Medically Complex Home Care and Caregiver Strain

Cameron Macdonald, PhD, Sara M. Moorman, PhD
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Sara M. Moorman, PhD*1 and Cameron Macdonald, PhD2

1Department of Sociology and Institute on Aging, Boston College, Chestnut Hill, Massachusetts.
2Department of Sociology, University of Wisconsin-Madison.

*Address correspondence to Sara M. Moorman, PhD, Department of Sociology, Boston College, 140 Commonwealth Avenue, 426 McGuinn Hall, Chestnut Hill, MA 02467. E-mail: moormans@bc.edu

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Purpose of the study: To examine (a) whether the content of caregiving tasks (i.e., nursing vs. personal care) contributes to variation in caregivers’ strain and (b) whether the level of complexity of nursing tasks contributes to variation in strain among caregivers providing help with such tasks. Design and methods: The data came from the Cash and Counseling Demonstration and Evaluation study conducted in Arkansas, Florida, and New Jersey. The paper analyzes the physical and emotional strain of 1,926 paid American caregivers who helped adult Medicaid recipients with personal and nursing care in the home. Results: Over 80% of home caregivers were providing assistance with nursing care, and over 50% of those were providing help with moderate or high complexity tasks. Caregivers who were providing any type of nursing care reported significantly more strain than caregivers who were providing only personal care. Those providing highly or moderately complex nursing care exhibited more caregiver strain than did those providing low-complexity nursing care. Implications: Medical complexity is an important contributor to caregiver strain. Policymakers should consider medical complexity in the development of practices to assist the caregivers of Medicaid long-term care recipients, especially through consumer-directed supportive service programs.

Key Words: Care work, Consumer-directed supportive services, Home and community based services, Long-term care, Medicaid

Unprecedented numbers of long-term care recipients—approximately 10.9 million persons—are cared for at home in the United States today (Kaye, Harrington, & LaPlante, 2010). Eighteen percent of elder care recipients and 7.8% of younger disabled persons rely on paid help (Kaye et al., 2010). Some of the assistance they receive consists of personal care, or activities of daily living (ADLs), such as helping care recipients dress, eat, and bathe. Other aspects consist of running errands, managing finances, and housekeeping tasks, known as instrumental activities of daily living (IADLs). Eligibility for personal care assistance through Medicaid is based on assessments of the recipient’s inability to perform some or all necessary ADLs and/or IADLs. Correspondingly, policies and interventions to support caregivers of elderly and disabled individuals are typically constructed on the assumption that these are the only tasks caregivers perform (Albert, 2004; Benjamin & Matthias, 2004).

However, as third-party payers become increasingly unwilling to fund stays in hospitals and long-term care facilities, home-based care has become more medically complex; involving operation of technological equipment, sophisticated diagnostic skills, substantial risks to care recipients, and/or working with bodily fluids in ways that were the exclusive domain of professional nursing staff in the past. Over 40% of family caregivers perform nursing tasks, including administering intravenous
medications, running feeding tubes, and wound care (Donelan et al., 2002). This figure reflects a dramatic transformation in the type of work performed by caregivers in the home. Yet, very little research has been conducted on the implications of this transformation for paid and unpaid caregivers and care recipients.

The Cash and Counseling Demonstration and Evaluation (CCDE) study of consumer-directed use of Medicaid funds is the only large-scale data set to measure both caregiver strain and the provision of medically complex nursing care. This study uses data from the CCDE to examine levels of physical and emotional strain in 1,926 paid caregivers to elderly and disabled Medicaid home care recipients. We address two research questions with the aim of more fully describing caregivers’ experiences in home and community-based long-term care than has been documented before: First, does task content (i.e., nursing vs. personal care) contribute to variation in caregivers’ strain? Second, does the level of medical complexity contribute to variation in strain among those caregivers providing help with nursing tasks?

Measuring Care Work

Historically, caregiver effort has been measured in terms of the number of hours of care provided, caregiving duration, and the number of ADLs and IADLs they perform (Reinhard, 2004). These measures are intended to indicate the magnitude of necessary care, as well as its potential to be overwhelming (Pearlin, Mullan, Semple, & Skaff, 1990). These dimensions are traditionally called care intensity (e.g., Donelan et al., 2002).

However, experts recognize that traditional measures of care intensity overlook important parts of the caregiving job. Levine, Reinhard, Feinberg, Albert, and Hart (2004) include behavior supervision, complex nursing care, pain management, managing other homecare workers, and advocacy in negotiating the health care system as potentially stressful aspects of caregiving that are not reflected in typical care intensity measures. In the present paper, we explore the element of complex nursing care, what we call medically complex care.

In a sample representative of the U.S. population, Donelan and colleagues (2002) found that 19% of family caregivers were responsible for changing dressings on wounds, 15% for helping with equipment such as dialysis pumps, and 39% for administering medications. Less than half of each group reported having received any instruction on the task, and 12% of those administering medicine admitted making errors. Yet, although the extent of complex care delivery in the home has been assessed on a large scale, the effects of providing such care have been understudied (Donelan et al., 2002). Bioethicists have assumed its stressfulness (Arras & Dubler, 1994), and qualitative research has examined family caregivers’ difficulties in providing of certain types of home nursing care (e.g., Guberman et al., 2005; Macdonald, 2008). In the present study, we seek to statistically link the provision of nursing care to caregiver strain, net of traditional measures of care intensity. Thus we ask the research question: Does the provision of nursing care contribute to variation in caregivers’ strain, net of care intensity?

Medically Complex Caregiving

We do not, however, expect that all types of nursing care are equally stressful. In a recent qualitative study of family members performing an array of nursing tasks at home, Macdonald (2008) found medically complex care tasks to include four dimensions of concern to lay caregivers: operation of technological equipment, sophisticated diagnostic skills, exposure to bodily fluids, and/or substantial risks to care recipients.

The “high-tech” element requires that caregivers master devices such as intravenous devices and respiratory ventilators. Caregivers tending respiratory ventilators must know how to connect ventilators to tracheostomy sites, respond to various alarms and power failures, and understand how to adjust the flow of oxygen (Lewarski & Gay, 2007). Caregivers tending enteral feeding tubes must program pumps that regulate the delivery of the liquid nutrition, and monitor for problems such as blocked or disconnected tubes or signs of infection (Hitchings, Best, & Steed, 2010). A second related feature of medically complex care is the degree of diagnostic work required. Caregivers must be able to respond to subtle signs of complications such as electrolyte deficiencies in tube feeding, insufficient or excessive oxygen flow or signs of incipient pneumonia in vent-dependent care recipients, or early signs of infection in wound care.

Third, medically complex care involves exposure to a wide range of bodily fluids. Sociologists refer to this as “bodywork,” or labor that involves another person’s excrement, bodily fluids (e.g., blood), or products of illness (e.g., vomit; Twigg,
2000). Bodywork can be demeaning, disgusting, traumatizing, stigmatizing, and embarrassing for caregivers and care recipients alike (Stacey, 2005). However, most studies of bodywork focus on the bodily fluids associated with ADLs such as bathing and toileting, and do not therefore include the bodily products that are involved when tubes are inserted into the body or caring for open wounds, which health care professionals normally tend. This kind of bodywork not only creates discomfort among caregivers but also implies risk to care recipients and to the caregivers themselves.

Risk to the care recipient in the case of caregiver error is the fourth and final dimension of high-complexity home care. Adverse events ranging from drug side effects, to infections, to falls, to equipment malfunctions, may happen to as many as 13% of home care recipients (Masotti, McColl, & Green, 2010). Caregivers and care recipients express considerable anxiety over their ability to administer treatments correctly, especially in emergencies (Briscoe & Woodgate, 2010).

We expect that just as more intense care is more stressful, likewise, more complex care will be more stressful. The strain caregivers experience will be in part a function of the complexity of the care they must provide. Thus we ask the research question: Does the level of nursing care complexity account for any of the variation in strain among caregivers providing help with nursing tasks, net of care intensity?

Consumer-Directed Supportive Services in Medicaid Home and Community Based Long-Term Care

The data for the present study are drawn from an evaluation of the Cash and Counseling program. Traditionally, Americans receive home care benefits through the Medicaid program in the form of payment for services rendered by aides placed by licensed home care agencies. But consumer-directed supportive service programs such as Cash and Counseling are nontraditional programs within Medicaid that “permit service recipients—as opposed to medical or social work professionals—comparatively greater choice and control over all aspects of service provision: from hiring the attendant, to defining the attendant’s duties, to deciding when and how specific tasks or services are performed” (Dory, Kasper, & Litvak, 1996). In the past 20 years, consumer-directed plans for elderly and disabled persons have been adopted in 38 states in the United States and in multiple countries in Europe (Ng, Harrington, & Howard, 2011). Recipients may use their benefits to directly hire a paid caregiver (including a family member), purchase assistive devices, or pay for home modifications, thereby increasing their independence and potentially reducing the need for attendants.

The influence of these plans on care providers has been evaluated in a number of ways: survey assessment of paid workers’ levels of job stress, job satisfaction, care intensity, and caregiver strain (Benjamin & Matthias, 2004; Delp, Wallace, Geiger-Brown, & Muntaner, 2010; Foster, Brown, Phillips, & Carlson, 2005; Foster, Dale, & Brown, 2007); employee retention (Benjamin, Matthias, Kietzman, & Furman, 2008); and survey assessment of the factors that draw caregivers into work in consumer-directed programs (Howes, 2008). All of these evaluation studies share a common assumption—that care providers are giving “personal and supportive, rather than medical” care (Benjamin & Matthias, 2004, p. 487). These studies measure the difficulty of providing care in terms of hours of care provided and number of ADL/IADLs provided, as well as measures of behavioral problems and/or abuse by the care recipient. They do not account for the health impairments of the care recipients or for the nursing tasks associated with these health impairments. Due to the extent of nursing care found in national samples of unpaid family caregivers (Donelan et al., 2002), and to the strain this care likely poses, in the present study we assess our research questions in data collected to evaluate the Cash and Counseling program.

Methods

Participants

The CCDE study took place in Arkansas, Florida, and New Jersey between 1998 and 2002 and involved all Medicaid beneficiaries who expressed interest in enrolling in Cash and Counseling. In total, 5,585 elderly and/or disabled persons aged 18 and older were enrolled in the study. A random 50% of enrollees were assigned to receive Cash and Counseling benefits; the remaining enrollees were assigned to a control group that continued to receive standard benefits. All participants were interviewed over the telephone upon enrollment, and again 9 months later. During the 9-month interview, participants identified the person(s) who had provided them with the most paid and unpaid assistance with personal care and household tasks in the past week. Each recipient’s primary paid and
unpaid caregiver(s) was/were interviewed by telephone about 10 months after enrollment of the care recipient. (Some care recipients were associated with only one caregiver, either because they lacked both a paid and an unpaid caregiver or because one caregiver provided both paid and unpaid care.)

Paid primary caregivers of adult care recipients who provided help with any personal and/or nursing care comprise the subsample of the CCDE considered in the present study (N = 1,926). (Unpaid caregivers were excluded from this study because they were not asked about the nursing tasks they performed.) The care recipient 9-month interview measured whether their paid caregivers had helped with each of nine nursing care tasks in the past 2 weeks: “giving or taking medicine”; “caring for pressure sores or other chronic wounds”; “use and care of a feeding tube (to stomach)”; “care of a urinary catheter to empty the bladder”; “range of motion or other exercises”; “care of a ventilator or other care of the lungs”; “special care of the feet because of poor circulation”; or “other routine health care at home.”

**Caregiver Strain**

Caregivers answered two items on their experience of strain: “By choosing a number from 1 to 5, please tell me how much physical strain you experience helping [care recipient]. One means little or none and five means a great deal.” The second item was identical except that it asked about emotional strain. We analyzed physical and emotional strain separately and also together as a measure of total strain where responses were summed and averaged (α = .65).

**Medical Care Complexity**

Recall that caregivers reported whether they completed nine specific nursing tasks (e.g., caring for pressure sores or other chronic wounds) or any other routine health care at home. When asked about other routine health care, 13.1% of the sample volunteered that they monitored the care recipient’s vital signs and 3.1% volunteered that they helped care recipients test their blood sugar. No other routine health care task was volunteered in sufficient numbers for statistical analysis; therefore, there are measures of 11 nursing tasks. The proportion of sample caregivers who helped with each task is presented in Table 1.

The standard measure of care intensity is to sum the number of tasks the caregiver performed (Reinhard, 2004). We believe that summing is an inappropriate method for assessing care complexity, given that nursing tasks differ in their difficulty. A sum scale imposes the assumption that tasks are of equivalent difficulty, and that adding any one more would add a similar amount of strain. We constructed a new measure of care complexity based on the four dimensions of medical complexity (i.e., technical complexity, degree of required diagnostic work, bodywork, and risk to care recipient) identified in prior qualitative research on high-tech home care (Macdonald, 2008). Results obtained with a measure summing the number of nursing tasks performed are available upon request.

**Table 1. Complexity of Nursing Tasks for an Untrained Caregiver**

<table>
<thead>
<tr>
<th>Task</th>
<th>% of 1,926 caregivers performing</th>
<th>Technical complexity</th>
<th>Diagnostic work required</th>
<th>Exposure to bodily fluids (bodywork)</th>
<th>Risk to care recipient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ventilator</td>
<td>10.3</td>
<td>High</td>
<td>High</td>
<td>Moderate</td>
<td>High</td>
</tr>
<tr>
<td>Feeding tube</td>
<td>4.6</td>
<td>High</td>
<td>High</td>
<td>High</td>
<td>High</td>
</tr>
<tr>
<td>Urinary catheter</td>
<td>7.1</td>
<td>Moderate</td>
<td>Low</td>
<td>High</td>
<td>Low</td>
</tr>
<tr>
<td>Colostomy bag</td>
<td>2.3</td>
<td>Moderate</td>
<td>Low</td>
<td>High</td>
<td>Low</td>
</tr>
<tr>
<td>Pressure sores</td>
<td>18.7</td>
<td>Low</td>
<td>Moderate</td>
<td>High</td>
<td>Moderate</td>
</tr>
<tr>
<td>Foot care</td>
<td>36.3</td>
<td>Low</td>
<td>Moderate</td>
<td>High</td>
<td>Moderate</td>
</tr>
<tr>
<td>Medications</td>
<td>59.3</td>
<td>Moderate</td>
<td>Moderate</td>
<td>High</td>
<td>Moderate</td>
</tr>
<tr>
<td>Vital signs</td>
<td>13.1</td>
<td>Moderate</td>
<td>Moderate</td>
<td>Low</td>
<td>Moderate</td>
</tr>
<tr>
<td>Blood sugar</td>
<td>3.1</td>
<td>Moderate</td>
<td>Moderate</td>
<td>Low</td>
<td>Moderate</td>
</tr>
<tr>
<td>Range of motion</td>
<td>60.3</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
</tr>
<tr>
<td>Any of the previous tasks</td>
<td>83.2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: As rated by 22 registered visiting nurses experienced in training family caregivers to provide nursing care at home.*
The second author conducted three focus groups with a total of 22 registered visiting nurses who had a range of 2–12 years of experience in teaching family members to provide nursing care at home. In these focus groups, nurses were asked to perform four tasks: (a) discuss and verify the four dimensions of complex medical home care; (b) rank, from a nurse’s perspective, the difficulty of the nursing tasks listed in the Cash and Counseling caregiver survey according to the four dimensions; (c) rank, from an untrained caregiver’s perspective, the difficulty of the same tasks according to the same dimensions; and (d) discuss differences in their rankings and come to a consensus ranking on each of the measures. Their consensus rankings of the difficulty of these tasks for an untrained caregiver are presented in Table 1.

We then coded the 10 tasks according to these nurses’ consensus rankings. Tasks that the nurses deemed highly complex for an untrained caregiver on two or more of the four dimensions were coded as highly complex. These included help with a ventilator or feeding tube. Tasks that nurses considered highly complex for an untrained caregiver on one of the four dimensions were coded as moderately complex. These included care of pressure sores, a colostomy, a urinary catheter, and foot care. Finally, tasks that nurses concluded were not highly complex for an untrained caregiver on any dimension were coded as low complexity. These included help with medicines, range of motion/exercise, taking vital signs, and blood sugar testing. Finally, caregivers were placed into exhaustive, mutually exclusive categories on the basis of the most complex task they reported performing. For example, a caregiver who helped a care recipient with a feeding tube and to take medication was coded as having given highly complex care.

Care Intensity

**Number of Personal Care Tasks Performed.**—Recall that care recipients reported whether they received paid help with five ADLs (e.g., eating). These responses were summed to produce a count of the number of personal care tasks the caregiver performed, as is standard in the literature on care intensity (Reinhard, 2004).

**Number of Household Tasks Performed.**—Care recipients also reported whether they received paid help with light housework or laundry; shopping; transportation; and other help around the house or community. Responses were summed to produce a count of the number of household tasks the caregiver performed.

**Hours of Care.**—Caregivers reported the number of hours for which they had earned pay to care for the care recipient during the past 2 weeks. We categorized the continuous reports to create three dichotomous indicators: fewer than 40 hr (reference category), 40–60 hr, and 61 or more hours.

**Duration of Paid Caregiving.**—Most caregivers were asked how long they had been providing care; using the response options 1 (less than 6 months), 2 (6 months to 1 year), 3 (1–2 years), and 4 (more than 2 years). Family members who were unpaid caregivers prior to Cash and Counseling and became paid under the program were asked to give the month and year they began to be paid. (They were not asked to report the date they began unpaid care to the care recipient.) The data also included the month and year the interview was completed. The number of months these caregivers had been giving care were coded using the 1–4 scale all other caregivers used to respond.

**Caregiver Type**

Of the 1,926 caregivers, 819 were family members of a Cash and Counseling recipient, 307 were caring for a Cash and Counseling recipient but were not related to him or her (i.e., were a friend, neighbor, or aide hired on the unregulated “grey” market), and 800 were caring for a control group care recipient to whom they were not related (i.e., were home health aides to traditional Medicaid recipients, employed and paid through agencies). Additionally, 38 caregivers were family members of a control group care recipient. Because home care agency employment is unusual for family caregivers, we excluded this small group from our analyses. Response rates were 95% among those caring for a Cash and Counseling care recipient and 78% among those caring for a control group care recipient (Brown & Dale, 2007).

**Sociodemographic Characteristics**

**Educational attainment.**—Caregivers reported the level of education they had obtained. We coded this information into three dichotomous variables: less than a high school education, high school graduate (reference), and education past high school.
Gender.—Caregivers reported whether they were male (reference) or female.

Age.—Caregivers reported their age in years. The youngest caregiver was 16 years old and the oldest caregiver was 80 years old, with a median age of 45.5 years.

Race/ethnicity.—Caregivers were asked “Do you consider yourself to be of Hispanic or Latino origin, such as Mexican, Puerto Rican, Cuban, or other Spanish background?” and “Do you consider yourself to be white; African American or black; American Indian or Alaska native; Asian; native Hawaiian or other Pacific Islander; another race?” We coded these responses into four mutually exclusive categories: non-Hispanic white (reference), non-Hispanic black, Hispanic, and other race/ethnicity.

Analytic Strategy

To address strain and complexity of nursing care, we first conducted ordinary least squares linear regressions to compare the physical, emotional, and total strain of caregivers providing nursing care to caregivers providing personal care only, controlling for other aspects of care intensity, caregiver type, the caregiver’s sociodemographic characteristics, and state (i.e., Arkansas, Florida, or New Jersey). Second, examining only the caregivers who were providing nursing care, we compared the physical, emotional, and total strain of those who were providing high, moderate, and low complexity care. This model also included care intensity, caregiver type, the caregiver’s sociodemographic characteristics, and state.

Missing data were uncommon in the survey. Of the 1,926 cases, 90.2% (N = 1,738) provided responses for all measures used in the present study. Listwise deletion was used throughout the analyses.

Results

Research Question 1: Task Content Versus Care Intensity and Caregiver Characteristics

The average caregiver in the full sample was helping with 3.55 personal care tasks and 2.83 household tasks. He or she helped for fewer than 40 hr in the past 2 weeks and had been receiving pay for providing care to this care recipient for 6 months to a year. Seventy-two percent of care recipients were female and 55% of care recipients were aged 65 or older.

Of all caregivers, 83.2% were providing help with one or more nursing tasks. Caregivers who were providing any type of nursing care reported significantly more physical, emotional, and total strain than their counterparts who were providing personal care only. Nursing caregivers’ total strain averaged 2.48 (SD = 1.33) on a scale of 1 (lowest strain) to 5 (highest strain), whereas personal caregivers’ total strain averaged 1.78 (SD = 1.13). However, nursing caregivers were providing more intense care than personal caregivers: Those providing nursing care also helped with more personal care tasks and more household tasks than personal-care-only caregivers, and they spent more hours doing caregiving. Only in duration of caregiving did personal-care-only caregivers significantly exceed nursing caregivers. There were sociodemographic differences as well, with nursing caregivers including a larger proportion of family members, men, and Hispanic persons than the personal caregivers. Larger proportions of personal caregivers than nursing caregivers were female, white, and in the control group (i.e., agency aides under standard Medicaid). Descriptive statistics for all measures used in the study are presented in Table 2.

In the multivariate regressions, caregivers providing nursing care experienced significantly more total strain than their counterparts who were providing personal care only (B = 0.43, p < .01). That is, net of differences in care intensity and the sociodemographic characteristics, nursing caregivers averaged two-fifths of a point higher on the strain scale. Analysis of physical and emotional strain separately indicated that both physical and emotional strain were higher among nursing caregivers. Care intensity also mattered: Performing a larger number of personal care tasks (B = 0.07, p < .001); performing 40 or more hours of care in the past 2 weeks (40–60 hr: B = 0.15, p < .05; 61 or more hr: B = 0.28, p < .001); and longer duration of caregiving (B = 0.12, p < .001) were associated with significantly greater strain. Other measures that were independently associated with greater total strain included having completed more than a high school education and Hispanic ethnicity. Complete results are presented in Table 3.

Research Question 2: Medical Care Complexity

Most caregivers’ most complex nursing task was of moderate complexity (providing help with
pressure sores, a catheter, a colostomy, or foot care), with 36.9% of the sample providing moderate care (44.4% of caregivers providing any nursing care). Only low-complexity nursing tasks (providing help with medications, range of motion or exercise, taking vital signs, or testing blood sugar) were performed by 33.1% of the sample caregivers providing it (39.7% of caregivers providing any nursing care). The smallest proportion of caregivers, 13.3% (15.9% of all caregivers providing any nursing care) had one or more tasks of high complexity (ventilator, feeding tube). Care complexity did not vary significantly among the three types of caregivers (i.e., family/Cash and Counseling, unrelated/Cash and Counseling, unrelated/control, not shown).

Among the nursing caregivers, the higher the complexity of the most complex task, the more total strain caregivers reported. Caregivers who provided moderate \((B = 0.14, p < .05)\) or high \((B = 0.25, p < .01)\) complexity care-to-care recipients experienced significantly more total strain than did caregivers who provided low complexity care. That is, caregivers providing high complexity care scored a quarter of a point higher on the strain scale, and caregivers providing moderate complexity care, 0.14 points higher, than caregivers providing low complexity care. Analysis of physical and emotional

| Table 2. Characteristics of Paid Caregivers in the Cash and Counseling Demonstration and Evaluation |
|-----------------------------------------------|-----------------------------------------------|
| Caregivers providing nursing care \((N = 1,603)\) | Caregivers providing personal care \((N = 323)\) |
| Mean \((SD)\) or proportion                  | Mean \((SD)\) or proportion                  |
| Caregiver strain                             |                                               |
| Physical strain \((1 = \text{little or no}; 5 = \text{a great deal})\) | 2.60 \((1.51)\) | 1.85*** \((1.31)\) |
| Emotional strain \((1 = \text{little or no}; 5 = \text{a great deal})\) | 2.34 \((1.56)\) | 1.68*** \((1.27)\) |
| Total strain \([\text{physical} + \text{emotional}] / 2\) | 2.48 \((1.33)\) | 1.78*** \((1.13)\) |
| Care complexity                              |                                               |
| High (ventilator/feeding tube)               | 0.16                                          | – |
| Moderate (pressure sores/urinary catheter/colostomy/foot care) | 0.44 | – |
| Low (administering medicines/range of motion/vital signs/blood sugar) | 0.40 | – |
| Care intensity                               |                                               |
| Number of personal care tasks                | 3.78 \((1.43)\)                               | 2.47*** \((1.70)\) |
| Number of household tasks                    | 2.93 \((1.15)\)                               | 2.30*** \((1.12)\) |
| Hours of care, past two weeks: Under 40      | 0.42                                          | 0.86*** |
| Hours of care, past two weeks: 40 – 60       | 0.28                                          | 0.12*** |
| Hours of care, past two weeks: 61 or more    | 0.30                                          | 0.02*** |
| Duration of paid caregiving \((1 = \text{less than 6 months}; 4 = \text{2 years or more})\) | 2.03 \((0.89)\) | 2.17* \((1.04)\) |
| Caregiver type                               |                                               |
| Family caregiver, Cash and Counseling        | 0.48                                          | 0.15*** |
| Unrelated caregiver, Cash and Counseling     | 0.16                                          | 0.16 |
| Unrelated caregiver, control group           | 0.36                                          | 0.69*** |
| Sociodemographic characteristics of the caregiver |                                   |
| Less than high school education              | 0.25                                          | 0.24 |
| High school graduate                         | 0.38                                          | 0.44 |
| More than high school education              | 0.37                                          | 0.32 |
| Female                                       | 0.89                                          | 0.95*** |
| Male                                         | 0.11                                          | 0.05*** |
| Age (years)                                  | 45.65 \((13.37)\)                            | 44.51 \((12.75)\) |
| White                                        | 0.38                                          | 0.49*** |
| Hispanic                                     | 0.25                                          | 0.17*** |
| Black                                        | 0.32                                          | 0.31 |
| Other race or ethnicity                      | 0.05                                          | 0.03 |

*Note: Means and standard deviations are presented for continuous measures; proportions are shown for categorical measures. Chi-square tests (for categorical measures) and t tests (for continuous measures) were conducted to assess statistically significant gender differences, where \(^* p < .05\), \(^{**} p < .01\), \(^{***} p < .001\).
strain separately indicated that these results were due to the higher physical strain of moderate and high complexity caregiving. Complete results are presented in Table 4.

Discussion

In this study, we examined the physical and emotional strain of 1,926 paid American caregivers who were helping adult Medicaid care recipients with personal care and/or some form of nursing care. Caregivers who were providing any type of nursing care reported significantly more strain than caregivers who were providing help with ADLs. Further, those providing highly medically complex care—help with a ventilator or feeding tube—and moderately medically complex care—help with colostomy, catheter, pressure sores, or foot care—exhibited more caregiver strain than did those providing low-complexity medical care. These findings have important implications for the evaluation of the efficacy of consumer-directed supportive service programs, and for future assessments of caregiver strain.

The Special Challenges of Medically Complex Care

We found that over 80% of home caregivers were providing assistance with some type of nursing care and that over 50% of those were providing help with moderate or high complexity tasks. The former figure is twice estimate of Donelan and colleagues (2002), but our sample was comprised of caregivers of Medicaid recipients, a sicker, and more disabled population than persons with private insurance (Kaiser Family Foundation, 2011a). Nonetheless, the complexity of the nursing care performed by the caregivers in this sample is notable.

Traditional measures of care intensity, especially providing 61 or more hours of care in the past 2 weeks, were associated with greater caregiver strain. However, provision of nursing care was associated with greater physical and emotional strain in our sample over and above the strain explained by duration of caregiving, hours of care, and functional limitation of the care recipient. Further, the more complex the nursing task in terms of operation of technological equipment, sophisticated diagnostic skills, substantial risks to care recipients, and/or working with bodily fluids the greater the strain the caregiver experienced. Our findings are consistent with prior qualitative research indicating that complex home nursing care is a source of caregiver strain (Guberman et al., 2005; Macdonald, 2008). Our study contributes

Table 3. Ordinary Least Squares Regressions of Caregiver Strain on Task Type

<table>
<thead>
<tr>
<th>Task Type</th>
<th>Physical strain</th>
<th>Emotional strain</th>
<th>Total strain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provides any nursing care (vs. personal care only)</td>
<td>0.58*** (0.10)</td>
<td>0.26** (0.10)</td>
<td>0.43*** (0.09)</td>
</tr>
</tbody>
</table>

Note: Regressions control for state (AR, FL, NJ). B’s are unstandardized regression coefficients.

*p < .05  **p < .01  ***p < .001.
were providing assistance with some type of nursing care. The Special Challenges of Medically Complex Care: Caregivers who were providing help with ADLs. Further, caregivers who were providing help with a ventilator or feeding tube — and moderately more caregiver strain than did those providing care to moderate or high complexity tasks.

Discussion

The former figure is twice estimate of Donelan and colleagues (2002), but our sample was comprised of caregivers of Medicaid recipients, a sicker, and more disabled population than persons with private insurance (Kaiser Family Foundation, 2011a). Research indicating that complex home nursing care is important to consider when assessing caregivers’ needs and developing policy and programming to assist them. Interventions based on the assumption that family members and other home caregivers provide only or mostly personal care fail to address major stressors in caregivers’ experience, including — though not limited to — the need to provide nursing care (Levine et al., 2004). Notably, supplemental interaction analyses indicated that nursing complexity had similar effects on caregivers’ strain regardless of their status as family or unrelated caregivers, and regardless of their status as Cash and Counseling or standard Medicaid caregivers (not shown). This similarity suggests that the benefits of the Cash and Counseling program are not tailored for complex care. Complex nursing caregivers may benefit from forms of assistance such as coordination of care across medical settings and providers, communication with highly trained health care providers, and training at nursing tasks (Levine, Halper, Peist, & Gould, 2010).

Limitations

This study is limited in several important respects. First, the study contains little information on the prior literature by confirming this finding statistically in a large sample.

We believe our results have two implications. The first concerns future research endeavors: Medical complexity is important to measure when accounting for caregiver strain. Large numbers of untrained, and usually unpaid, caregivers provide nursing care at home, and the nature of these tasks is an important contributor to their levels of strain. Meta-analytic research indicates that traditional measures of care intensity, including number of personal care tasks, duration of caregiving, and hours of care provided, have significant but modest correlations with caregiver burden (Pinquart & Sorensen, 2003). Further, these standard measures account for only a quarter of the variation in caregiver burden (Pinquart & Sorensen, 2003). Adding measures of positive and negative behaviors on the part of the caregiver accounts for somewhat more variance (Ingersoll-Dayton & Raschick, 2004). Future research seeking to explain levels of caregiver strain should include measures of nursing care complexity.

The second implication of the present study concerns the structure of consumer-directed supportive service programs such as Cash and Counseling:

### Table 4. Ordinary Least Squares Regressions of Caregiver Strain on Care Complexity

<table>
<thead>
<tr>
<th>Complexity of nursing care provided (vs. low)</th>
<th>Physical strain</th>
<th>Emotional strain</th>
<th>Total strain</th>
</tr>
</thead>
<tbody>
<tr>
<td>High (ventilator/feeding tube)</td>
<td>0.36*** (0.11)</td>
<td>0.10 (0.11)</td>
<td>0.25** (0.10)</td>
</tr>
<tr>
<td>Moderate (pressure sores/urinary catheter/colostomy/foot care)</td>
<td>0.19* (0.08)</td>
<td>0.07 (0.08)</td>
<td>0.14* (0.07)</td>
</tr>
</tbody>
</table>

Care intensity

- Number of personal care tasks: 0.11*** (0.03), 0.02 (0.03), 0.06*** (0.02)
- Number of household tasks: -0.11* (0.04), -0.01 (0.04), -0.06 (0.03)
- Hours of care, past two weeks: 40–60: 0.11 (0.10), 0.18 (0.10), 0.14 (0.08)
- Hours of care, past weeks: 61 or more: 0.15 (0.10), 0.39*** (0.10), 0.26* (0.09)
- Duration of paid caregiving (1 = <6 months; 4 = ≥2 years): 0.11* (0.04), 0.12** (0.04), 0.12** (0.04)

Caregiver type (vs. unrelated caregiver, control group)

- Family caregiver, cash and counseling: -0.12 (0.11), 0.21 (0.11), 0.04 (0.09)
- Unrelated caregiver, cash and counseling: -0.20 (0.12), -0.15 (0.13), -0.17 (0.11)

Sociodemographic characteristics of the caregiver

- Less than high school education: 0.01 (0.10), -0.07 (0.10), -0.02 (0.08)
- More than high school education: 0.18* (0.09), 0.18* (0.09), 0.18* (0.07)
- Female: 0.25* (0.13), 0.00 (0.13), 0.13 (0.11)
- Age (years): 0.01 (0.01), 0.01 (0.01), 0.01 (0.01)
- Hispanic: 0.56*** (0.11), 1.04*** (0.11), 0.79*** (0.09)
- Black: -0.06 (0.09), -0.27** (0.09), -0.15 (0.08)
- Other race or ethnicity: -0.08 (0.19), 0.06 (0.18), -0.02 (0.16)

N 1,452 1,442 1,459

F; df 10.0; 18 16.8; 18 15.9; 18

Note. Regressions control for state (AR, FL, NJ). B’s are unstandardized regression coefficients.

*p < .05. **p < .01. ***p < .001.
about the nature of caregivers’ work with medication, and thus we may have underestimated the complexity of helping with medicine when coding the 11 tasks. On one end of the spectrum, helping with medications could be as simple as handing the care recipient a cup of water and a pill once a day. On the other end of the spectrum, helping with medications could involve multiple medications at doses dependent on the care recipient’s current status, at multiple times during the day and night, in various forms (e.g., oral, intravenous). Nationally, 12% of caregivers report helping a care recipient with 10 or more medications, and of these caregivers, 16% report having made an error (Donelan et al., 2002). The nurses in our focus groups concurred that they would consider medication regimes including polypharmacy to be high risk to the care recipient when performed by an untrained caregiver.

Second, although unpaid caregivers experience more strain than do paid caregivers, unpaid caregivers in the CCDE were not asked what nursing tasks they performed and so were excluded from the present study (Foster et al., 2005). Information about unpaid caregivers’ workload is essential to efforts to write policy, given that the vast majority of family caregivers are unpaid (Wolff & Kasper, 2006). Performing medically complex care without benefit of pay or training may prove especially stressful, especially if it means that family members provide this care while also working outside of the home for pay.

Third, it is not entirely clear where the line between nursing care and personal care should be drawn. We included range of motion exercises in our focus group evaluations and in this analysis because they were included among the nursing tasks listed in the CCDE. The visiting nurses in our focus groups ultimately agreed on a low difficulty ranking for range of motion, acknowledging that range of motion exercises were the task most similar to ADLs. However, they also stated that context matters. Untrained caregivers of frail elderly patients sometimes find range-of-motion exercises daunting because of perceived risk of injuring the patient. This blurry line between personal and medical care reflects the challenges inherent in assessing caregiver needs for training and support as more complex nursing needs move into the home.

Fourth, the CCDE does not include any means of identifying dementia patients. But there are no cognitive functioning criteria for eligibility in Cash and Counseling, and there are likely dementia patients among this sample. We presume that dementia would only add to nursing caregivers’ strain, given patients’ likely confusion about the need for nursing care, decreased ability to report symptoms, and need for near-constant monitoring.

Finally, the data from the CCDE are over 10 years old, and may therefore underestimate the number of Medicaid caregivers providing complex nursing care today. We anticipate that the extent of “offloading,” or transfer of care from institutions to the home, has risen in conjunction with rises in health care costs (Kaiser Family Foundation, 2011b).

Conclusion

Among home caregivers of Medicaid recipients, a majority provides highly or moderately medically complex services such as assistance with a ventilator or colostomy bag. These caregivers experience heightened emotional and physical strain compared to their peers who provide low complexity nursing care (e.g., monitoring blood sugar) and personal care (i.e., ADL assistance). We suggest that policymakers, especially those involved with consumer-directed supportive service programs such as Cash and Counseling, pay greater attention to the needs of those persons providing home care that includes technological complexity, diagnostic ability, risk to care recipients, and/or extensive exposure to bodily fluids.

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