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Beyond Functional Support: The Range of Health-Related Tasks Performed In The Home By Paid Caregivers in New York

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Abstract

Paid caregivers (e.g. home health aides, personal care attendants) are formally tasked with helping older adults with functional impairment meet their basic needs at home. This study used semi-structured interviews (n=30) with dyads of patients or their proxies and their paid caregivers in New York City to 1) understand the range of health-related tasks paid caregivers perform in the home and 2) determine if these tasks are taught in the New York State government's Department of Health curricula. We found that patients, proxies, and paid caregivers all described that paid caregivers performed a wide range of health-related tasks that were often not a part of their formal training. Creating clear competencies for paid caregivers that reflect the full breadth of health-related tasks they may perform at home will help maximize the potentially positive impact of the paid caregiver workforce on the lives of patients living at home with functional impairment.

Background

Older adults prefer to remain living at home even with the substantial functional impairment that is common in the last years of life.(1,2) This fact, in combination with growing evidence of the cost effectiveness of community-based long-term care, is driving interest in shifting the locus of long-term care from institutions to the community.(3–6) Paid caregivers (e.g. home health aides, personal care attendants, and other direct care workers) will increasingly be needed to provide the hands-on care that supports this shift.(7) The large and growing workforce of paid caregivers spends hours each day with patients with functional impairment and witnesses their chronic health needs, changes in health status, and

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psychosocial stressors. As a result, paid caregivers have the potential to serve as valuable members of patients' multidisciplinary health care team and influence health outcomes.

Yet little can be inferred about what paid caregivers do in the home to support the health of patients with functional impairment. The training and supervision of paid caregivers providing long-term care to this vulnerable population can vary significantly based on how caregivers are employed, who is paying them to provide care, and in which state they live.(8–10) For example, New York State (where this study took place) is one of the 29 states that requires licensure for home care agencies.(8) The minimum training for paid caregivers providing Medicaid-funded long-term care (with the exception of those providing care through the Office of People with Developmental Disabilities Waiver) is completing a 40 hour, state-developed of Home Care Curriculum and passing a competency evaluation.(11) Some Medicaid-funded paid caregivers have completed the more comprehensive home health aide training, which in New York State includes 75 hours of training mandated by the federal government.(10,12) Paid caregiver training programs in New York State are regulated by either the New York State Department of Health (for trainings operated by providers such as Licensed Home Care Service Agencies) or the State Education Department (for trainings operated by educational organizations like community colleges or for-profit schools). No unified system to monitor the quality of trainings (e.g. qualifications of instructors) exists.(13)

In sum, the training and supervision of those who provide long-term care in the home is highly variable. Even when state-level requirements are present, training often covers basic skills rather than health-related tasks.(8) Furthermore, guidance from home care agencies about allowed or expected tasks may not match the lived experience of paid caregivers, who are on their own confronting complex patient needs at home.(14,15)

Existing research on paid caregivers has largely been limited to workforce issues such as recruitment, retention, and job satisfaction.(16–19) To lay the groundwork for understanding how paid caregivers can play a larger role in the health and team-based health care of older adults with functional impairment, we conducted a qualitative study of paid caregivers, patients, and their proxies living in New York City. We sought to explore the health-related tasks that paid caregivers perform in the course of their routine care of patients with functional impairment and determine whether these tasks were covered in the basic training that New York State requires for paid caregivers providing Medicaid-funded care.

Methods

Participants

In order to obtain multiple perspectives on paid caregiver tasks, we conducted qualitative interviews with patients (or their proxies if patients lacked capacity to consent) and their paid caregivers.(20)

We recruited patients who were currently enrolled in an ongoing randomized controlled trial of home-based primary care in New York City.(21) Patients were eligible for this larger trial if they met the Medicare definition of homebound,(22) were ≥65 years of age, had ≥1 recent

hospitalization and impairment in ≥2 activities of daily living (bathing, grooming, dressing, toileting, feeding, and continence), and spoke English or Spanish. We then selected individuals who received ≥8 hours paid caregiver support per week and who had consistent support from a particular paid caregiver for 6 months or more. A research assistant affiliated with the larger trial sequentially approached eligible individuals (or their proxies if previous evaluation had indicated they lacked capacity to consent)to assess interest in participating in our study. If they expressed interest, the research assistant obtained permission to approach the patient's paid caregiver for participation as well. All paid caregivers of eligible patients were included regardless of source of funding (Medicaid-funded vs. private pay) or previous training.

In the course of recruitment, five older adults and one paid caregiver declined participation. Participants were only interviewed if both members of the dyad consented. Written informed consent was obtained from all participants, who were provided a $50 gift certificate as compensation for their time. A total of thirty interviews were conducted with eight patient-paid caregiver dyads and seven proxy-paid caregiver dyads.

Design and Data Collection

A multidisciplinary research team developed semi-structured interview guides that asked respondents to first describe the general care provided by the paid caregivers. Respondents were then prompted to describe recent instances when paid caregivers were present as patients experienced symptoms or health concerns, had changes in clinical status, or required hospitalization. The interview guides for the three groups covered the same content but were tailored to the specific participant type. Paid caregiver demographic and employment information was collected at the start of the interview. Patient demographic information and functional status was collected based on self-report at their enrollment in the trial and patient clinical condition information was determined by chart review.

Patients, proxies, and paid caregivers were interviewed separately in a private location of their choosing and responses were not shared. Interviews lasted 40–60 minutes and were audiotaped and professionally transcribed. This study was approved by the Icahn School of Medicine at Mount Sinai Institutional Review Board.

Analysis

Data were analyzed using thematic analysis.(23) The research team met to discuss themes and create a preliminary coding scheme to apply to all interviews. The coding scheme was iteratively revised and expanded. Two members of the research team independently applied the final coding structure to each interview and interviews were continued until thematic saturation was achieved.(23) Coding was conducted using NVivo (QSR International, Melbourne, Australia).

The research team then reviewed the New York State Home Care Curriculum(11) to determine whether the health-related tasks identified in the thematic analysis were addressed in the curriculum. While this curriculum is required only for those paid caregivers funded through Medicaid, and therefore was not mandatory for all paid caregivers included in this study, it is the only widely-available document guiding long-term paid care in New York.

This 40-hour training curriculum is composed of 12 modules each with 3–5 distinct units and includes objectives for each module and unit, the minimum amount of time required for each module or unit, and suggested teaching and evaluation methodologies. The 12 modules and the minimum time requirement for each (in hours) are as follows: Introduction to Home Care (1.5), Working Effectively with Home Care Client (3), Working with the Elderly (2), Working with Children (1), Working with People who are Mentally Ill (1), Working with People with Developmental Disabilities (1), Working with People with Physical Disabilities (1), Food Nutrition and Meal Preparation (4), Family Spending and Budgeting (0.5), Care of the Home and Personal Belongings (1.5), Safety and Injury Prevention (1.5), and Personal Care (22).

Limitations

This study was conducted with patients, proxies, and paid caregivers in New York City, NY. The health-related tasks performed by paid caregivers may differ in locales with different community resources and living arrangements. Training curricula for paid caregivers are also not standardized across the country and the formal training received by participants in this study likely differs from those working in other states.(8) Yet despite the question of generalizability, this study provides an important benchmark in understanding the health-related activities of paid caregivers and the extent to which they might be informed by formal training.

Our study focused on paid caregivers caring for homebound patients with significant functional impairment and high health care utilization who were enrolled in a clinical trial. While the health-related tasks paid caregivers perform may be less common in patients with fewer needs, the patients with serious illness like those included in this study receive disproportionally low value health care (poor quality, high cost),and innovative approaches to improving their care are essential.(24)

Finally, we only included paid caregivers, patients, and proxies whose relationships were of 6 months or more in duration. While the length of these relationships may impact paid caregiver willingness to perform health-related tasks, strong relationships are valued not only by patients and paid caregivers themselves,(14,15,25) but also those working in the long-term care field to improve paid caregiver retention and decrease turnover.(16,26)

Results

Sample Characteristics

Patient mean age was 84 years. Eighty percent were female, 47% identified as white non-Hispanic, 60% had Medicaid, and 67% lived alone. These patients experienced considerable functional impairment and depended on their caregivers for support with, on average, three basic activities of daily living and five instrumental activities of daily living. They also had multiple serious chronic illnesses (average four chronic conditions), including 40% with dementia.

The mean age of paid caregivers was 44 years and all but one were female. Thirteen percent were born in the United States, 67% had a high school education or greater, and 53%

reported English as their second language. Eighty percent worked through a licensed home care agency and 60% reported working ≥40 hours per week. Two thirds had been caring for their current client for over a year (total time working together ranged from 8 months to 11 years) and 75% had worked as a paid caregiver for ≥5 years. While all paid caregivers reported they received basic training in providing care in the home, several paid caregivers had training well beyond the New York State Home Care Curriculum including one certified nursing assistant and one registered nurse.

Health-Related Tasks Performed by Paid-Caregivers

When asked about what paid caregivers do in general, respondents most often reported functional tasks such as bathing the patient, helping with cooking, and providing reminders to take medications. However, when respondents were asked to talk about times when patients experienced health needs, patients, proxies, and paid caregivers all described paid caregivers performing a broad range of health-related tasks. We categorized paid caregiver health-related tasks into four categories, each encompassing several unique tasks (Exhibit 1): 1) address acute medical issues, 2) assist with chronic health management, 3) promote general health, and 4) promote mental health and well-being.

Paid caregivers recognized acute changes in patient condition related to conditions such as hyperglycemia, infection, arrhythmias, and skin ulcerations. As one paid caregiver described, “When I see that she’s not herself I… check if she’s OK. Then I have to decide if she’s having a bad day or if there’s really something wrong with her.” Paid caregivers then responded in a variety of ways to make sure patients got needed care such as activating emergency services or contacting family or the health care team urgently. This sometimes involved first convincing a patient to get needed care. A patient explained, “Because sometimes I don’t wanna go [to the hospital] and she’ll kinda coax me into going… she’ll be like, ‘Come on, you know you need to go.”

Similarly, paid caregivers assisted with the management of multiple chronic diseases including diabetes, constipation, and chronic pain. Many respondents described the important ways paid caregivers communicated about patients’ chronic diseases to health care providers and families. A proxy stated, “I used to go in [to the doctor] but then I realized they were asking me questions I didn’t know so I would call the aides in… they know [the patient] better than I do on a day-to-day basis.” A paid caregiver described, “The family is pretty tight, so they will call to check up on him… The main person, his nephew, apart from calling… will text me and say, ‘Give me an update. Is he okay?’”

Paid caregivers played an important role in promoting patients’ general health and advocating to have patient needs met. A paid caregiver described, “When I came and [saw] her feet I said ‘You need a podiatrist.’ And that’s how we started seeing the podiatrist.” Paid caregivers also encouraged increased physical activity and healthy eating. They provided the supervision that helped keep patients safe at home. As a patient’s proxy explained, “Now they are protecting my mom, trying to keep her safe in her own house… by watching her when she gets up and walk and stumble to the bathroom, they right behind her.”

In addition, paid caregivers supported patient's overall mental health and well-being in a variety of ways. Sometimes this support was in the form of companionship. A paid caregiver described, "Giving her a positive environment… she just needs somebody to talk to… being with somebody makes them feel better, it is really part of the job too." Others described paid caregivers working to improve their patients' depression and anxiety or contributing to their patients' global sense of security. A patient's proxy explained, "[The patient] just sees them and… I think she feels secure. When she goes to a place that she doesn't know, she can feel worried but if [the paid caregivers] are with her she's fine."

These health-related tasks were presented as a core part of the every-day paid caregiver care in the home. While the number of respondents who endorsed each task varied (Exhibit 1), respondents within the dyads were generally in agreement about the scope of paid caregiver care. The one exception to this pattern was a dyad where the patient reported her paid caregiver was intimately involved helping her manage her physical and mental well-being, while the paid caregiver described a much more circumscribed role. We did not directly assess how length of patient-paid caregiver relationships impacted the paid caregiver's performance of health-related tasks, though when asked how long it took for the patient-paid caregiver relationship to develop answered varied from "we hit it off that first day" to "a month or two" to "now at three years it is more like a family."

Many of the health-related tasks most frequently endorsed by respondents (such as recognizing acute problems, contacting family or the health care team urgently, reporting health status to health care providers, and providing companionship and person support) were included in the New York State Home Care Curriculum (Exhibit 1). The majority of these topics were covered in the 180-minute module entitled, "Working Effectively with Home Care Clients" module, which included units on Theories of Basic Human Needs, Communication and Interpersonal Skills, and Caregiver Observation, Recording, and Reporting. However, health-related tasks including monitoring chronic conditions, keeping family informed of health status, advocating to have general health needs met, and encouraging physical activity were not addressed (Exhibit 1).

Discussion

In the course of their day-to-day activities, paid caregivers went beyond assisting with activities of daily living by attending to patients' acute medical problems, assisting them with management of their chronic diseases, promoting their general health, and fostering mental health. Paid caregivers, patients, and proxies saw these health-related tasks as core features of the services they provided or received. Moreover, these findings suggest directions in which the paid caregiver workforce may be further developed to achieve better patient outcomes, allow more patients to remain in the community for longer periods of time, and realize greater value for Medicaid dollars spent on long-term care.

We found that half of the health-related tasks performed by paid caregivers were not included in the basic training for Medicaid-funded paid caregivers in New York. It appears that rather than limiting their tasks to those proscribed by their formal training, paid caregivers individualized and expand their roles to performing health-related tasks they and

their clients perceived as appropriate and necessary based on personal and professional attitudes and experience. These findings have implications for standardization of quality and regulatory oversight of this large and growing segment of the health care workforce.

The gap between paid caregivers formal training and their actual job experience raises several important questions and concerns. We know little about how the paid caregiver's individual experiences, attitudes, and role perceptions impact the care they deliver to their clients. How paid caregivers respond when confronted with challenges beyond their expertise and training has not been studied and paid caregivers may experience negative physical, social, and emotional consequences from providing care beyond what they have been trained to do.(27) Finally, and perhaps most importantly, in the absence of formal training and role definition/clarity, it is possible that paid caregivers may sometimes provide care or counsel that places patients at risk of harm. The answers to these questions require a different study, but our findings warrant additional research.

Progress toward enhancing the positive impact of paid caregivers on patient health while ensuring patient safety could start by advocating for increased focus on the health-related tasks that are already part of paid caregivers' training so that training time spent on health-related tasks matched more closely the training time spent on functional support tasks. In New York State in particular, this means enhanced paid caregiver training around recognition of changes in patient condition paired with new training in the communication skills required to effectively share this information with families and the health care team should be undertaken. Patients may also benefit from new training for paid caregivers that focuses on improving paid caregivers' understanding of the health care system, which would allow paid caregivers to better perform tasks like tracking patient appointments or advocating for patient health needs.

Progress could also be made by implementing competency-based training for paid caregivers in order to standardize the health and non-health related care they provide.(28,29) These competencies should include the core skills that underlie many of the health-related tasks described here, including interpersonal skills and good health literacy. Given that health-related tasks are often specific to patient and family needs, initial training for paid caregivers should be complemented by continuing education as well as by ongoing supervision, mentoring, monitoring for quality, and evaluation of competency attainment. When competencies are clear and agreed upon by paid caregivers, patients, families, and health professionals, the health care team can develop shared expectations for the paid caregiver role.

Two recent pilots provide evidence that paid caregivers can successfully perform the health-related tasks described in this study, potentially leading to increased paid caregiver engagement and better patient outcomes. A pilot study in which paid caregivers were trained to provide health coaching for patients with chronic illness was positively viewed by paid caregivers and resulted in improved self-care maintenance for patients.(30) In another pilot study, paid caregivers were trained to use a telephone-based reporting tool to inform the agency care manager about changes in patients' clinical status; changes were found after 2%

of all shifts, and a randomized trial is currently underway to assess the impact of these paid caregivers reports on patient hospitalizations.(31)

Other health-related tasks identified in this study may be equally amenable to incorporation into interventions where, with training, paid caregivers play an active role in improving patient health. For example, paid caregivers could report established patient goals of care to providers as patients move between health care settings or report socially isolated patients to community-based social workers for further evaluation. Paid caregivers, as part of the existing workforce currently caring for patients with functional impairment and serious illness in the community, are uniquely positioned to share in the health care of these vulnerable patients.

An important barrier to both standard, competency-based paid caregiver training and an expanded role for paid caregivers on the health care team is likely to be increased cost, including costs incurred from additional training, ongoing supervision, and increased paid caregiver wages commensurate with their additional responsibilities. Continued research in this area will facilitate the accumulation of an evidence base to determine whether the cultivation of the health-related tasks currently considered part of paid caregiver practice and the broadening of the paid caregiver scope of practice are effective and feasible.(32,33)

Conclusion

Paid caregivers perform a wide variety of health-related tasks as they care for functionally dependent, seriously ill patients in their homes. Training of paid caregivers should embrace the breadth of tasks that impact patient health and ensure paid caregivers have the skills to perform them. Clear competencies that clarify paid caregiver role may help promote paid caregiver integration with the health care team and enable systems of long-term care to capitalize on the unique role of the paid caregiver workforce.

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Exhibit 1 (table):

How Paid Caregiver Health-Related Tasks Correspond to New York State Home Care Training

Task	Curriculum Objective	Respondents Endorsing
Address Acute Medical Issues		
Recognize acute problems	"Describe the components of trained observation using the senses and know the normal."	6
Activate emergency services	"Identify situations that require immediate attention by self or EMS/911 services."	4
Convince patient to get needed emergency care	No corresponding objective.	3
Contact family or health care team urgently	"Discuss guidelines for reporting changes in client condition and/or environment."	3
Assist with Chronic Health Management		
Monitor chronic health conditions	No corresponding objective.	5
Track health needs and appointments	No corresponding objective.	3
Report health status to health care providers	"Discuss the interaction among health care team members" and "Describe observing and reporting responsibilities."	9
Keep family informed about health status	No corresponding objective.	5
Promote General Health		
Advocate to have health needs met	No corresponding objective.	6
Encourage physical activity	No corresponding objective.	6
Encourage healthy eating	"Plan well-balanced diets using the five major food groups" and "Give examples of foods that should be avoided or encouraged for a variety of modified diets."	4
Prevent injury and keep safe	"Identify common factors that contribute to accidents in the home."	5
Promote Mental Health and Well-being		
Provide companionship and personal support	"Discuss ways to establish a therapeutic relationship: planned, purposeful, built on trust."	8
Reduce worry and calm anxiety	No corresponding objective.	3
Combat depression and bring happiness	No corresponding objective.	4
Promote a global sense of security	"Discuss how human needs [ex: safety and security needs] are or can be met."	5

SOURCE: Authors analysis of interviews with patients, proxies, and paid caregivers; the New York State Home Care Curriculum