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Leveraging the Experiences of Informal Caregivers to Create Future Healthcare Workforce Options

Sara S. Phillips, BAS¹, Daiva M. Ragas, BA¹, Nadia Hajjar, MPH², Laura S. Tom, MS³, XinQi Dong, MD, MPH⁴, and Melissa A. Simon, MD, MPH^{1,5,6}

¹Department of Obstetrics & Gynecology, Northwestern University

²Access Dupage

³Institute for Public Health and Medicine, Northwestern University

⁴Institute for Healthy Aging, Rush University Medical Center

⁵Department of Preventive Medicine, Northwestern University

⁶Robert H. Lurie Comprehensive Cancer Center of Northwestern University

Abstract

Our primary objective was to gather pilot data from informal caregivers regarding the potential for a training program to assist current or past caregivers in re-entering the job market, offering a pathway to economic resilience. In an effort that could foster a sustainable and competent caregiving market to help meet the needs of an aging America, we explored whether training informal caregivers might help them transition into a paid caregiving or other health-service role. We interviewed 55 caregivers of a chronically or terminally ill family member or friend in a suburban collar county near Chicago. The interview guide addressed household economic impact of illness, emotional burden, and training program interest. We found that more than half of caregivers (56%) were interested in training to work outside the home, caring for patients in other households. Notably, 84% indicated a desire to learn more about health care and 68% reported a desire to explore job possibilities in health care. Most of the caregivers (82%) were experienced in working with an older adult who was at least 50 years old. Informal caregivers' interest in a training program to bolster their qualifications for a role within the healthcare workforce, including the option of a formal caregiver position, supports the demand for such a program.

Corresponding author: Melissa A. Simon, MD, MPH, Department of Obstetrics and Gynecology, Northwestern University, Robert H. Lurie Comprehensive Cancer Center, Northwestern University, Institute for Public Health and Medicine, Northwestern University, Department of Preventive Medicine, Northwestern University, 633 N St. Clair, Suite 1800, Chicago, IL 60611, Phone: (312) 503-8780, Fax: (312) 503-6583, m-simon2@northwestern.edu.

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Considering the need for healthcare workers to serve the growing elderly demographic and the desire of informal caregivers to find gainful employment, this informal caregiver demographic could provide the impetus to invest in informal caregiver training in the future.

Keywords

Informal Caregiver; Training and Employment; Economic Resilience; Geriatrics Workforce; Workforce Enhancement

INTRODUCTION

Informal or family caregivers, dubbed a “shadow workforce” (1), often go unnoticed even as they fill gaps in our health care system while saving the system money. Approximately 21% (44.4 million) of the U.S. adult population is an unpaid caregiver to an adult (2), providing a family member or friend with the care needed while lessening the household’s medical expenses and helping curb growing Medicare and Medicaid costs (3, 4). Notably, unpaid caregivers save the country an estimated \$450 billion each year (5). Given the extent of the unpaid caregiving workforce and the services they provide in the U.S., economic opportunity for caregivers is a critical area for research.

While studies have examined the economic and emotional burden resulting from caregiving (6–10), there exists a dearth of resources to support caregivers through the post-caregiving transition. Caregivers are often forced to reduce the hours they work to provide care, limiting their work experience. Future re-employment is complicated by the stigma and decreased experience associated with taking time off work, similar to mothers who exit the workforce to care for their children. To date, resources for caregivers have focused on emotional and economic support during caregiving, such as public policy changes for paid leave, support services, tax deductions, credits and stipends covering long-term care (11). A coordinated system offering policies that train and support individuals both during caregiving and in the post-caregiving transition are needed (1, 7). Caregivers may sustain a heavy financial burden due to reduced work hours and increased medical expenses of their loved ones (7). Informal caregivers in developing countries have demonstrated interest in a training program that would serve as an economic resilience option to help them transition from unpaid to paid caregivers (8, 9). To date, no studies of informal caregivers have unveiled the potential for such a program in the United States.

The skills and knowledge acquired through lived experiences while caring for a family member or friend could be supplemented by formal education and training to facilitate caregivers’ employment in the health care industry, and ultimately help caregivers rebound from financial hardship. The goals would include employment of experienced caregivers in the healthcare industry, facilitation of household economic resilience in the face of illness, and supply of experienced caregivers into the burgeoning caregiver and broader healthcare workforce. A training program could facilitate past informal caregivers to apply for positions as clinic or hospital administrative assistants, personalized living assistants for seniors, home health aide, community health worker, health insurance advisors, hospital operations personnel, patient navigators, or medication managers. Research supports both

the existence of a healthcare talent shortage in the U.S. and lends credence to the theoretical benefits of addressing the healthcare talent shortage by assisting past-caregivers in re-entering the workforce in the healthcare sector. Furthermore, this descriptive research highlights the financial impact caregivers face as they cope with the economic difficulties associated with illness, and the resulting challenge of achieving economic resilience. Economic resilience is defined as the ability to rebound from an economic hardship back to the pre-illness financial level (7).

Research is needed to explore informal caregivers' interest in a training program. To that end, this paper explores the financial burdens of informal caregivers and their interest in pursuing training for a paid, formal healthcare position following their informal caregiving experiences, including their interest in performing various caregiving tasks in a future paid job. Findings from our pilot study will provide insight into the feasibility of a training program to serve as an economic resilience option for informal caregivers (herein referred to as caregivers) and thereby harness the skills and knowledge gained during the caregiving experience.

METHODS

Setting & Participants

This study was conducted as a collaborative effort between Northwestern University and Access DuPage, a non-profit organization that enables more than 14,000 DuPage county residents to receive primary and specialty care services. DuPage County is a collar county near Chicago, Illinois in which the population of low-income and ethnic minority residents has risen swiftly in the last decade (12). Between 2000 and 2009, the percentage of DuPage County residents living below the federal poverty line rose by 182%. In 2013, 13% of the population was age 65 or over. (13). Between 2005 and 2007, the percent of the working age population (ages 16–64) with a disability was 7%. These disabilities did not preclude gainful employment, as 51% of those disabled were employed and 6% were unemployed but actively looking for work (14).

Our study mirrors the pilot interview studies conducted by Emanuel et al. in India and Uganda, which explored the financial burden of illness and introduced the idea of economic resilience options for caregivers in a developing setting (8, 9). We adapted these approaches to the local context of DuPage County, Illinois. Adaptation was achieved by adding questions to the interview guide regarding demographic data, computer skills, tasks performed as a caregiver, and job search strategies. This study was the first of its kind conducted in the U.S.

Through the help of our Access DuPage partners, who maintain close proximity to community members and partner organizations, we recruited a convenience sample of 55 caregivers of chronically or terminally ill family members. Our Access DuPage partners searched their files for caregivers who qualified and helped us to contact them to assess their willingness to participate. Recruitment was conducted in two phases to allow for editing of the interview guide between Phase I and Phase II. For both Phase I and Phase II eligible study participants were: (1) current or past caregivers to a family member or friend over age

18; (2) over 21 years of age; (3) legally employable in the United States; (4) English speaking; and (5) residents of DuPage County. All study protocols were approved by the Northwestern University Institutional Review Board.

Data Collection

Trained research assistants obtained written informed consent, collected demographic data, and then conducted in-person interviews. On average, the interviews lasted about 30 minutes and caregivers received a \$10 gift card for completing the interview. Caregivers were interviewed in one of two phases in this exploratory study.

Phase 1 Interviews—We conducted an extensive literature search to identify established and validated questionnaires and instruments (15, 16, 17, 8), both quantitative (closed-ended) and qualitative (open-ended), for use in our Phase 1 interview guide. Questions were chosen and adapted based on applicability to the local context of DuPage County. The final Phase 1 interview guide consisted of 99 questions (with multiple choice response options) across seven domains related to the caregivers financial need for, and interest in, a training program: Patient Personal Information (7 items), Caregiver Personal Information (11 items), Illness Information (6 items), Household and Environmental Information (9 items), Economic Information (49 items), Schooling Information (10 items), and Potential Programmatic Information (7 items).

The Phase 1 interview guide also included three qualitative, open-ended questions: “1) Is there anything else you would like to say about how this illness has affected the household’s economics? 2) Is there anything you think an outside source could do that would help alleviate the hardship caused by this illness? 3) Can you describe what things we should consider in building a training program to formally train caregivers like yourself to be able to provide care to other patients?” These open-ended questions were followed by the 14-item Caregiver Burden Assessment.

Phase 2 Interviews—After analyzing Phase 1 interview responses, it was necessary to revise the interview guide to omit items that respondents had difficulty understanding. These included questions regarding selling specific assets to help pay for medical care. Based on preliminary analyses of participants’ responses in Phase 1, we also added additional questions to the interview guide regarding caregivers’ skills gained through caregiving, ability to use computers and the internet, interest to participate in a training program, and demographic characteristics. Two questions were adapted from an MTURK survey assessing informal caregiver financial burden and interest in training programs like the one described in this paper; these two questions assessed the desire to learn more about healthcare and explore job opportunities in healthcare using a scaled response where 1=not at all and 7=very much so (7). The final Phase 2 Interview Guide comprised the 14-item Caregiver Burden Assessment, 86 closed ended questions related to the caregivers financial need for, and interest in, a training program, and five open-ended questions. The five open-ended questions were: “1) Is there anything else you would like to say about how this illness has affected the household’s finances and budget? 2) Is there anything you think an outside source could do that would help alleviate the financial hardship caused by this illness? 3)

What technical skills should we teach in a training program to formally train caregivers like yourself to be able to provide care to other patients? 4) Would you personally prefer an in-person training program, an online training program, or a mixture of the two? 5) What would be your biggest concern if you were to go through training to become a certified caregiver?”. Upon revising the interview guide, we initiated recruitment efforts in the same manner and with the same inclusion and exclusion criteria as Phase I.

Analysis

We used descriptive statistics to describe the sociodemographic characteristics of study participants, caregiver roles and responsibilities, financial burden associated with caregiving, caregivers’ interest in pursuing training for a paid, formal healthcare position following their informal caregiving experiences, and interest in performing various caregiving tasks in a future paid job. We report only descriptive statistics and did not perform significance testing; we had opted to modify the interview guide in the second phase which enabled us to explore additional realms related to skills gained through caregiving and interest in participating in a training program, but several cell sizes were inadequate for more rigorous quantitative analyses. All descriptive analyses were conducted using SPSS version 19.0 (IBM Corporation, New York, NY) and included all available data. Open-ended responses were transcribed by trained research assistants. Using ATLAS.ti qualitative data analysis software version 6.2, two authors [DR, SP] iteratively coded transcripts using inductive and deductive coding techniques. Transcripts were reviewed by authors DR and SP to identify initial coding schemes, in addition to the pre-defined themes per our interview guide. These pre-defined themes are equivalent to the domains discussed above. Schemes were compared and discussed to reach consensus on a final coding scheme. Transcripts were then independently coded, with coding discrepancies resolved by a third research team member (NH).

RESULTS

Caregiver Characteristics

The study sample included 55 caregivers; 30 caregivers participated in Phase 1 interviews and 25 caregivers participated in Phase 2 interviews (Table 1). Most caregivers were female (78%) and over 50 years of age (78%); most cared for a family member who was at least 50 years of age (82%), with 60% caring for someone over age 60. Nearly half of caregivers (46%) were the sole provider of care to the patient. However, 31% were assisted by one non-primary caregiver, often another family member, although ten households reported hiring paid help and three households reported receiving caregiving support from a volunteer. Half of primary caregivers provided between 24 and 40 hours of care per week, while 22% provided around-the-clock care. More than half of primary caregivers (60%) had cared for the patient for more than 2 years. The most frequent diagnoses among care recipients were cancer, diabetes, or a heart condition. Most households had access to medical insurance (82%).

Financial Impact

Caregivers in our study sustained heavy financial burdens. A large majority (70%) of caregivers experienced a change in work level, with 70% reporting a decrease in monthly income following the onset of the patient's illness. Over half (60%) of caregivers worked full-time before the care recipient fell ill while only 24% worked full-time after. Fifty-three percent of caregivers missed time or quit work to provide care for the patient. Of caregivers who reported a change in work level, over a third dropped out of the workforce entirely. In five households, some degree of school or training was missed, ranging from one week to one year. Forty percent of caregivers regarded the cost of the patient's illness and medical care a "great financial hardship" for the household. Several households participated in the Cash and Counseling program or enlisted the help of a local free service, such as DuPage County Senior Services.

Our qualitative data reiterated the economic impact of caregiving and illness. A common theme among the sample was that the household's financial burden "put a huge damper on everything." Notably, caregivers also expressed the desire for better access to support services, financial resources, and information. As one caregiver stated, "It's a hardship trying to find out what's out there, where you can get the money and where's the help, trying to find out where the information is...it's not readily available."

Training Interest

A majority of caregivers expressed interest in a training program to transition them into a formal caregiver position. Sixty-two percent of caregivers interviewed felt that they would be comfortable receiving training and 56% reported that they would like to receive training to care for patients in other households. Caregivers who were not comfortable receiving training or did not want to receive training to care for patients in other households reported discomfort caring for a stranger, lack of time or energy, physical limitations, emotional burden, and having other interests. Caregivers also noted the utility of trained caregivers; 64% of individuals indicated that if local trained caregivers had been available, the household would have enlisted their help. Caregivers who would not have enlisted the help of local trained caregivers if they had been available gave reasons ranging from household financial burden to household discomfort with hiring a stranger, and respect for the patient's attachment to his or her current caregiver. Nevertheless, 76% of caregivers queried postulated that outside help would have resulted in fewer economic changes for the household. Over half (60%) were open to the possibility of hiring a caregiver in their place if they were able to find a paid job to more than cover the cost of hiring a caregiver.

The majority of the participants (84%, n=21) interviewed in Phase 2 indicated having gained at least a moderate desire (at least 5 on a 7-point Likert scale), and 64% (n=16) reported a very high desire (7 on a 7-point Likert scale) to learn more about health care as a result of their caregiving responsibilities; similarly, 68% (n=17) reported at least a moderate desire, and 52% (n=13) reported a very high desire to explore job possibilities in health care.

Many respondents corroborated the need for assistance transitioning back into the workforce. Among the 25 caregivers who took part in Phase 2 interviews with questions

exploring job prospects following caregiving, nearly half (44%, n=11) anticipated that they would not be able to easily find a job in the future, once caregiving responsibilities subsided. Only 40% (n=10) had ever considered seeking employment as a paid caregiver, and 44% (n=11) did not feel it would be easy to find employment as a paid caregiver or companion of an ill or elderly person. Most participants in the Phase 2 interviews had access to and knew how to use a computer with Internet (88%, n=22). About half indicated that they would search the Internet to look for employment opportunities as a paid caregiver and one in five caregivers reported that they would connect with a health care services organization or utilize their social network for job opportunities.

Table 2 presents Phase 2 results of the tasks caregivers performed while caregiving as well as the tasks they would be willing to perform in a paid job. A majority of caregivers (72%, n=18) who administered medicine while caregiving informally would be willing to do so in the future. Similarly, although less than half of caregivers administered IV's and injections, assisted with breathing aides and bedpans, or operated hospital beds, a majority of caregivers noted that they would be willing to perform each of these medical tasks. Additionally, many caregivers reported assisting with management of the patient's bills, taxes, and other paperwork (68%, n=17).

DISCUSSION

We explore caregivers' financial burdens and accumulated caregiving experiences that could translate to future health care workforce positions, with findings suggesting caregiver need for, and interest in participating in a training program that would leverage their gained skills and knowledge to transition back into the workforce as paid caregivers. Existing literature demonstrates both theoretical and practical support for creating a training program that could help meet the need of a healthcare talent shortage, including findings from two previous pilot studies in a developing setting in Uganda and India (8, 9). Research was needed to underscore the potential of economic resilience options for caregivers in consideration of the illness-poverty cycle outside of developing settings. The findings of the present study suggest that caregivers in the U.S. are also interested in pursuing a training program to care for others in a paid capacity and might further wish to pursue health care career options at large – lending support to the creation of training programs directed towards various paid positions within the healthcare sector for interested caregivers.

Our interviews revealed the heavy financial burdens borne by caregivers and households and the need for programs toward economic resilience. Almost half of caregivers considered the cost of illness and medical care a great financial hardship, echoing previous literature documenting the financial burden of illness at large (7, 9, 18) and the financial burden experienced by caregivers in particular (5). Time away from the workforce further compounds this burden as re-entry is difficult because of lost work experience and the time passed since previous work. Nationally, seven out of ten caregivers change their hours, switch jobs, quit work, take a break, or make other changes to accommodate their caregiving responsibilities (19). Caregivers in our study similarly experienced disruptions to their employment, as a majority changed their working status and lost income following the illness of their family member. Furthermore, nearly half of caregivers in Phase 2 (n=11)

anticipated not being able to easily find a job in the future once their caregiving responsibilities subside. This finding highlights the difficulty caregivers expect in transitioning to a paid job following their informal work.

Many caregivers in Phase II interviews expressed the desire to explore job possibilities in health care at large. Considering the range of skills acquired by caregivers informally, health care employment opportunities outside of caregiving support the creation of a training program that would fit the diverse interests and experiences of caregivers. By providing various modules to train informal caregivers, caregivers could train to apply for a range of job opportunities in the healthcare sector.

Literature demonstrates that caregivers' involvement in medical care catapults them into a paramedical role whereby they serve as a "cross-institutional link" between various medical institutions (1). The majority of caregivers reported helping their loved ones with financial and organizational tasks, suggesting that caregivers could apply practical skills learned through caregiving to a wide range of roles in health care. Over half of caregivers were interested in performing skilled medical tasks including aiding with IVs, injections, pain management, using a bedpan with a frail patient, operating a hospital bed, and breathing aids. Given that less than half were experienced in these tasks as informal caregivers, creating a training program that would include practical medical skills training sessions would fill an important gap in their knowledge. Caregivers' lack of experience in these medical areas combined with their desire to perform such tasks underscores the desirability of a program providing skill building in preparation for employment in the healthcare sector. Further research is needed to illustrate caregivers' engagement in the health care system as well as how they are trained and supported to conduct medical tasks (20).

We acknowledge that such a training program would not be suitable or appealing to some caregivers, including those who continue to work full-time while caregiving. As of 2011, more than one in six full or part-time workers in America were also caregivers (21). This subsection of caregivers requires more socio-emotional support in balancing their dual duties rather than resources in finding employment after caregiving (22).

Study limitations must be noted. First, our interview guide was assembled from a literature review of existing instruments and adapted to a caregiving population; future psychometric testing of our data collection instruments may be needed to speak to the validity of our study findings. Moreover, as an exploratory, pilot study using a small convenience sample of English-speaking caregivers recruited with assistance from our DuPage County community partners, study findings should be interpreted with caution. Further research with a larger sample size of caregivers nationally in racially and ethnically diverse communities, and with more in-depth statistical analyses, is needed to substantiate a case for implementing caregiver training programs in other areas in the U.S. Additionally, collecting and examining additional contextual characteristics, such as whether or not caregivers lived with the care-receivers and the care demands associated with patients' conditions, is needed to paint a more comprehensive picture of caregiver burden and skills that can be leveraged in formal caregiving settings. Furthermore, many participants chose not to share information regarding income status, an important piece of information which could not be analyzed. Nevertheless,

this study provides groundwork for future exploration in the development of training programs for transitioning informal caregivers into the healthcare workforce.

Conclusion

Findings from this study underscore the financial burden of caregivers and a pressing need for resources to educate caregivers both during and following caregiving. Furthermore, results support creating of training programs for interested caregivers to provide formal education in preparation for a variety of job opportunities within the healthcare sector, leveraging the skills caregivers gain informally, and helping to transform often emotionally or physically challenging caregiving experiences into a personal asset (7). This research provides impetus to pursue funding and policies in support of building such a training program for informal caregivers that could facilitate economic resilience and simultaneously help serve the needs of the growing geriatric demographic in America.

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Table 1Sample characteristics (*N*=55)

Caregivers	<i>n</i>	(%)
Age		
31–40	1	(1.8)
41–50	11	(20.0)
51–60	24	(43.6)
61	19	(34.5)
Gender		
Female	43	(78.2)
Male	12	(21.8)
Education		
5–8 years	1	(1.8)
9–12 years	8	(14.5)
13–16 years	41	(74.5)
17+ years	5	(9.1)
Marital status		
Divorced	8	(14.5)
Married	32	(58.2)
Separated	3	(5.5)
Single, never married	5	(9.1)
Widowed	7	(12.7)
Relationship to care recipient		
Daughter	15	(27.3)
Husband	7	(12.7)
Mother	5	(9.1)
Sister	4	(7.3)
Wife	11	(20.0)
Other *	12	(21.8)
Ethnicity (25 responses)		
Hispanic or Latino	2	(8.0)
Not Hispanic or Latino	23	(92.0)
Race (25 responses)		
African American	2	(8.0)
Asian or Pacific Islander	1	(4.0)
Mixed race	1	(4.0)
White	21	(84.0)
Primary language (25 responses)		
English	21	(84.0)
Other *	4	(16.0)
Care Recipients	<i>n</i>	%

Caregivers	<i>n</i>	(%)
Age		
50	10	(18.2)
51–60	12	(21.8)
61	33	(60.0)
Gender		
Female	32	(58.2)
Male	23	(41.8)
Ethnicity (25 responses)		
Hispanic or Latino	3	(12.0)
Not Hispanic or Latino	22	(88.0)
Race (25 responses)		
African American	1	(4.0)
Asian or Pacific Islander	1	(4.0)
Mixed race	1	(4.0)
White	22	(88.0)
Primary language (25 responses)		
English	22	(88.0)
Other *	3	(12.0)
Diagnosis		
Alzheimer's/Dementia	8	(14.5)
Arthritis	3	(5.5)
Cancer	15	(27.3)
Diabetes	11	(20.0)
Epilepsy	5	(9.1)
Heart condition	11	(20.0)
Mental illness *	9	(16.4)
Physical disability (general)	7	(12.7)
Stroke	5	(9.1)
Other *	10	(18.2)
Insurance status		
Access to insurance	45	(81.8)
Enrolled in insurance	39	(70.9)
Recipient of Medicare (25 responses)	16	(64.0)
Recipient of Medicaid (25 responses)	5	(20.0)

* Relationship to care recipient under Caregiver includes: Aunt, cousin, daughter-in-law, father, friend, girlfriend, granddaughter, niece, son, son-in-law

* Other under Primary Language of Caregiver includes: Filipino, Greek, Polish, Spanish

* Other under Primary Language of Care Recipient includes: Filipino, Spanish

* Mental illness under Diagnosis includes: Anxiety, depression, bipolar

* Other under Diagnosis includes: Brain tumor, cerebral palsy, Down syndrome, Multiple Sclerosis, Pancreatitis, Parkinson's, Spinal Cord Injury

Table 2

Tasks performed versus tasks willing to perform in future paid job (Phase 2, n=25)

Task	Performed n (%)	Willing to perform n (%)
Assisting shower/bathe	17 (68.0)	14 (56.0)
Assisting toileting	14 (56.0)	16 (64.0)
Administering IV	4 (16.0)	15 (60.0)
Monitoring blood sugar	10 (40.0)	16 (64.0)
Lifting/moving patient	18 (72.0)	17 (68.0)
Cooking & serving food	24 (96.0)	16 (64.0)
Cleaning	22 (88.0)	16 (64.0)
Cleaning wounds	16 (64.0)	16 (64.0)
Administering medicine	21 (84.0)	18 (72.0)
Assisting with physical therapy/exercise	16 (64.0)	17 (68.0)
Injections	6 (24.0)	14 (56.0)
Breathing Aides (BiPAP, ventilator)	7 (28.0)	18 (72.0)
Pain management (IV or oral)	12 (48.0)	18 (72.0)
Using a bedpan with a frail patient	6 (24.0)	16 (64.0)
Operating a hospital bed	10 (40.0)	18 (72.0)
Oral care, skin care, or other hygienic care	16 (64.0)	17 (68.0)