caregiver depressive and anxiety symptoms as continuous variables. Analyses using the continuous measures do not change the results obtained.

[4] Care recipient-reported unmet ADL need and unmet IADL are moderately correlated (Pearson's r = 0.38). However, research suggests they appear at different stages of disability and have different predictors (Tennstedt, McKinlay, & Kasten, 1994). Sensitivity analyses in which I include unmet need as a composite measure show no change the pattern or strength of statistical significance on other coefficients, but the composite measure masks the distinct ways in which unmet ADL and IADL need operate. I therefore include the the two unmet need measures in the models separately.

laundry, getting groceries, moving around outside, cooking, banking, taking medicines) because there was no one there to help (=1), or whether the recipient had no difficulty performing IADL due to lack of help.[5]

Moderators (social support indices) at Wave 1.

Marital status. Recipient marital status is dichotomous measure indicating whether recipient self-reports they are currently married/partnered (=1), or separated/divorced, widowed, or never married (=0).

Number of children is a continuous measure indicating the number of living biological or adopted children the recipient reports ever having.

No confidante to is a dichotomous variable indicating whether recipient reports currently having "no one to talk to" in their social network (=1) or whether they have persons they can talk to about important things (=0).

Other helpers is a dichotomous measure indicating whether the recipient reports receiving assistance from helpers other than the primary caregiver (=1), or whether the recipient has no other helpers (=0).

Structural and contextual / Confounding factors at Wave 1.

Care recipient factors

Recipient gender is a dichotomous variable indicating whether the recipient reports being female (=1) or male (=0).

[5] Including unmet need variables as continuous or categorical (coded as no unmet need, one unmet need, and two or more unmet needs) does not change the results obtained.

Recipient age is a categorical measure of whether the recipient reports being "young old" (65-74 years old), "old old" (75-84 years old), or "oldest old" (85 years or older).

Recipient race is a categorical variable indicating whether the recipient self-identifies as non-Hispanic white (reference), non-Hispanic Black, or other.

Recipient socioeconomic status.

Recipient education is a categorical variable indicating whether the recipient's self-reported highest education level is less than high school (reference), high school or equivalent, some college or technical school, or college degree or above.

Recipient homeownership is a dichotomous variable indicating whether the recipient reports currently owning a home (=1) or not (=0).

Recipient social assistance is a dichotomous variable indicating whether the recipient reports receiving any type of social assistance (food stamps, other types of food assistance, or gas and electricity assistance) (=1) or not (=0).

Recipient baseline health.

Number of ADL disabilities is a continuous measure of the total number of ADL (eating, bathing, toileting, dressing, moving around inside, and getting out of bed) that the recipient reports being unable to perform without assistance at Wave 1.

Recipient self-rated health is a dichotomous measure indicating whether the recipient reports having "very good" or "excellent" (=1) versus "poor," "fair," or "good" health (=0).

Recipient baseline depression symptoms and anxiety symptoms at Wave 1 are adjusted as described in the Secondary Stressors section.

Caregiver factors

Caregiver gender is a dichotomous variable indicating whether the caregiver reports being female (=1) or male (=0).

Caregiver education is a categorical variable indicating whether the caregiver's self-reported highest education level is less than high school (reference), high school or equivalent, some college or technical school, or college degree or above.

Caregiver relationship type is a categorical variable indicating whether the caregiver reports being the recipient's spouse (reference), adult child, or other relative or non-relative.

Long-term caregiver is a dichotomous measure indicating whether the caregiver reports providing care for recipient for fewer than five years (=0) or for five years or more (=1).[6]

Total hours spent caregiving to recipient in past month is a categorical variable indicating whether the caregiver reports spending fewer than 20 hours (reference), 21 to 63 hours, or 64 hours or more providing care to recipient in past month. Cut-off points are based on response distribution terciles.[7]

Methods

I use binary logistic regression models to examine the association between caregiver experience and care recipient mental health. I estimate a series of models,

[6] Sensitivity analyses including the number of years spent caregiving as a continuous variable suggest that the measure does not have a linear association with the latent variable. I include the variable as categorical to examine the possibility of adaptation to caregiving.

[7] Sensitivity analyses including hours per month caregiving as a continuous variable suggest that the measure does not have a linear association with the dependent variable. I therefore include the variable as categorical.

sequentially including blocks of relevant variables. I first estimate bivariate models for the unadjusted association between the caregiver's experience type (measured at Wave 1) and recipient's likely depression and anxiety (measured at Wave 3) in Model 1. I then include variables in blocks to examine whether the association persists after taking into account conceptually relevant and known recipient health predictors. In accordance with the stress appraisal conceptual framework, I adjust the baseline model for secondary stressors (Model 2), contextual/structural factors including the lagged dependent variable (Model 3), social support (Model 4), and caregiver control variables (Model 5).

To examine whether caregivers' depressive and anxious symptoms and recipients' unmet ADL and IADL needs act as mediators of the association between caregivers' experiences and recipients' mental health, I also conduct a correlational analysis of the associations between caregivers' experience types and recipient depression and anxiety. I then conduct mediation analysis evaluating the relevant variables against mediation criteria (Hayes & Preacher, 2014). Caregiver mental health or recipient unmet need should explain the association between experience types and recipient mental health when entered in a model including all three factors; a weakened association between caregiving experience types and recipient mental health offers evidence of partial mediation. I employ the bootstrapping method to formally test for mediation effects.

Table 4.1 shows unweighted sample descriptive statistics. Tables 4.2 and 4.3 show binary logistic regression results predicting recipient depression and anxiety at Wave 3.[8] Each table displays odds ratios (exponentiated coefficients) and robust standard

[8] Multicollinearity did not pose a problem for the present analysis, with no variance inflation factor for covariates in the model exceeding 2. In models shown, the link test of the logistic regression equation predicting care recipient depression and anxiety was not significant (depression hatsq=-0.10, sd=0.10, p=0.318; anxiety hatsq=-0.12, sd=0.09, p=0.170), suggesting no specification error. The Homer-Lemeshow

errors for all variables in each model. I tested interaction terms between primary/secondary stressors and social support indicators, as the conceptual model suggests that social support factors moderate the stress process (results not shown). Because none of the interactions between primary or secondary stressors and social support measures was statistically significant, I do not include any interactions in final models.

Results

Caregivers' experiences and recipient anxiety

Older adults with caregivers who report any caregiving benefits, even alongside burden (unless the burden is very high), are less likely to experience anxiety. In unadjusted Model 1 (Table 4.2), older persons receiving assistance at baseline from Balanced, Relationship, and Satisfied Caregivers (reporting benefits or benefits alongside low to moderate burden) have lower odds of experiencing anxiety at the follow-up interview than their counterparts receiving assistance from Dissatisfied Caregivers (reporting only burden). These associations persist and remain robust after including secondary stressors, contextual factors with the lagged dependent variable, social support factors, and control variables. In the fully-adjusted model (Model 5), compared to older adults receiving assistance from Dissatisfied Caregivers, those receiving assistance at baseline from Balanced Caregivers (reporting moderate burden and high benefits) had

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goodness-of-fit (depression df=718, chi2=742.15, p=0.259; anxiety df=714, chi2=734.2, p=0.292) does not suggest issues of model fit. Lowess graphs indicate that the log odds of each outcome are linearly associated with the covariates in the model. The classification table indicates that the model correctly classifies the majority of the sample (74.90% of all cases in predicting depression; 80.51% of all cases in predicting anxiety). For both outcomes, the analytic sample did not contain any cases exhibiting high leverage.

63% lower odds (or=0.37, p<0.01) of having anxiety three years later. Those receiving care from Relationship Caregivers (reporting interpersonal burden and benefits), had 66% lower odds (or=0.34, p<0.01), and those receiving care from Satisfied Caregivers (reporting only benefits) had 67% lower odds (or=0.33, p<0.001) of anxiety, again relative to those receiving assistance from Dissatisfied Caregivers. Older persons receiving care from Intensive Caregivers (reporting high burden and moderate benefits) and Dissatisfied Caregivers (reporting burden only) did not differ significantly from one another in their likelihood of anxiety. In sum, older adults whose caregivers report any benefits from caregiving are less likely to experience anxiety, unless their caregivers are also reporting very high burden.

Mediation analysis. Recipient unmet need and caregiver mental health partially mediate between caregiver experiences and recipient anxiety. Caregiver experience types maintain a statistically significant but weaker association with recipient anxiety when potential mediators (caregiver depression and anxiety symptoms, recipient unmet ADL and IADL need) are entered in the model. Formal analyses using bootstrapping with case resampling, 1000 repetitions, and bias-corrected confidence intervals to obtain effect standard errors suggests that the mediation effects of recipient unmet ADL need (b=-0.02, p<0.05), and total indirect effects (b=-0.09, p<0.001) are statistically significant. Together, caregiver mental health and recipient unmet need account for 53% of the total effect (b=-0.17, p<0.001) of caregiver experience type on recipient anxiety in the model adjusted for all mediators (Model 2). Contextual factors explain away the initial association between recipient unmet ADL need and subsequent anxiety (Model 4), but in the fully adjusted model (Model 5), mediators still account for 37% of the total effect

(b=-0.10, p<0.05). Results thus suggest that unmet ADL need partly mediates the association between caregiving experience types and recipient anxiety. Further, although not statistically significant on its own as a predictor of recipient anxiety, caregiver depression and anxiety have statistically significant total indirect effects on recipient mental health. The findings indicate that caregiving experiences may shape recipient anxiety through unmet need and caregiver mental health.

Other predictors of recipient anxiety. Recipients' education and baseline anxiety are also associated with subsequent anxiety in initial models (Model 3). Control factors explain away the association between recipients' education and subsequent anxiety, but prior poor mental health remains a significant predictor of anxiety three years later (Model 5). Compared to recipients who were not anxious at the first interview, those with anxiety at baseline have 228% higher odds (or=3.28, p<0.001) of anxiety at follow-up. No other secondary stressors, contextual factors, social support factors, or control variables are associated with recipient anxiety at Wave 3, net of anxiety at Wave 1.

Caregivers' experiences and recipient depression

Only older persons with caregivers reporting benefits and no burden are less likely than counterparts with burdened caregivers to subsequently experience depression. In unadjusted Model 1 (Table 4.3), care recipients receiving assistance from Satisfied Caregivers (reporting benefits only) at baseline have lower odds of experiencing depression three years later, relative to their counterparts receiving assistance from Dissatisfied Caregivers (reporting only burden). The coefficient size and level of significance remain stable following covariate additions, and the effects are significant in

the final model (Model 5). In the fully-adjusted model (Model 5), recipients with Satisfied Caregivers (reporting only experiencing benefits) at baseline had 47% lower odds (or=0.53, $p<0.05$) than recipients with Dissatisfied Caregivers of having depression three years later. Those receiving care from caregivers who perceive benefits, but also report any burden level, do not differ in depression likelihood from counterparts receiving care from caregivers reporting burden only (Dissatisfied Caregivers). In sum, only older adults whose caregivers report perceiving benefits but no burden at baseline are less likely than persons receiving care from burdened caregivers to experience depression three years later.

Mediation analysis. Caregiver mental health and recipient unmet need partially mediate the association between caregiver experiences and recipient anxiety. Entering potential mediators in the model weakens the association between caregiver experiences and recipient depression. Formal analysis using bootstrapping with case resampling, 1000 repetitions, and bias-corrected confidence intervals to obtain effect standard errors suggests that the mediation effects of recipient unmet ADL need (b=-0.03, $p<0.01$), unmet IADL need (b=-0.02, $p<0.05$), total direct effects (b=-0.11, se=0.01, $p<0.05$) and total indirect effects (b=-0.07, $p<0.01$) are statistically significant. Caregiver mental health and recipient unmet need mediate approximately 38% of the total effect (b=-0.19, $p<0.001$) of caregiver experience types on recipient depression in the model including all mediators; in the fully adjusted model, mediators account for 17% of the total effect of caregiver experiences on recipient depression (b=-0.14, $p<0.01$). Thus, part of caregiver experiences' association with recipient depression operates through caregiver mental health and recipient unmet need. Additionally, unmet ADL need exacts significant direct

effects on recipient depression: In the full model (Model 5), compared to recipients not reporting any unmet ADL need at baseline, recipients who report unmet ADL need have 41% higher odds (or=1.69, $p<0.05$) of depression three years later.

Other predictors of recipient depression. Recipients with relatively more education may be less likely to experience depression than their counterparts with less education, and those reporting depression at baseline are likely to experience the condition three years later in the full model (Model 5). Older persons with some college education have 48% lower odds (or=0.52, $p<0.05$) of depression compared to recipients with less than high school education. Compared to older adults not depressed at baseline, those with depression at Wave 1 have 107% higher odds (or=2.07, $p<0.001$) of experiencing the condition at the three-year follow-up. No other secondary stressors, contextual factors, social support factors, or control variables are associated with recipient depression at Wave 3.

Discussion

I examine whether and how informal caregivers' appraisal of benefits and burdens is prospectively associated with their care recipients' mental health. Overall, I find that caregivers' experiences matter for care recipients' depression and anxiety in distinctive ways, indicating that improving conditions for caregivers may have benefits for both members of the caregiving dyad. More specifically, I find a robust association between the caregiver's reports of caregiving burden and benefits at baseline and the recipient's depression and anxiety at the three-year follow-up. Recipients whose caregivers report benefits, even alongside low to moderate burden, are less likely to subsequently

experience anxiety; older adults whose caregivers report benefits without any burden are also less likely to experience depression. These associations persist after the addition of conceptually relevant covariates, including recipients' baseline health, and are mediated by caregiver mental health and recipient unmet care need.

My analyses yielded five main findings. First, caregivers' baseline appraisals are associated with subsequent recipient depression and anxiety, but in ways contrary to expectations. Second, older persons whose caregivers report high benefits and high burden do not differ in outcomes from counterparts whose caregivers report only high burden. Third, recipients' unmet ADL but not IADL need prospectively shapes their mental health. Fourth, caregiver mental health has indirect effects on recipient mental health. Finally, contextual factors explain variation in recipient mental health better than social support factors.

Caregiver experiences matter for recipient mental health

I find that caregivers' baseline reports of both beneficial and ambivalent caregiving experiences are associated with better subsequent recipient mental health. Older adults are less likely to experience anxiety when receiving care from either caregivers who report only benefits, or from caregivers who report benefits alongside low to moderate burden, compared to those receiving care from caregivers reporting only burden. In contrast, only older adults receiving assistance from caregivers who perceive caregiving as beneficial with no reported burden are less likely to experience depression; those with caregivers reporting benefits alongside any level of burden do not fare differently from counterparts with caregivers reporting exclusively burden, in terms of

depressive symptoms. Interactions with a burdened caregiver, regardless of whether the caregiver also perceives benefits, may be stressful for the recipient; my findings thus suggest that frequent interpersonal stressors may matter more for depression than anxiety (Han, Kim, & Burr, 2017; Moos, Brennan, Schutte, & Moos, 2005; Robles, Slatcher, Trombello, & McGinn, 2014). Such stressors may be more likely to engender feelings of sadness and helplessness, which are more characteristic of depression than anxiety (Chen et al., 2014; Haugan et al., 2013).

This finding is contrary to the expectation that recipient depression—and not anxiety, a more trait-like condition that describes individuals' relatively stable propensity to negatively respond to stressful circumstances— would be more responsive to stressors (Gidron, 2013; Lee et al., 2016; McCrae & Costa, 1995). It is possible that the GAD-2 screener measuring recipient anxiety that asks about feeling nervousness, being on edge, and worrying, is better capturing state anxiety than trait anxiety. State anxiety refers to more transient negative emotional responses, like feelings of fear, worry, and uncertainty, and these feelings may be a response to daily stressors and interactions with caregivers (Spielberger, 1972). Alternatively, depression may be more likely to be inherited than anxiety disorders, and thus be a more stable characteristic less responsive to context (Sullivan, Neale, & Kendler, 2000). The likelihood of depression also increases in old age, and it is possible that positive caregiver experiences are not sufficient to mitigate this risk (Blazer, Landerman, Hays, & Simonsick, 1998; Kessler, Foster, Webster, & House, 1992; Sutin, et al., 2013).

Regardless, caregiver experiences shape both recipient depression and anxiety, and results suggest that in cases where it is not possible to reduce caregivers' burden, it

may still be beneficial to design interventions increasing their perceived and objective benefits. Recipients are less likely to experience anxiety if their caregivers perceive benefits from caregiving, even when their caregivers also report low to moderate burden. Such interventions may focus on fostering caregiver resilience and facilitating the development of coping skills like positive reframing (Toohey, Muralidharan, Medoff, Lucksted, & Dixon, 2016). To decrease the likelihood of recipient depression, my findings suggest that it may be most important to reduce caregivers' perceived or objective burden. Access to support services, nursing care training, additional assistance from paid caregivers, and availability of respite care may help alleviate caregiving burden (Hunt & Reinhard, 2015; Zarit, Kim, Femia, Almeida, & Klein, 2014).

High benefits may not counterbalance caregivers' high burden

Older adults whose caregivers report high benefits alongside high burden do not differ significantly in their risk of either depression or anxiety from counterparts whose caregivers report high burden without any benefits. This suggests that caregivers reporting the highest burden levels may be at a threshold beyond which their potential positive appraisals no longer counter-balance the spillover consequences of burden, or provide benefits for recipient mental health.

Caregivers reporting high burden are likely providing intensive care, beyond those controlled in the analysis (Pinquart & Sorensen, 2003). Despite their perception of benefits, they are themselves at risk of developing poor mental health. Although a rare occurrence, it is possible that caregivers may engage in elder neglect and abuse (Beach et al., 2005). Their actions and interactions with the recipient may be of poorer quality, and

older adults respond more poorly than younger individuals to negative interpersonal interactions, taking longer to recuperate emotionally (Birditt, 2013; Charles, 2010). Poor social interactions may also be more salient for recipients than positive ones (Antonucci et al., 2002). Thus, despite caregivers' high positive appraisals, the consequences of their high burden may have a stronger or more lasting impact on older persons' well-being.

Caregivers reporting the highest burden levels may therefore be the group most in need of assistance. Respite care and adult day care centers may reduce objective and perceived burden for caregivers providing intensive care, and for those who are co-resident with the care recipient or have little time for themselves (Zarit et al., 2014). Beyond benefits for caregivers themselves, my findings suggest that providing such support to these caregivers may also have implications for their recipients' quality of life (Sorensen, Pinquart, & Duberstein, 2002).

Recipient unmet ADL but not IADL need shapes their mental health

Among secondary stressors, I find that unmet ADL need, but not IADL need, is a key factor shaping older adults' depression. Although I cannot ascertain the quality of care provided, caregivers experiencing high burden are at risk of engaging in elder neglect, including omitting or poorly performing tasks related to recipients' personal care, feeding, or other necessary activities of daily living (Reay & Browne, 2001). The finding may thus suggest that the caregiver's experiences are objectively transmitted to affect recipient mental health through care quality (rather than emotionally transmitted, as discussed in the following section). Caregivers reporting high burden may give lower

quality or inadequate care, reflected in their recipients reporting unmet ADL need and poorer mental health (MacNeil et al., 2010).

I do not find the same association between unmet IADL need and recipient mental health. Unmet IADL need is more common among older adults than unmet ADL need, but IADL need does not include the intimate tasks that the ADL need does (Tennstedt, McKinlay, & Kasten, 1994). IADL needs are typically instrumental rather than essential, and are often not required daily. Unmet need for ADL care, such as bathing and toileting, is therefore likely more detrimental to older persons' mental health than unmet need for tasks that are not immediate or essential. However, both unmet ADL and IADL need in part mediate the relationship between caregiving experience types and recipient depression and anxiety, and both factors may reduce older adults' quality of life (Allen & Mor, 1997; Branch, 2000; LaPlante, Kaye, Kang, & Harrington, 2004). Studies using nationally representative data show that over 40% of care recipients report at least one unmet care need in a given month, and over 30% report adverse consequences of such unmet need (Beach & Schulz, 2017; Freedman & Spillman, 2014). It is thus crucial for future research to examine reasons behind unmet need to establish whether it is due to caregiver burden or other factors, suggesting how to intervene. Although I do not find gender effects in this study (which includes a significant portion of spouse caregivers), in the case of unmet ADL need, it is possible that rather than only due to overwhelming burden, gender dynamics in performing intimate tasks for non-marital caregiving dyads may partly explain unmet need. Information on sense of control is only available for a subset of NHATS participants, but the implied loss of control on the part of the recipient

in adult child-parent dyads could similarly engender unmet need (Tennstedt, McKinlay, & Kasten, 1994).

Caregiver mental health has indirect effects on recipient mental health

Caregiver mental health is not directly associated with recipient depression and anxiety in any models. This finding suggests that emotional transmission may not the strongest mechanism through which the caregiver's experiences affect recipient mental health. This is unexpected, given research that suggests couples experience emotional contagion and frequently show concordance in depression and anxiety (Hippisley-Cox et al., 2002; Goodman & Shippy, 2002; Joutsenniemi et al., 2011; Meyler et al., 2007). However, different processes may operate among peers in marital and romantic relationships than among caregivers and recipients. The latter relation may be less egalitarian, with caregivers and recipients more imbalanced in terms of power; further, caregivers and recipients may be less likely than couples, who typically live together, to share environmental context. The resulting lack of consistent exposure to the same stressors may partly explain the absence of emotional contagion.

Although caregiver mental health is not directly associated with recipient mental health in the final models, it has significant indirect effects on recipient mental health in mediation analyses. In other words, caregiver experiences partly shape recipient's mental health through the caregiver's own depression or anxiety symptoms. About one-third of informal caregivers experience depressive symptoms, with burden preceding depressive symptoms, and depressed caregivers are more likely than their non-depressed counterparts to engage in potentially harmful behaviors and elder abuse (Beach et al.,

2005; Cuijpers, 2005; Epstein-Lubow et al., 2008; Knight et al., 1993; Lu et al., 2007; Stommel et al., 1990; Williamson et al., 2001). They are also more likely to show resentment toward the recipient and less likely to respect their wishes, feelings, or opinions (Dooley, Shaffer, Lance, & Williamson, 2007). Similarly to depression, caregiver anxiety has been linked to potentially harmful behaviors and abuse (Reay & Browne, 2001). I cannot measure care quality in this study, but I find evidence of unmet care need in the sample. Unmet need may be a potential outcome of elder abuse and neglect (Beach & Schulz, 2017). Future research with data that includes indicators of potential elder abuse and neglect may thus evaluate these as potential pathways from caregivers' mental health to recipients' well-being (Beach et al., 2005; Butterworth & Rodgers, 2006; Ohaeri, 2003; Piquart & Sorensen, 2003; Tower & Kasl, 1995; Townsend, Miller, & Guo, 2001).

Contextual factors explain variation in recipient mental health better than social factors

I find that background and contextual factors explain the variation in older adults' mental health better than social support factors. Among background factors, as expected, older persons with higher education levels are less likely to experience depression than peers with lower education. This is consistent with studies showing that older persons of lower SES are more likely to experience poor mental health than those with high SES (Beattie, Pachana, & Franklin, 2010). Recipients reporting depression or anxiety symptoms at baseline are also more likely to experience the respective condition three years later, in line with research indicating that past symptoms of mental illness are

strongly associated with experiencing poor mental health in old age (Berkman et al., 1986; Creighton, Davison, & Kissane, 2016).

Besides contextual factors, the stress process model suggests that receiving social support moderates the association between stressors and outcomes for older adults. However, I do not find social support receipt factors to be associated with care recipients' mental health, or to contribute importantly to explaining variation beyond contextual factors. This is contrary to research showing that social and emotional support are key factors shaping older adults' mental health and well-being (Almeida, Draper, & Pirkis, 2012; Beekman et al., 2000; Creighton, Davison, & Kissane, 2016). It is possible that as adults age, they become more selective in maintaining social relationships, but remain equally content with their quality of life despite having a smaller social support network (Fiori, Antonucci, & Cortina, 2006; Carstensen, Isaacowitz, & Charles, 1999). Extensive social support may thus be less relevant for older adults' mental health if the recipient also has a small but close relationship network. Alternatively, it is possible an older adult's caregiver is an integral part of the former's social support system; the caregiver's stress levels may impede support provision, or engender other tensions in the family network that are detrimental rather than beneficial for older adults' mental health (Amirkhanyan & Wolf, 2003).

Limitations

This study is the first to use dyadic data to examine how caregivers' conceptually and statistically distinct experiences of perceived burden and benefit prospectively affect

two aspects of their care recipients' mental health. However, the study has four main limitations.

First, I consider only a limited set of moderating variables. Social support—the moderating factor in the analyses—may not be a coping indicator sufficiently comprehensive to detect an association with older adults' mental health. Further, I am unable to discern whether the care recipient deems their caregiver a confidante or someone who offers them social support. The stress process model also suggests that in addition to social support, psychological resilience moderates stress process outcomes. Some measures of sense of control, subjective age, and affect (but not recipient-reported relationship quality) are available in NHATS, but were not asked of proxy respondents. Due to sample size issues and potential sample bias, these factors were not included in the present analysis. However, studies consistently show that subjective wellbeing and interpersonal resources shape older persons' mental health (Arean & Reynolds, 2005). Studies using data from future or pooled NHATS and NSOC waves may be better able to evaluate the role of other coping resources focal to the stress process, like perceived control and psychological resilience, for older adults' mental health.

Second, although NHATS provides multiple waves of data, NSOC currently only provides two waves (collected in 2011 and 2015), and its samples only include approximately 200 of the same caregivers in both waves. Although analyses presented here use dyadic data to prospectively examine recipient outcomes and I control for caregiving duration, I was not able to include other information about informal caregivers' experiences over time. Subsequent NSOC waves consistently tracking the same caregivers will make possible analyses using longitudinal caregiver data.

Third, I only consider two aspects of recipients' mental health. Caregiver experiences may be important for older adults' other mental health outcomes, like drinking or suicidal ideation. In addition, through physiological mechanisms, stress also introduces strain on an individual's physical body. The cardiovascular system and the immune system are two potential pathways through which social relationships and interactions with caregivers may be linked to recipients' physical health (Burns & Goodwin, 1997; Castle, 2000; Graham, Christian, & Kiecolt-Glaser, 2006; Kiecolt-Glaser & Glaser, 2001; Kiecolt-Glaser, 1999; Kiecolt-Glaser et al., 2005; Rasul, Stansfeld, Hart, & Smith, 2005; Stansfeld, Fuhrer, Shipley, & Marmot, 2002). Studies using linked NHATS data or other datasets that include biomarkers may be able to explore caregiving dyads with respect to physical health outcomes.

Finally, I am unable to deduce caregivers' primary reason for caregiving. Although NSOC asks caregivers about how much and what types of assistance they offer to the care recipient, it does not ask about reasons why they assumed the caregiving role. Reasons for caregiving may offer a global description of the nature of caregiving (accounted for with number of hours spent caregiving and long-term caregiving status), or additional information about the care recipient's overall health status (accounted for with ADL disabilities, self-rated health, mental health in the present analyses). Reasons for caregiving may also indicate whether or not the caregiver took on the role voluntarily; whether or not a caregiver assumed the role voluntarily or by necessity could shape both their own experiences, mental health, and care quality. Thus, researchers should consider incorporating indices of caregiving reasons in investigating caregiving experiences, when available.

Conclusion

I used longitudinal, dyadic data, and a nationally representative typology of caregiving experiences, to show that older persons who receive assistance from caregivers perceiving only benefits are less likely than older adults receiving care from caregivers reporting only burden to subsequently experience depression; and that those receiving assistance from either caregivers perceiving only benefits, or caregivers perceiving benefits alongside low to moderate burden, are less likely to experience anxiety. Importantly, these effects persist net of contextual factors such as recipients' demographic and socioeconomic characteristics, and net of objective caregiving experience aspects including hours of care provided. I further suggest that researchers examine caregiver mental health and recipient unmet need to better understand how they shape the relationship between caregivers' experiences and recipient outcomes.

Caregivers' experiences thus have implications for recipients' mental health beyond the provision of care itself, and as the number of older persons in need of assistance continues to grow, the US long-term care system will increasingly rely on informal caregivers (Federal Interagency Forum on Aging-Related Statistics, 2004; US Census Bureau, 2016). Given that caregiver trajectories are typically long, progressing from sporadic help to personal and end-of-life care, an increasing number of older adults wishing to continue residing outside facilities will share frequent and long-term interactions with informal caregivers (Gitlin & Schultz, 2012; Schulz & Tompkins, 2010). Thus, it is crucial to better understand the implications of these caregivers' perceptions and experiences for older adults' mental health, and changes therein as they adapt to their roles (or become increasingly overwhelmed) over time. Both depression

and anxiety in old age are associated with a number of other adverse outcomes, with excess annual adjusted healthcare costs of over $27 million per 1,000,000 older adults for depression, and $80 million for anxiety (Vasililadis et al., 2012).

My results demonstrate that caregiving has interpersonal dimensions and is situated within an older adult's larger family and friend networks, and it is therefore important for researchers and practitioners to consider caregiving as a dyadic process. Beyond the dyad, caregivers and recipients are part of broader social context; caregiving dynamics and their mental health outcomes may have implications for interactions and assistance demands among extended family relationships and support systems.

Tables

Table 4. 1. Unweighted sample descriptive statistics (N=781).

	% / mean(sd)
Care recipient (CR) mental health	
CR likely case of depression W3 (PHQ-2)	27.18
CR likely case of anxiety W3 (GAD-2)	21.16
Primary stressor	
Caregiver (CG) experience type	
Intensive caregivers	11.52
Balanced caregivers	20.61
Dissatisfied caregivers (reference)	9.22
Relationship caregivers	21.25
Satisfied caregivers	37.39
Secondary stressors	
CG likely case of depression (PHQ-2)	10.82
CG likely case of anxiety (GAD-2)	14.01
CR unmet ADL need (=1)	30.35
CR unmet IADL need (=1)	25.86
Contextual factors	
CR female (=1)	70.93
CR race	
White (reference)	59.67
Black	31.63
Other race	8.71
CR age	
Young old (65-74)	25.48
Old old (75-84)	40.85
Oldest old (85+)	33.67
CR education	
Less than high school (reference)	37.79
High school	25.96
Some college	22.75
College or higher	13.50
CR owns home (=1)	55.13
CR receives assistance (=1)	24.20
CR # ADL disabilities (0 to 6)	2.99 (1.75)
CR excellent/very good self-rated health (=1)	22.05
CR likely case of depression W1 (PHQ-2)	26.76
CR likely case of anxiety W1 (GAD-2)	22.69
Social support	
CR married/partnered (=1)	38.92
CR # of children (0 to 13)	3.40 (2.34)
CR no confidante (=1)	4.23
CR has other helpers (=1)	38.41
Control variables	

CG female (=1)	67.48
CG education	
Less than high school (reference)	14.21
High school	26.23
Some college	34.75
College or higher	24.81
CG relationship to CR	
Spouse	27.91
Adult child	50.83
Other relation	21.25
CG long-term caregiver (=1)	53.42
CG hours spent caregiving	
Fewer than 25 (reference)	27.66
25-80 hours/month	34.31
84-744 hours/month	38.03

Notes: CG = caregiver. CR = care recipient.
W1 = Wave 1 (baseline). W3 = Wave 3.

Table 4. 2. Logistic regression results predicting whether care recipient has anxiety at wave 3.

	Model 1 Baseline		Model 2 + Secondary stressors		Model 3 + Contextual factors		Model 4 + Social support		Model 5 + Control variables	
	OR	SE	OR	SE	OR	SE	OR	SE	OR	SE
CG experience type (Wave 1)										
Intensive caregivers	0.85	0.28	0.68	0.24	0.50	0.19	0.50	0.19	0.46	0.19
Balanced caregivers	0.48*	0.15	0.45*	0.15	0.39**	0.13	0.39**	0.13	0.37**	0.12
Dissatisfied caregivers (reference)										
Relationship caregivers	0.24***	0.08	0.28***	0.10	0.30***	0.11	0.30***	0.11	0.34**	0.12
Satisfied caregivers	0.37***	0.11	0.42**	0.13	0.34***	0.11	0.34***	0.11	0.33***	0.11
Secondary stressors (Wave 1)										
CG likely depression (=1)			1.33	0.37	1.22	0.35	1.22	0.35	1.16	0.34
CG likely anxiety (=1)			1.26	0.34	1.15	0.32	1.15	0.33	1.15	0.33
CR unmet ADL need (=1)			1.74**	0.37	1.30	0.31	1.30	0.32	1.33	0.33
CR unmet IADL need (=1)			1.40	0.32	1.19	0.29	1.20	0.29	1.20	0.30
Contextual factors (Wave 1)										
CR female (=1)					1.43	0.33	1.47	0.37	1.47	0.41
CR race (ref=white)										
CR black					1.05	0.25	1.05	0.26	0.98	0.25
CR other race					1.35	0.46	1.34	0.46	1.28	0.45
CR age (ref=young old (65-74))										
CR old old (75-84)					1.03	0.26	1.03	0.27	0.99	0.27
CR oldest old (85+)					1.00	0.29	1.01	0.31	1.00	0.32
CR education (ref=less than HS)										
CR high school					0.77	0.19	0.76	0.19	0.78	0.21
CR some college					0.50*	0.15	0.50*	0.15	0.56	0.17
CR college or higher					0.69	0.24	0.69	0.25	0.81	0.30
CR owns home (=1)					0.87	0.18	0.87	0.18	0.84	0.18
CR receives assistance (=1)					1.38	0.32	1.39	0.32	1.32	0.31
CR # ADL disabilities					1.06	0.07	1.06	0.07	1.05	0.07
CR likely anxiety W1 (=1)					3.36***	0.72	3.36***	0.71	3.28***	0.71
CR above average SR health (=1)					1.01	0.27	1.01	0.27	1.00	0.27
Social support (Wave 1)										
CR married (=1)							1.03	0.26	1.17	0.38

CR has other helpers (=1)							0.94	0.19	0.92	0.19
CR # of children							1.01	0.04	1.00	0.04
CR no confidante (=1)							0.80	0.42	0.74	0.41
Control variables (Wave 1)										
CG female (=1)									1.12	0.27
CG education (ref=less than HS)										
CG high school									0.85	0.28
CG some college									0.85	0.27
CG college or higher									0.60	0.22
CG relationship to CR (ref=spouse)										
CG adult child									1.38	0.55
CG other relation									1.20	0.56
CG long-term caregiver (=1)									1.11	0.23
CG hours caregiving (ref=<25h/month)										
CG 25-80 hours/month									1.23	0.33
CG 84-744 hours/month									1.45	0.41
Constant	0.59*	0.15	0.39**	0.11	0.29**	0.14	0.27*	0.15	0.20*	0.15
McFadden's R^2	0.03		0.06		0.13		0.13		0.14	
Df	4.00		8.00		21.00		25.00		34.00	
Wald χ^2	25.92		43.51		87.28		87.79		95.25	
Pseudo log-likelihood	-374.11		-364.90		-336.83		-336.62		-334.10	

Note: *p<0.05, **p<0.01, ***p<0.001. N = 753. CR = care recipient. CG = caregiver. # = number. ADL = abilities of daily living. IADL = instrumental abilities of daily living. Odds ratios (exponentiated coefficients) and robust standard errors are provided.

Table 4. 3. Logistic regression results predicting whether the care recipient has depression at wave 3.

	Model 1 Baseline		Model 2 + Secondary stressors		Model 3 + Contextual factors		Model 4 + Social support		Model 5 + Control variables	
	OR	SE	OR	SE	OR	SE	OR	SE	OR	SE
CG experience type (Wave 1)										
Intensive caregivers	1.60	0.53	1.30	0.45	1.34	0.48	1.33	0.48	1.26	0.47
Balanced caregivers	0.74	0.23	0.69	0.22	0.71	0.23	0.71	0.23	0.69	0.22
Dissatisfied caregivers (reference)										
Relationship caregivers	0.61	0.19	0.70	0.23	0.82	0.27	0.82	0.27	0.83	0.28
Satisfied caregivers	0.53*	0.15	0.57	0.17	0.55	0.17	0.56	0.17	0.53*	0.17
Secondary stressors (Wave 1)										
CG likely depression (=1)			1.23	0.33	1.09	0.30	1.08	0.30	1.05	0.30
CG likely anxiety (=1)			1.01	0.27	0.95	0.28	0.93	0.27	0.97	0.29
CR unmet ADL need (=1)			1.94***	0.37	1.68*	0.36	1.67*	0.36	1.69*	0.37
CR unmet IADL need (=1)			1.54*	0.31	1.37	0.29	1.37	0.29	1.43	0.30
Contextual factors (Wave 1)										
CR female (=1)					1.23	0.26	1.27	0.29	1.18	0.28
CR race (ref=white)										
CR black					0.84	0.18	0.85	0.20	0.84	0.20
CR other race					1.37	0.42	1.38	0.43	1.31	0.42
CR age (ref=young old (65-74))										
CR old old (75-84)					0.89	0.20	0.90	0.21	0.83	0.20
CR oldest old (85+)					0.88	0.22	0.87	0.22	0.83	0.22
CR education (ref=less than HS)										
CR high school					0.92	0.21	0.91	0.21	0.93	0.22
CR some college					0.51**	0.13	0.50**	0.13	0.52*	0.14
CR college or higher					0.56	0.18	0.55	0.18	0.54	0.19
CR owns home (=1)					0.98	0.18	0.99	0.19	0.99	0.19
CR receives assistance (=1)					1.32	0.28	1.35	0.29	1.30	0.28
CR # ADL disabilities					1.03	0.06	1.04	0.06	1.03	0.06
CR likely depression W1 (=1)					2.06***	0.41	2.13***	0.43	2.07***	0.42
CR excellent/very good SR health (=1)					0.92	0.21	0.91	0.21	0.95	0.23
Social support (Wave 1)										
CR married/partnered (=1)							1.01	0.25	1.23	0.38

CR has other helpers (=1)							0.81	0.16	0.79	0.16
CR # of children							1.00	0.04	1.00	0.04
CR no confidante (=1)							0.47	0.22	0.44	0.21
Control variables (Wave 1)										
CG female (=1)									0.89	0.18
CG education (ref=less than HS)										
CG high school									0.88	0.25
CG some college									0.65	0.19
CG college or higher									0.90	0.30
CG relationship to CR (ref=spouse)										
CG adult child									1.54	0.55
CG other relation									1.28	0.53
CG long-term caregiver (=1)									0.95	0.17
CG hours caregiving (ref=<25h/month)										
CG 25-80 hours/month									1.11	0.27
CG 84-744 hours/month									1.25	0.32
Constant	0.52**	0.13	0.35***	0.10	0.32	0.14**	0.34*	0.17	0.33	0.22
McFadden's R^2	0.02		0.05		0.09		0.10		0.10	
Df	4		8		21		25		34	
Wald χ^2	20.86		47.05		75.55		78.98		85.13	
Pseudo log-likelihood	-431.58		-418.09		-399.85		-397.95		-395.19	

Note: *p<0.05, **p<0.01, ***p<0.001. N = 753. CR = care recipient. CG = caregiver. # = number. ADL = abilities of daily living. IADL = instrumental abilities of daily living. Odds ratios (exponentiated coefficients) and robust standard errors are provided.

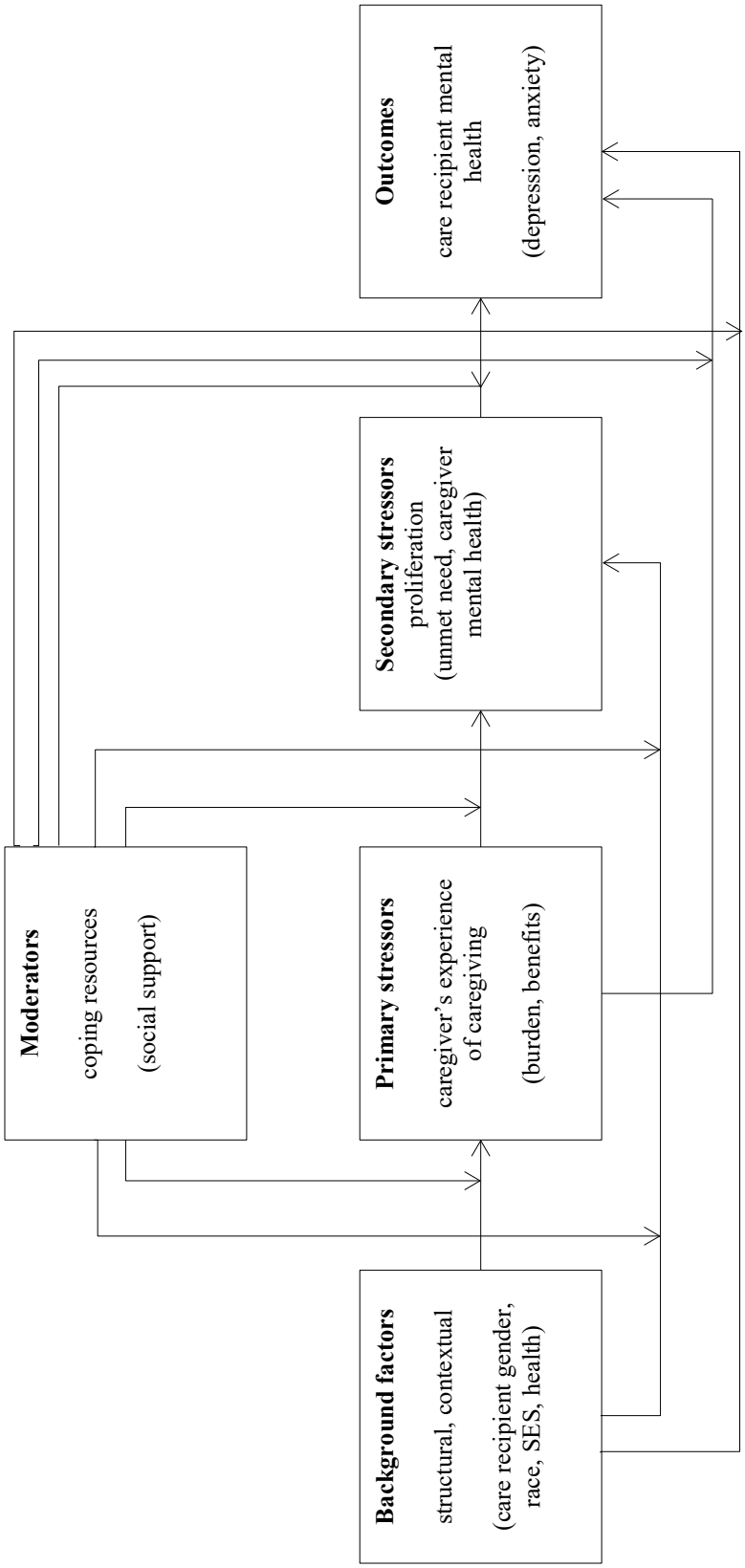

Figure 2. Conceptual model of the relationship between caregivers' experiences of caregiving and recipient mental health

Appendix

Table 4. 4. Variable correlation matrix.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27
1 CR gender	**1.00**																										
2 CR race	0.05	**1.00**																									
3 CR age	0.12	-0.14	**1.00**																								
4 CR education	-0.03	**-0.27**	-0.01	**1.00**																							
5 CR homeownership	-0.14	-0.09	-0.18	0.12	**1.00**																						
6 CR assistance rec.	0.05	**0.23**	-0.09	**-0.24**	-0.09	**1.00**																					
7 CR marital status	**-0.41**	-0.15	**-0.32**	0.18	**0.37**	-0.15	**1.00**																				
8 CR # helpers	0.10	0.04	0.03	-0.06	-0.06	0.09	-0.09	**1.00**																			
9 CR # children	-0.08	0.18	-0.10	-0.12	0.00	0.12	0.03	0.06	**1.00**																		
10 CR no one to talk to	0.01	0.07	-0.09	-0.05	0.09	0.02	0.03	0.03	0.04	**1.00**																	
11 CR # ADL disabilities	0.06	-0.05	0.15	-0.02	-0.06	0.07	-0.11	0.05	0.00	-0.05	**1.00**																
12 CR self-rated health	0.05	**-0.22**	0.17	0.18	-0.03	**-0.20**	0.02	-0.09	-0.14	-0.06	-0.18	**1.00**															
13 CR # dep W1	-0.01	0.15	-0.14	-0.10	0.01	0.17	0.00	0.08	0.08	0.01	0.15	**-0.34**	**1.00**														
14 CR dep.W3	0.04	0.07	-0.01	-0.12	-0.02	0.11	-0.05	-0.02	0.03	-0.06	0.14	-0.14	**0.27**	**1.00**													
15 CR # anx. W1	0.04	0.10	-0.05	-0.11	-0.05	0.20	-0.05	0.07	0.03	-0.02	0.15	**-0.31**	**0.53**	**0.23**	**1.00**												
16 CR anx. W3	0.05	0.08	0.00	-0.12	-0.06	0.14	-0.06	0.01	0.03	-0.03	0.13	-0.12	**0.25**	**0.39**	**0.32**	**1.00**											
17 CR unmet ADL need	0.02	0.06	-0.07	-0.06	-0.02	0.12	-0.06	0.02	0.02	-0.01	**0.43**	**-0.25**	**0.25**	0.20	**0.28**	0.15	**1.00**										
18 CR unmet IADL need	0.03	0.03	-0.07	-0.02	-0.01	0.12	-0.09	0.06	0.02	-0.05	**0.28**	-0.20	0.20	0.17	**0.24**	0.13	**0.38**	**1.00**									
19 CG experience type	0.04	0.01	-0.10	-0.09	-0.01	-0.05	0.03	0.00	-0.03	0.08	**-0.22**	0.09	-0.09	-0.15	-0.14	-0.12	-0.16	-0.17	**1.00**								
20 CG dep. symp.	-0.08	-0.02	-0.02	-0.04	0.05	0.11	0.08	-0.04	0.02	-0.01	0.13	-0.15	0.14	0.10	0.17	0.11	0.13	0.08	**-0.35**	**1.00**							
21 CG anx. symp.	-0.10	-0.02	0.00	-0.05	0.02	0.08	0.01	-0.02	-0.02	-0.05	0.09	-0.09	0.11	0.08	0.15	0.11	0.08	0.09	**-0.36**	**0.56**	**1.00**						
22 CG gender	**-0.25**	0.05	0.11	-0.11	-0.08	0.01	-0.08	-0.01	0.04	-0.09	0.04	-0.03	0.03	0.01	0.04	0.06	0.00	0.06	-0.11	0.02	0.11	**1.00**					
23 CG education	0.13	-0.15	**0.22**	**0.37**	-0.06	**-0.21**	-0.12	-0.03	-0.07	-0.05	0.06	0.18	-0.17	-0.06	-0.14	-0.09	-0.04	0.02	-0.13	-0.12	-0.03	0.03	**1.00**				
24 CG relat. to CR	**0.29**	0.17	**0.25**	-0.18	**-0.30**	0.17	**-0.56**	**0.21**	-0.18	-0.03	0.07	-0.05	0.01	0.03	0.13	0.06	0.06	0.08	0.02	-0.06	-0.01	0.11	0.05	**1.00**			
25 CG long-term	0.04	0.02	0.03	-0.09	-0.02	0.06	-0.04	-0.04	0.05	0.00	0.00	0.02	-0.01	0.00	0.04	0.04	0.01	0.01	-0.03	0.05	0.03	-0.06	0.01	-0.02	**1.00**		
26 CG # hours	-0.03	0.13	-0.02	-0.04	0.09	0.13	-0.01	0.12	0.13	0.04	**0.23**	-0.14	0.15	0.10	0.11	0.12	0.13	0.12	**-0.25**	0.15	0.11	0.12	-0.11	-0.09	0.00	**1.00**	
27 CG in HH	-0.16	-0.01	**-0.22**	0.01	0.16	-0.09	**0.38**	-0.08	0.05	0.07	0.01	-0.04	0.08	0.01	-0.04	0.04	-0.01	-0.04	-0.05	0.08	0.04	-0.08	-0.10	**-0.49**	-0.03	**0.29**	**1.00**

Note: N = 781. CR = care recipient. CG = caregiver. # = number. Correlation coefficients ≥|0.30| are bolded to facilitate interpretation.

Table 4. 5. Item response probabilities for five-class model of the subjective experience of informal caregiving to older adults in analytic sample.

		Intensive CGs	Balanced CGs	Dissatisf. CGs	Relationship CGs	Satisfied CGs
	Predicted class membership	12%	20%	9%	22%	37%
Caregiving burden	*Emotional*					
	Emotionally difficult	**0.82**	**0.68**	**0.84**	0.28	0.20
	No time for self	**0.78**	**0.82**	**0.70**	0.14	0.23
	Too much to handle	**0.78**	**0.91**	**0.70**	0.19	0.14
	Establish routine, need change	**0.66**	**0.51**	**0.53**	0.08	0.18
	Interpersonal					
	Recipient argues with you	**0.87**	**0.69**	**0.94**	**0.56**	0.52
	Recipient gets on nerves	**0.90**	**0.81**	**0.98**	**0.72**	0.59
	Physical					
	Exhausted when you go to sleep	**0.81**	**0.85**	**0.79**	0.20	0.28
	Physically difficult	**0.64**	0.39	0.27	0.08	0.13
	Financial					
	Financially difficult	**0.61**	0.44	0.37	0.03	0.11
	Kept from work	**0.51**	0.16	0.08	0.02	0.02
	Social					
	Kept from visiting friends/family	**0.86**	0.15	0.24	0.01	0.05
	Kept from religious services	**0.61**	0.06	0.00	0.01	0.01
	Kept from outings for enjoyment	**0.77**	0.11	0.12	0.02	0.01
	Kept from caring for others	0.36	0.02	0.00	0.00	0.00
	Kept from volunteering	0.49	0.05	0.03	0.03	0.02
Caregiving benefits	*Emotional*					
	Gives you satisfaction	**0.87**	**0.97**	**0.58**	**0.84**	**1.00**
	Interpersonal					
	Brought closer to care recipient	**0.70**	**0.90**	0.00	**0.54**	**0.97**
	Enjoy being with care recipient	**0.76**	**0.91**	0.37	**0.89**	**1.00**
	Care recipient appreciates you	**0.72**	**0.95**	0.44	**0.91**	**0.98**
	Behavioral/cognitive					
	More confident in abilities	**0.52**	**0.62**	0.16	0.03	**0.86**
	Taught you how to deal	**0.56**	**0.79**	0.34	0.08	**0.80**

Notes: Item response probabilities higher than 0.50 are highlighted to facilitate interpretation. The conditional probability of not endorsing the item can be obtained by subtracting the probability of endorsing it from 1. CG = caregiver.

Table 4. 6. Item response probabilities for five latent class model of the subjective experience of informal caregiving to older adults in US population.

		Intensive CGs	Balanced CGs	Dissatisf. CGs	Relationship CGs	Satisfied CGs
	Predicted class membership	10%	18%	15%	26%	32%
Caregiving burden	*Emotional*					
	Emotionally difficult	**0.82**	**0.61**	**0.79**	0.16	0.17
	No time for self	**0.9**	**0.77**	**0.57**	0.24	0.25
	Too much to handle	**0.82**	**0.73**	**0.54**	0.19	0.15
	Establish routine, need change	**0.69**	**0.54**	0.48	0.09	0.12
	Interpersonal					
	Recipient argues with you	**0.79**	**0.79**	**0.79**	**0.52**	0.38
	Recipient gets on nerves	**0.87**	**0.84**	**0.93**	**0.58**	0.36
	Physical					
	Exhausted when you go to sleep	**0.85**	**0.81**	**0.54**	0.25	0.26
	Physically difficult	**0.57**	0.39	0.28	0.09	0.04
	Financial					
	Financially difficult	0.45	0.34	0.24	0.07	0.06
	Kept from work	0.39	0.09	0.08	0.02	0.03
	Social					
	Kept from visiting friends/family	**0.80**	0.16	0.15	0.01	0.02
	Kept from religious services	**0.59**	0.06	0.05	0.02	0.01
	Kept from outings for enjoyment	**0.84**	0.07	0.10	0.00	0.00
	Kept from meetings, groups	**0.62**	0.04	0.02	0.00	0.00
	Kept from caring for others	0.28	0.01	0.03	0.00	0.01
	Kept from volunteering	0.40	0.06	0.04	0.00	0.01
Caregiving benefits	*Emotional*					
	Gives you satisfaction	**0.84**	**0.95**	**0.60**	**0.80**	**0.98**
	Interpersonal					
	Brought closer to recipient	**0.57**	**0.95**	0.21	**0.54**	**0.96**
	Enjoy being with recipient	**0.68**	**0.96**	0.39	**0.89**	**0.98**
	Care recipient appreciates you	**0.68**	**0.91**	**0.56**	**0.95**	**0.98**
	Behavioral/cognitive					
	More confident in abilities	0.45	**0.62**	0.11	0.06	**0.88**
	Taught you how to deal	**0.56**	**0.82**	0.30	0.04	**0.87**

Notes: Item response probabilities higher than 0.50 are highlighted to facilitate interpretation. The conditional probability of not endorsing the item can be obtained by subtracting the probability of endorsing it from 1.

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Chapter 5

Conclusion

Summary

This dissertation explored the experiences of informal caregivers to US older adults. Previous research has failed to acknowledge potentially ambivalent perceptions among caregivers, and to capture how social support may be simultaneously associated with perceptions of both benefits and burdens from caregiving. Focusing primarily on caregiver well-being, prior work also overlooked the implications of these experiences for recipient outcomes. I addressed those gaps in three analytic chapters. I drew on the caregiving stress appraisal framework and conducted LCA and regression analysis on a nationally representative sample of informal caregivers matched to US older adults. In the first analytic chapter, I developed and identified factors associated with five caregiving experience subtypes, each uniquely characterized by the presence or absence, level, and domain of perceived burden and benefits. In the second analytic chapter, I explored how informal and formal social support are associated with experience types, and whether support buffers caregiving stressors. Finally, in the third analytic chapter, I assessed how caregivers' experiences shape recipient mental health over time, and examined caregiver mental health and recipient unmet care need as potentially mediating factors. Informal caregiving has a key role in US long-term care for older adults; this dissertation provides timely evidence about caregivers' heterogeneous experiences and needs that researchers and decision-makers may use to design policies and programs facilitating the well-being of both caregivers and their care recipients.

Contributions

This dissertation made four key contributions to caregiving research and our understanding of informal caregivers' experiences.

First, I provided a multifaceted characterization of diverse caregiving experience subtypes that is generalizable to the population of informal caregivers to US older adults. Prior research often used clinical and convenience samples of caregivers to older persons with particular types of impairments or illnesses (Abbate et al., 2011; Acton & Kang, 2001; Brodaty, Green, & Koschera, 2003; Iecovich, 2011; Jennings et al., 2015; Norton et al., 2009; Parker, Mills, & Abbey, 2008; Sorensen, Pinquart, & Duberstein, 2002). Although past findings provided insight into the needs of special caregiver groups, these findings also resulted in an incomplete understanding of US caregivers' perceptions, which likely differ across task profiles, care intensity, and other key factors. For example, prior research focusing on dementia and Alzheimer's disease caregivers finds that almost 40% of informal caregivers experience high strain (Jennings et al., 2015); my analyses using a generalizable sample showed that this proportion is lower for caregivers overall, and that burden coexists with benefits in almost 30% of cases. This dissertation thus provided a representative assessment of US informal caregivers' experiences.

Second, I used a novel methodological approach to integrate burden and benefit perceptions, and to better understand how they shape recipient health. Past studies focused predominantly on caregivers' perceptions of burden, and did not account for the co-existence, different levels, and domains of both positive and negative appraisals that each caregiver may experience (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989;

Lawton, Moss, Kleban, Glicksman, & Rovine, 1991). For example, prior research counting negative or positive caregiving events to compose summary indices disregards information about whether caregivers experience benefits that are cognitive, social, or of a different kind. Studies only examining how burden and benefits broadly correlate do not identify which positive and negative domains commonly manifest together, or how prevalent their distinctive combinations are. Further, studies showing that recipients whose caregivers are burdened are more likely to be institutionalized do not account for an important facet—caregivers' perception of benefits—that may in fact be beneficial for recipients' well-being (Cohen, Colantonio, & Vernich, 2002; Gaugler, Mendiondo, Smith, & Schmitt, 2003; Lin, Fee, & Wu, 2012). Using latent class analysis with burden and benefit indicators, I comprehensively evaluated caregiving experiences, their predictors, and their importance for recipient mental health. My analyses extended prior work with evidence that burden and benefits indeed coexist, with almost half of informal caregivers reporting ambivalent experiences. Results also suggest that some burden types, like social burden, may only be characteristic for those providing the highest levels of care, and that interpersonal burden frequently manifests alongside interpersonal benefits. Finally, the findings indicate that even recipients with burdened caregivers are less likely to experience anxiety when these caregivers also perceive any benefits alongside burden. Rather than treating burden and benefits in isolation, I thus showed how both factors simultaneously characterize caregiving experiences and their impact.

Third, I measured caregiver factors using caregiver reports, and recipient factors using recipient reports to mitigate potential informant bias. Prior research frequently used measures obtained from a single reporter, typically the caregiver, which may have

introduced bias due to the proxy informant's underlying mood, mental health, or valuation. For example, prior research found that recipients are institutionalized early when their caregivers are burdened, but caregivers—rather than care recipients themselves—reported on the recipient's behavioral symptoms and other stressors (McClendon & Smyth, 2015). This complicates our understanding of whether objective or perceived circumstances shape caregiver experiences and subsequent recipient outcomes. I combined two datasets, NHATS and NSOC, to obtain caregivers' as well as their recipients' own reports on relevant factors. Using dyadic data, I was able to better capture how caregiver-reported experiences respond to recipient-reported stressors, and avoided potentially biased proxy reports. Thus, this dissertation provided a more accurate representation of caregiving stress appraisal.

Finally, I used longitudinal data to show that caregivers' experiences are consequential for care recipients' mental health. Most prior studies examining caregiver experiences and recipient outcomes were cross-sectional (Braun et al., 2009; Chiao, Wu, & Hsiao, 2015; Ejem, Drentea, & Clay, 2014; Iecovich, 2015; Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2016). For example, previous cross-sectional research found that caregiver emotional distress is associated with recipient depression symptoms, but could not establish whether a strained caregiver contributed to negative recipient outcomes, or whether poor recipient health added to greater burden (Ejem et al., 2015). Using two NHATS waves, I temporally disentangled this association and found that older adults' mental health depends on caregivers' experiences measured three years earlier, even after controlling for care recipients' mental health in the first wave. In this way, I showed that caregiving is a dyadic process situated in social context.

Key Findings

Five distinguishable caregiving experience subtypes and their predictors

Caregiving can be a physically and psychologically demanding activity, and most US informal caregivers report feeling burdened. At the same time, most also report benefits like developing new skills or a closer relationship with the recipient. In the first analytic chapter, I used LCA with indicators of both burden and benefits to develop five distinguishable caregiving experience types on a nationally representative sample of US informal caregivers. I further identified caregiver and recipient factors associated with experience types. I extended prior research by recognizing the ambivalence of caregiving, and provided a generalizable assessment of informal caregivers' experiences.

The presence and absence, level, and domain of perceived benefits and burden uniquely characterize each identified experience type. In two types (labeled "Intensive" and "Balanced Caregivers"), burden and benefits co-occur. Intensive Caregivers represent 10% of US informal caregivers; they report high burden and moderate benefits across emotional, interpersonal, physical, and social domains. Their perceived burden is highest compared to other groups, but their perceived benefits are comparable to those of caregivers reporting very low or absent burden. Balanced Caregivers (18%) also report ambivalent experiences, but with moderate burden and high benefits similar to that of caregivers reporting benefits only. Contrary to Intensive Caregivers, Balanced Caregivers report no social burden. In the third type ("Dissatisfied Caregivers"), caregivers report predominantly burden. They constitute 15% of all informal caregivers. Although Dissatisfied Caregivers report levels of burden that are similar to the Intensive and Balanced Caregivers', contrary to these two groups, Dissatisfied Caregivers do not

perceive their experiences positively: they report few benefits and endorse them weakly. Finally, the experiences of two types ("Relationship Caregivers" and "Satisfied Caregivers") are predominantly positive. Relationship Caregivers, constituting 20% of all informal caregivers, report high interpersonal benefits and some burden limited only to the interpersonal domain. Satisfied Caregivers, representing 32% of US caregivers, report perceiving only benefits, without any burden. Overall, the caregiving experience types that emerged from my LCA analysis demonstrate that ambivalence is common and that even at high burden levels, caregivers may still experience a high level of benefits. Further and notably, for almost half of US informal caregivers, the experience of caregiving is predominantly positive.

I found that several factors are associated with perceiving predominantly burden (i.e., predictive of being in the Dissatisfied Caregiver group). Caring for an older adult with more depression symptoms or more diagnosed medical conditions puts caregivers at risk of being Dissatisfied Caregivers. Older, co-resident, and long-term caregivers, caregivers in poor mental health, and those caring for men are also especially likely to be Dissatisfied Caregivers. At the same time, Black caregivers, individuals providing between 20 and 60 hours of care, more frequent ADL assistance, and medical task assistance are likely to have ambivalent experiences, or to be Intensive or Balanced Caregivers. Black caregivers and nonrelatives are likely to be Satisfied Caregivers and to have predominantly positive experiences. In sum, I identified groups—those most likely to be Dissatisfied Caregivers—that would benefit most from assistance. I further showed that factors typically indicating intensive care may engender ambivalent experiences (not only burden, but also perceived benefits); assistance programs and interventions may thus

focus on increasing benefits perceptions where it is not possible to reduce perceived or objective burden (Toohey, Muralidharan, Medoff, Lucksted, & Dixon,2016). Finally, although Black caregivers and nonrelatives currently report beneficial experiences, minority health disparities are growing and family demography is changing. Black caregivers may soon be assisting older adults with greater impairments, and nonrelatives may find themselves offering help to those who previously received care from close family. These findings provide a generalizable survey of caregiver needs, rather than focusing only on identifying those of caregivers to recipients with one type of impairments; caregiver needs in dementia and Alzheimer's, for example, are often disease-specific (Jennings et al., 2015). Researchers and policymakers should work to provide appropriate training and ensure all caregiver groups continue to have beneficial experiences.

The role of formal and informal support in caregivers' experiences

Caregivers can receive formal support for their caregiving activities through institutionally provided training, education, respite, and other services. Many also rely on family, friends, and fellow caregivers to cope with their tasks and stress. In the second analytic chapter, I used LCA regression analysis on a nationally representative informal caregiver sample to examine how receiving informal or formal social support is associated with caregiving experience types. Cross-sectional data precluded me from identifying causation, but I showed that individuals receiving informal support are more likely to have predominantly beneficial than predominantly burdensome experiences. Conversely, those receiving formal support are less likely to experience only benefits, or

a combination of benefits and burden than to experience only burden. Further, I found that support does not buffer caregiving stress; it operates independently of stress levels. My research adds to prior work by examining how support provision matters for caregivers broadly (rather than for select groups providing assistance for older persons with particular impairments), and by examining associations with experience types that include both burden and benefits (rather than focusing on burden alone).

Informal support receipt is thus associated with more positive caregiving experience types, and those receiving more informal support are likely to be Relationship or Satisfied Caregivers. Importantly, they are likely to report only beneficial experiences both in contrast to perceiving burden only, and in contrast to having ambivalent experiences. These individuals can draw on relationships with family and friends to get help with daily tasks, to care for the recipient, and to get emotional support. Supportive and close relationship as a source of informal support may thus play an important role in reducing caregivers' objective and perceived burden. Given that such relationships are often enduring and stable, they may also be crucial in facilitating caregivers' well-being and continued assistance as their recipients age. With the projected shortage of informal caregivers in the US, to support continued care provision, it will thus become increasingly important to ensure that those providing care are not socially isolated.

In contrast with informal support, receiving formal support is associated with more negative experiences, and individuals receiving more formal support are likely to be Dissatisfied Caregivers. They are likely to perceive only burden, rather than benefits or a combination, with one exception: they have an equal risk of being Intensive Caregivers, reporting high burden and moderate benefits, as they do to be Dissatisfied Caregivers

perceiving burden alone. Because I was unable to establish causality and the direction of any causal effects with cross-sectional data, these findings may show that formal assistance may not notably reduce perceived or objective burden, may not efficiently increase benefits, and/or that caregivers do not seek out formal support until they experience significant burden (i.e., reverse causality). Given changing family demography and geographic patterns and reduced availability of informal caregivers, formal support for caregivers may increase in importance in the coming decades. It is therefore crucial to improve caregivers' experiences with formal assistance, to facilitate access to formal services, to destigmatize their use, and to identify and focus on programs that can increase caregivers' perceived benefits when not possible to reduce burden.

Finally, I found that neither informal nor formal support buffer the association between caregiving stressors and the resulting experiences in moderation analyses. Both support types directly and robustly shape caregiving experiences, but their association with caregiving experiences does not depend on stress levels. Social support may thus operate independently and may, in the case of informal support, be beneficial regardless of task burden, recipient impairments, or other stressors. Family and friends may give informal support to caregivers in the form of financial assistance, time to recuperate from caregiving tasks, or help them with cognitive reframing and emotional support. Such assistance may lower negative and increase positive appraisals regardless of whether the recipient is severely impaired and requires constant assistance, or only needs occasional or instrumental help. In the case of formal support, it is possible that efficient interventions must be specifically targeted to particular caregiving groups' needs. My results indicated that caregivers might not seek formal assistance until their burden is

already significant; at that time, broadly designed assistance programs aimed at common caregiver difficulties (such as developing coping abilities or learning cognitive reframing) may not be effective, and caregivers may benefit most from skills tailored to managing the recipient's disease or condition (for example, providing training with nursing tasks).

Caregivers' experiences shape recipient mental health

One in five US older adults experiences symptoms of depression or anxiety, but poor mental health is not a normal part of aging, and it may worsen older persons' physical health and social functioning (Centers for Disease Control, 2008; McGuire, Strine, Okoro, Ahluqalia, & Ford, 2007). The caregiving relationship is dyadic, and caregivers may contribute to, or may decrease the likelihood of poor mental health in their care recipients. In the third analytic chapter, I used logistic regression on a sample of caregivers matched to their care recipients to explore whether and how caregivers' experiences are prospectively linked to recipient depression and anxiety. I found robust associations showing that older adults whose caregivers perceive benefits, even alongside low or moderate burden, are less likely to subsequently experience anxiety, net of their initial anxiety levels. Older persons whose caregivers report benefits without burden are also less likely to experience depression, accounting for their depression symptoms at the first wave. I also found that unmet ADL need shapes recipient mental health, and that caregiver mental health contributes indirectly (but not directly) to recipient mental health. I contributed to prior research by evaluating the association between caregivers' perceptions and recipient health comprehensively (using caregiving experience types, I considered both burden and benefits perceptions), by using both caregiver and recipient

reports on relevant factors to avoid potential single-reported bias, and by examining the association over time rather than cross-sectionally, which allowed me to offer preliminary evidence of temporal ordering.

Overall, I concluded that caregivers' experiences matter for recipients' mental health, but in distinct ways for anxiety versus depression. In the case of depression, only those receiving care from Satisfied Caregivers—reporting benefits only—are less likely to be depressed three years later after baseline, net of initial levels of depression. In the case of anxiety, older adults whose caregivers report benefits even alongside low to moderate burden are less likely to be anxious. However, there is no difference in poor mental health likelihood (either depression or anxiety symptoms) when a caregiver reporting high burden provides the assistance, even if high perceived benefits accompany the reported burden. These results are robust to the inclusion of conceptually relevant covariates, including baseline recipient physical and mental health.

The findings suggest that caregivers' and recipients' well-being are linked. Given that recipients' anxiety is lower even when caregivers have ambivalent experiences, interventions and caregiver assistance programs may focus on increasing benefits perceptions where it is not possible to reduce burden. At the same time, only recipients whose caregivers don't feel burdened at all are less likely to become depressed, and caregivers reporting the highest burden levels appear to be at a threshold beyond which their positive perceptions no longer provide benefits for recipients' mental health. It therefore remains important to also alleviate caregivers' perceived and objective burden. Increasing access to support services like respite and adult day care to supplement informal care, education and nursing care training for informal caregivers, and assistance

from paid caregivers may accomplish these goals. My findings show that improving caregivers' well-being in this way may "spill over" and improve recipients' mental health; this finding is strengthened given that I examined how recipient-reported health responds to caregiver-reported experiences, rather than relying on caregivers' assessments of recipient health. Prior research using information from a single reporter to consider recipient health outcomes like mortality may have been biased, as caregivers' experience appraisal may also affect their reports of recipient health (McClendon & Smyth, 2015).

Besides caregivers' experiences, I also found that unmet care need shapes recipient depression, but not recipient anxiety. This suggests that the GAD-2 instrument used to measure recipient anxiety may be better capturing trait- than state anxiety, or that anxiety may respond less to situational context than depression. Relatedly, I found that caregiver mental health may be one pathway to poorer recipient mental health. When recipients report unmet ADL need at baseline, they are more likely to be depressed three years later. The same does not hold for unmet IADL need. It is likely that unmet need with ADL, which includes personal and intimate tasks like bathing and toileting, is more detrimental for recipients' mental health that unmet need for IADL tasks such as shopping. However, unmet ADL need may also be a manifestation of elder neglect, and burdened caregivers are at risk of engaging in neglect and abuse. Although caregiver mental health is not directly associated with recipient depression and anxiety, it has significant indirect effects, suggesting that caregivers' experiences partly shape recipients' mental health through caregivers' own depression or anxiety symptoms. Estimates using the same NHATS data suggest that over a third of older persons report at

least one unmet care need (Freedman & Spillman, 2014). Better understanding the reasons behind unmet care need, and further exploring elder abuse and neglect as a potential link between poor caregiver and recipient mental health, would highlight potential points of intervention.

Limitations and Future Research

Below, I outline three important limitations of my dissertation, and offer relevant directions for future research.

The first limitation is that the caregiver-level data are cross-sectional and do not allow for an exploration of caregivers' evolving experiences over time. Although two NSOC waves are currently available, data were collected five years apart, and only about 200 caregivers participated in both waves. The resulting sample yields a sample size too small for adequately powered analysis, particularly when considering recipient attrition between the two data collection points. I partially addressed this limitation by including caregiving duration in my analyses to account for potential changes in caregiving perceptions.

However, further NSOC waves are planned, and in the future researchers will be able to use the longitudinal dataset to provide insights about how caregivers' experiences change as their recipients grow older, or as recipients' health declines. Care trajectories can be long, and caregivers may experience several transitions in their caregiving roles. They may experience a stressful period when first becoming care providers and subsequently adjust to caregiving demands; alternatively, as they transition from occasional assistance with instrumental activities like shopping to intensive personal and end-of-life care, they may appraise caregiving as increasingly burdensome (Gitlin &

Schultz, 2012; Pinquart & Sorensen, 2003). Using latent class transition analysis with longitudinal NSOC data would allow for an examination of caregiving experiences longitudinally.

Second, in exploring the importance of social support for caregivers' experiences, I was unable to definitively ascertain causal ordering with the cross-sectional data. Although I provide evidence that informal support is associated with experience types characterized by benefits, and formal support is associated with experience types that include predominantly burden, cross-sectional data preclude me from establishing a temporal order. Caregivers in NSOC report about receiving formal support in the past year, lending some credence to the interpretation that individuals may not seek formal help until their objective or perceived burden is high. However, questions on receiving informal support were not framed with "in the past year," and informal support from family and friends may generally be an enduring and more constant factor. Thus, although I showed associations between receiving support and experience types in a nationally representative sample, I could not temporally disentangle the links. Intervention studies may be better suited to do so, but may also be limited in generalizability. As above, studies using subsequent NSOC waves accounting for formal and informal support over time will be better able to capture how caregiving experiences change with support provision, and to identify at which points in time caregivers seek different types of assistance.

Finally, NSOC and NHATS lack measures on several factors relevant to caregiving experiences. NSOC does not collect information about reasons for caregiving, and about whether individuals took on the caregiving role voluntarily. The survey gathers

information about types and frequency of assistance, and NHATS sample persons provide information about their health status, but it is not possible to establish caregivers' motivations for taking on their roles. Caregiving is an "unexpected career" or an unwanted transition for many (Aneshensel, Pearlin, & Schuler, 1993). Although caregiving cannot necessarily be deemed completely voluntary—individuals must decide about taking on the role when the need for caregiving is already present—the motivation for caregiving likely shapes experiences (Pearlin & Anashensel, 1994; Quinn, Clare, & Woods, 2010; Quinn, Clare, McGuinness, & Woods, 2012). Similarly, the dataset does not contain details about the informal and formal support that caregivers receive; it is unknown from which person or institution the caregiver receives support, and whether this support was primarily instrumental or emotional in nature. It is also not possible to deduce the reasons why a caregiver did not use formal support—such as due to financial strain, geographic unavailability, or for other reasons. Further, I could not directly measure care quality in this dissertation. I included recipient-reported unmet care need as a proxy, but direct measures of elder abuse and neglect would be better suited for evaluating pathways from caregiving experiences to recipient health explored in this dissertation (Beach & Schulz, 2017). Because these indicators are absent in NSOC and NHATS, researchers interested in exploring reasons and motivations for caregiving, further examining informal and formal support, or evaluating care quality may instead use other nationally representative caregiving datasets. The National Long Term Care Survey (NLTCS) and the National Social Life, Health, and Aging Project (NSHAP) may be particularly well suited for exploring these questions in the US context.

Policy Implications

Over 34 million Americans currently provide informal care to older adults. Population aging, growing numbers of older persons living with chronic and degenerative conditions, and changing family demography are increasing the demand for informal care (US Census Bureau, 2016; US Department of Health and Human Services, 2003). As using a combination of informal and formal assistance declines, the US is expected to experience a shortage of almost 4 million informal caregivers by 2030 (Federal Interagency Forum on Aging-Related Statistics, 2004; Osterman, 2017). Almost a quarter of Baby Boomers are projected to become "elder orphans," without a family member to care for them in old age (Carney et al., 2016). Poor working conditions, lacking incentives, and restrictive immigration policies may hamper efforts to address this shortage by expanding the homecare workforce (Poo & Whitlach, 2016). This dissertation suggested four main ways in which researchers and policy-makers can improve caregivers' experiences and contribute to a long-term care system that is well-suited to support the well-being of both caregivers and their recipients.

First, this dissertation highlighted the heterogeneity and ambivalence of caregivers' experiences. I showed that a large proportion of US informal caregivers reports perceiving benefits even alongside moderate and high burden. Thus, for caregivers facing objective or perceived burdens that cannot be reduced, assistance programs can aim to increase positive perceptions. In the US context, facilitating caregiver satisfaction and continuing caregiving is crucial; the need for care services will increase sharply in the coming decade, resulting in a projected shortage of almost 4 million informal caregivers by 2030 (Osterman, 2017; US Census Bureau, 2016; US

Department of Health and Human Services, 2003). Interventions to increase caregivers' benefits perception may focus on fostering resilience and a sense of control, and on facilitating the development of coping skills like positive reframing (Toohey et al., 2016). Psychosocial interventions providing training in stress management can successfully improve caregivers' feelings about their role, life satisfaction, positive mood, and social participation (Bourgeois, Schulz, Burgio, & Beach, 2002; Cox, 1998; Millan-Calenti et al., 2000; Zanetti, Metitieri, Bianchetti, & Trabucchi, 1998). Caregivers who perceive benefits have better mental and physical health, and continue assisting longer than those without positive experiences (Cohen et al., 2002; Cohen, Gold, Shulman, & Zucchero, 1994; Pinquart & Sorensen, 2003). Beyond psychosocial interventions, programs that allow caregivers to spend time attending to their own needs—like respite or adult day care, further discussed below, which offer a temporary break from caring for the recipient—may increase caregiver satisfaction, quality of life, and benefits perception (Zarit, Kim, Femia, Almeida, & Klein, 2014).

Second, I identified informal caregiver groups that are most likely to report burden only; these caregivers may benefit most from support services. Older, coresident, and long-term caregivers, caregivers in poor mental health, those caring for men, older persons with depression, or with multiple diagnosed medical conditions are at risk of appraising caregiving negatively. These caregivers are likely providing intensive care; to alleviate their burden, it is necessary to expand availability and access to support services like respite care and care training (Zarit et al. 2014). Long-term care insurance is frequently financially unavailable to caregivers, and few receive Medicare compensation for in-home assistance (Johnson, 2016). Temporary respite and adult day care may be a

more accessible solution for caregivers; respite programs may reduce objective and perceived burden, and allow caregivers to recuperate. Programs pairing caregivers with medical staff to provide short-term training may similarly help caregivers undertake demanding nursing tasks more efficiently, and could reduce perceived burden (Hunt & Reinhard, 2015). Expanding the homecare workforce may further provide more temporal resources for these caregivers, and current estimates show that personal care aides, home health aides, and nursing assistants are some of the fastest-growing occupations (Bureau of Labor Statistics, 2017). Finally, workplace programs that accommodate caregiving—like paid family leave and employer-sponsored referral services—may offer caregivers financial security and better work-life balance (Redfoot, Feinberg, & Houser, 2013). National programs like the Family and Medical Leave Act provide leave for individuals to provide care, but the leave is unpaid, only permitted up to 12 weeks, and covers only about half of all workers. Although some states and corporations offer their own policies with paid caregiving leave, the US lags behind other Western countries without a national program of paid caregiving leave (Osterman, 2017).

Third, I showed that caregivers receiving informal social support have predominantly beneficial experiences, and that caregivers receiving formal support are reporting experiences characterized primarily by burden. Friends and family may provide emotional support, financial assistance, and task assistance that may improve caregivers' experiences; over 70% of informal caregivers currently report having such support. However, with changing family demography and higher geographic mobility, the availability of such support may change (Chappell & Funk, 2011). National estimates project that an increasing number of US adults—currently 22%—will become "elder

orphans," or individuals living alone with no close relative to provide support and care (Carney et al., 2016). Caregivers may come to increasingly rely on formal services to address their own well-being and to better support their care recipients (Jette, Tennstedt, & Branch, 1992). My finding suggest that formal support receipt is associated with negative experiences and high burden, and in line with prior research, this suggests that caregivers may not seek formal assistance until they face significant burden. It is thus important to address barriers to formal service use. Financial concerns, geographic unavailability, guilt about being unable to provide care for a loved one, stigmatization, and lack of awareness may prevent caregivers from using formal support. To encourage service use and participation in formal programs that may improve caregivers' experiences, it is important to make such assistance available and accessible. Programs may be subsidized and offered with geographic and temporal flexibility (for example, by providing online and round-the-clock support). Information provision, designing services with sensitivity to the caregiver-recipient relationship, and familiarizing caregivers with their options may make them less reluctant to use formal assistance (Ducharme et al., 2011; Gendron, Poitras, Dastoor, & Perodeau, 1996; Moniz-Cook, Agar, Gibson, Win, & Wang, 1998). Caregiving trajectories are typically long, progressing from sporadic help to personal and end-of-life care, and it is important to introduce caregivers to support resources early in their role (Gitlin & Schultz, 2012; Schulz & Tompkins, 2010).

Fourth, beyond benefits for caregivers themselves, this dissertation showed that providing support and improving experiences for caregivers may also have implications for their recipients' quality of life. Poor mental health in older adulthood is associated with other adverse outcomes and with excess annual adjusted healthcare costs in the US

of over $27 million per one million older adults for depression, and $80 million for anxiety (Vasililadis et al., 2012). I found that caregivers' experiences shape both recipient depression and anxiety; older persons receiving assistance from caregivers perceiving benefits, even alongside low or moderate burden, are less likely to subsequently experience anxiety. Older adults whose caregivers report benefits and no burden are also less likely to become depressed. It is therefore crucial to ensure that informal caregivers are aware of and have access to resources that can help them maintain their own health and continued well-being. My results demonstrated that caregiving has interpersonal dimensions, and that caregivers' experiences are linked with their recipients' mental health. Maintaining caregivers' well-being may facilitate quality care and a good relationship with the recipient, which may therefore also improve recipient mental health. In addressing caregivers' needs, it is important for researchers and practitioners to consider caregiving as a dyadic process situated in a broader network of social relations.

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