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Voices of Informal Caregivers and Community Stakeholders: Whether and How to Develop an Informal Caregiver Training Program

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Abstract

Our primary objective was to gather pilot data from caregivers and stakeholders to guide the development of a training program to assist informal caregivers in re-entering the job market. The goal of the program would be to help caregivers rebound from their incurred economic burden by transitioning into a paid caregiving or other health-service role. The economic burden they bear often necessitates a return to the workforce following caregiving; yet the act of returning is complicated by an extended absence from the workforce and a lack of experience in other verifiably skilled and paid roles. We interviewed 37 stakeholders and 25 caregivers of a chronically or terminally ill family member or friend in a suburban collar county close to Chicago. The interview questions considered the economic impact of illness, as well as the feasibility, logistics, and options of a training program for caregivers. Our data gathered from caregivers and leaders within this community support the acceptability of such a training program for informal caregivers, and also provide practical advice for development and implementation related to training cost, length, content, and instructional practices.

Keywords

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

Introduction

Informal caregivers assume many different responsibilities in providing care support for ill or elderly family members. They coordinate logistics, care management, advocacy, medical interpretation, and medical decision-making, performing many functions that direct-care workers perform on a paid basis [1, 2, 3]. More effective education, training and support for direct-care workers was one of the major recommendations made by the Institute of Medicine in its 2008 report, *Retooling for an Aging America: Building the Health Care Workforce* [4].

Informal caregiver training currently focuses on the immediate caregiving situation and not the long term post bereavement re-entry into the workforce. Few programs exist to support caregivers as they transition post-caregiving. Many state and federal resources are directed towards aiding caregivers, including the Cash and Counseling Program, Adult Day Services, Caregiver Resource Centers, Caregiver Support Groups, and Respite Care. However, caregivers attempting to re-enter the job market lack programs and support services to aid their job search or capitalize upon their skills. Over a quarter of Americans (28.5%) serve as informal caregivers [5] and re-entry into the workforce is often desired and necessary for those who experience economic hardship as a result of the cost of illness and the opportunity cost of foregoing paid employment. Indeed, recent studies of multiple patient populations all underscore the economic cost of the informal caregivers experience [6, 7, 8]. Programs to support post-caregiver workforce re-entry are critical, but what might a training program to enable caregivers to enter the paid healthcare workforce and counteract the economic burden of caregiving look like?

In a prior study, we laid the theoretical foundation to support the case for an economic resilience option for informal caregivers, examining whether the human capital investment of training informal caregivers for related health care professions could be captured with supplemental training to allow them entry into health industry employment [9]. We also assessed economic impact of illness on caregivers, their interest in seeking a paid healthcare job, and interest in participating in a formal training program. We found that the majority of caregivers were interested in training to work outside the home caring for patients in other households and wished to explore job possibilities in healthcare [10]. While our prior research supports the theoretical and potential demand for such a program, in this paper, we explore caregiver and community stakeholders' recommendations on the development, content, and practical implementation details of such a training program for informal caregivers. Using qualitative interviews, we also examine stakeholders' perspectives on the feasibility of such a program given community resources and local client willingness to pay for a caregiver. These findings and input from both participant and sponsorship perspectives will guide the development of a training program toward economic resilience for informal caregivers.

Methods

Design and Setting

This qualitative 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 [11]. Between 2000 and 2009, the percentage of DuPage County residents living below the federal poverty line rose by 182% [12].

Data Collection

Through the help of our Access DuPage partners, we recruited a convenience sample of 25 caregivers of chronically or terminally ill family members and 37 community stakeholders. Caregivers eligible for this qualitative study were at least 21 years of age, current or past caregivers to a family member or friend, legally employable in the U.S., English-speaking, and residents of DuPage County, Illinois. Eligible community stakeholders were at least 21 years of age, English-speaking, and trainers/educators, human resources professionals, or former caregivers currently working in health care in DuPage County. Trained research assistants obtained written informed consent, collected demographic data, and then conducted in-person interviews. Each interview lasted about 30 minutes and participants received a \$10 gift card for completing the interview. All study protocols were approved by the Northwestern University Institutional Review Board.

Caregiver Interviews

Caregivers were asked a series of 86 closed ended questions and five open-ended questions across seven domains: 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 open-ended items). These questions in the interview guide were adapted from established and validated questionnaires [13, 14, 15, 16]. Questions were chosen and adapted based on applicability to the local context of DuPage County. For the purposes of this analysis, we focused on caregivers' data from the Caregiver Personal Information and Potential Programmatic Information domains. Findings from data collected in other domains are published elsewhere [10].

Stakeholder Interviews

Interviews with community stakeholders employed in a health care related capacity in DuPage County were conducted using an interview guide that comprised seven items collecting demographic/personal data and 11 open-ended items regarding perceptions of the economic impact of illness, the current caregiving and caregiver training market in DuPage County, interest in and acceptability of a training program among families in DuPage County, and potential programmatic information, including suggestions and concerns for developing a program.

Analysis

We used descriptive statistics to describe the sociodemographic characteristics of study participants and their suggested target components/skills for a potential formal caregiver training program. Open-ended responses regarding recommendations for programmatic development and implementation were transcribed by trained research assistants. Using ATLAS.ti qualitative data analysis software version 6.2, two authors [DR, SP] iteratively coded transcripts of open-ended items 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. 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

Sample Characteristics

Participant characteristics are presented in Table 1. Of 25 caregivers interviewed, all were over 40 years old and almost half were over the age of 61 (n=12; 48.0%). About three-fourths of caregivers were female (n=19; 76.0%) and had completed at least some college-level education (n=18; 72.0%). Sixty-eight percent (n=17) of caregivers cared for a family member or friend who was over 60 years of age. The 37 community stakeholders interviewed worked for local health care-affiliated organizations within DuPage County. Nearly half of these stakeholders were between the ages of 51 and 60 (n=17; 45.9%), and more than half held a master's degree or the equivalent (n=24; 64.9%). The majority of stakeholders were females (n=33; 89.2%). Sixty percent of the community stakeholders interviewed were also caregivers to a family member or friend, with 35% spending more than 10 hours a week caring for an elderly person.

Potential for Formal Training Options

Caregivers and community stakeholders commented on the difficulty of transitioning back into the workforce after caregiving. As one stakeholder noted, "...worst thing is when people give up their life during caregiving leaving a blank on their resume." Stakeholders also commented however that the current availability for both caregiver training and the provision of in-home care is limited by inadequate resources, attention, and funding. One community stakeholder indicated, for example, "A lot of people go for like a CNA license at the local community colleges, or maybe hospitals offer first aid classes that you can go to, but there isn't much. You'd have to pay to go to some kind of a school." Most were supportive of the idea of creating a training program for informal family caregivers. As one stakeholder stated, "It would be wonderful as a way to give people opportunity to earn gainful employment...to take something unwillingly forced into and allow it to turn positive." However, while 75.7% of stakeholders (n=28) believed that families in DuPage County would be amenable to accepting care from locally trained, non-family caregivers, some cautioned that local families would not easily trust an outsider. As one stakeholder noted, "unless [families] really need help they avoid bringing in unknown person."

Programmatic Suggestions

After describing their perspectives on the potential of a formal training program, caregivers and stakeholders provided programmatic suggestions related to training cost, length, content, and instructional practices. Stakeholders additionally voiced their concerns for program development and shared some additional suggestions and considerations.

Cost

Cost of a training program was a major concern for caregivers. When asked about practicalities of participating in a training program, caregivers who were interested in training favored paying the lowest cost possible for training; several caregivers indicated that training should be free of charge while others were willing to pay up to \$100 dollars. Similarly, stakeholders indicated that a training program should cost caregivers as little as possible and should cost no more than similar programs for CNA, home health aide, and other certifications.

Length

Caregivers noted they were willing to spend, on average, 30–60 hours total and 10–30 hours per week training. Community stakeholders recommended that a training program for family caregivers to become paid caregivers should be similar in length to existing health care training programs offered through community colleges or local and national organizations and allow for some flexibility for non-traditional students. They suggested that a training program should last one to two full days, at minimum, and a few months to one year or one to three semesters at most. Alternatively, some community stakeholders felt that training could take place in four to six sessions or within the span of a few weeks. Some community stakeholders indicated that while long-term training is preferable, short-term training may be more realistic considering time and cost constraints. Others noted that continuing education components would be important components: “Certainly I don’t think that it would be over a period of years, because I think that some of the preliminary skills are fairly rudimentary, but I think that that continuing education component would be important.”

Content

All caregivers were asked to identify important topics to cover and skills to instill within a training program for family caregivers to be able to provide care to other patients. Social and emotional skills (spanning “patience”, “emotional understanding”, “learning to relate and counsel”, “communication”, “compassion”, “people skills”, and “empathy”) and knowledge of disease processes and conditions (including “signs and symptoms”), were the most frequently reported non-tangible skills. Transferring the patient and basic activities of daily living (ADLs), including bathing, dressing, feeding, personal hygiene, and toileting, were the most frequently cited technical skills. Table 2 lists suggested training components by frequency.

Community stakeholders were also asked to identify important topics to cover and targeted skills to develop within a training program for family caregivers to be able to provide formal, paid care to other patients. As demonstrated in Table 2, stakeholders’ most frequently suggested non-technical skills to build upon in a training program were social and

emotional skills (such as empathy, disability etiquette training, boundaries between friend and caregiver, how to recognize abuse, understanding the family) and cultural competence. Patient advocacy was identified as an important skill as well, as summarized by one stakeholder: “Sometimes a caregiver is asked to be the eyes and ears for the physician or the medical community, meaning that they’re going to relay the information that the patient may not be able to relay, but also they need to advocate for the patient in terms of needs they might see for themselves.” Basic ADLs, transferring, and basic medical skills including CPR and first-aid were the most cited technical skills/components for formal caregivers to develop within a training program. Another stakeholder noted that caregivers should be taught skills to seek out resources: “I think that they probably need some ongoing resources so that they have someone or some ones to whom they can come with questions, and also maybe some peer support to learn how to sort of be ever-progressing toward being the best caregiver they can be.”

Instructional Practices

Other than cost, caregivers’ major concerns about participating in a training program revolved around proximity of location. Caregivers preferred that training take place in the classroom. As one caregiver noted, “it needs to be in person because seeing things in person is the only way to do it - there’s no substitute for one on one.” Some caregivers further suggested that training could be offered as a blend of online coursework with in-person classroom training that includes labs, workshops, and practical exams. Many community stakeholders (n=29; 78.3%) identified community colleges as an ideal location for training, and some stakeholders additionally identified social service organizations as potential venues for training (n=15; 40.5%). Only four stakeholders suggested that training could take place within home health agencies. Nearly half of stakeholders (n=17; 45.9%) recommended that a potential program should be taught in-person in the classroom, while 35% indicated that training should be conducted in a mixed format by blending in-person lectures and hands-on training with supplemental web-based self-study and coursework.

Stakeholders emphasized that flexibility would be a key component of a training program for informal caregivers, many of whom may be non-traditional learners. For example, one stakeholder stated, “...one of the questions would be how to create a training that was accessible to people who may need to work while they are completing the training so I think that an eye to the flexibility of a non-traditional student would be important...So that would mean that evening and weekend and flex learning is going to be an important piece.” Additionally, 64.8% of stakeholders validated the importance of including continuing education components.

Stakeholders’ Program Concerns and Suggestions

Stakeholders also described additional concerns for the development of a program. The most common concerns raised by stakeholders included screening candidates, identifying program advocates and financial support, and managing vulnerability issues. For example, stakeholders raised concerns about targeting appropriate candidates:

“If you create incentives financially for someone to do something that they may not in fact be the ideal candidate to do, you expose those vulnerable individuals that are

going to receive care to some level of risk [...] the challenge is how to bring the right people into the program and how to discern those folks that might not be the right people to do it so that we don't inadvertently support doing harm to someone who is very vulnerable. 'Cause caregiving by its nature has a lot of power dynamics that shouldn't be under anticipated." (P.8)

Several stakeholders stressed that a training program should have a screening process to verify potential candidates' background, suitability for and interest in training, and emotional and mental health. Stakeholders further voiced concerns related to preventing elder abuse and facilitating an environment of trust among, or gaining the trust of local families who may hire trained caregivers. Some recommended that a training program should be regulated by a state governing body.

Stakeholders additionally discussed advocacy and financial support for program development, stressing that securing reliable funding would be a major concern. Participants most commonly identified the local health department and its affiliates, large national special interest organizations, and local social service organizations for families and seniors as the best advocates for a potential training program for informal caregivers. They identified local, state, and federal governing bodies/agencies and private institutions or organizations offering grants as potential funding sources to support a formal caregiver training program.

Some additional concerns raised for program development included the cost of training for educators and candidates, program accreditation and certification versus licensure, quality control and monitoring, and career placement. Some stakeholders suggested that a new caregiver training program should consult CNA, health aide, or similar programs to build upon existing training models. Several community stakeholders also recommended that respite options should be provided for current caregivers who choose to pursue training. As one stakeholder noted, "If they're [currently] in the role of a caregiver, going to training is nearly impossible. You have a hard time getting them to come unless you also provide respite care." Many community stakeholders echoed this sentiment, stressing that respite opportunities should be provided alongside a training program.

Finally, community stakeholders indicated that advertisement and marketing of a training program for family caregivers would be key to enrollment success: "I think a website would be helpful. I think that materials could be available in offices that serve the chronically ill or diminished or some way or another. I could think of all kinds of ways to try to get the word out about it."

Discussion

Interest from caregivers and stakeholders warrants further exploration and development of a training program to help informal caregivers enter the paid healthcare workforce. Such a program could help connect family caregivers to training and certification for various health care employment options, ranging from the provision of direct care to social services and administrative support to the elderly, sick, or disabled. Findings from this qualitative study

illuminate caregiver and community stakeholders' recommendations on the development, content, and implementation of such a training program.

Our findings highlight the financial and time barriers caregivers face in engaging in training; a challenge that provides a parameter for program implementation. Caregivers also expressed preferences for a training program to be locally accessible, inexpensive or free, and offer both online and in-person training options. Furthermore, 62% of caregivers expressed how social and emotional skill-building should be critical component of the training content. These social and emotional skills included patience, communication, social networking, people skills, compassion, and empathy. Fostering social and emotional skill-building in an online format without in-person sessions might be a challenge, but innovations in distance education and technologies for fostering online learning communities may make this a possibility [17]. The second most popular content suggestion was to train caregivers how to successfully transfer patients. Thirdly, caregivers also requested knowledge of disease processes and conditions, which included signs and symptoms.

The parameters of a program envisioned by the caregivers and stakeholders we interviewed are somewhat unique among healthcare training programs. Participants were willing to pay \$100 and spend 30–60 hours total on a training program. In contrast, the average certified nursing assistant course for in-state students costs \$71.50 dollars per credit hour and requires 27–32 hours to complete. Therefore, the average CNA course costs \$1930.50–\$2288.00 before other student fees [18]. Therefore, if we can offer a healthcare training program for \$100, we will provide a distinct financial advantage over CNA courses. Fortunately, many online resources, including massive open online courses (MOOCs), provide for content for free and can be leveraged as supplementary resources for a caregiver training program. For example, existing MOOCs platforms such as Coursera, edX, and Khan Academy may be utilized not only as tools for gaining knowledge about disease processes, but also for skill building [19, 20, 21]. The “Career 911: Your Future Job in Medicine and Healthcare” MOOC is a free resource that can help informal caregivers explore career options and impart strategies for entry into the formal healthcare workforce – from resume and cover letter writing to networking and professional communications [22].

Limitations of our study include our convenience sample of caregivers and stakeholders within one county of Chicago. Further research involving more caregivers and stakeholders nationally may needed to generalize findings to communities outside of DuPage County. In addition, most of the caregivers interviewed were older and many had some college as their highest level of educational attainment. It's possible that caregivers recommendations may vary based on their background and experiences. However, recommendations caregivers made regarding the low cost and low time commitments of a potential program are likely echoed among younger and less educated caregivers, as these groups may have tight time constraints and poor financial reserve. Another limitation is the lack of specific health care roles discussed when considering programmatic content. The range of responses, however, indicates that caregivers and stakeholders foresee the feasibility of a diversity of health care roles and responsibilities.

Based on our findings, next steps for developing a training program for informal caregivers include establishing a physical location for offering classes, building an online platform, recruiting qualified teachers, developing the core content of the various job tracks, and advertising the program to local informal caregivers. Our stakeholder interviewees are leaders that could continue to inform the programmatic development phase. Their input as both community and caregiver experts is one of the strengths of our study. We would start by drafting the core content curriculum, and subsequently reconnecting with these community leaders as well as education specialists to gather their input on the educational content. This training program for informal caregivers would not only help provide economic resilience for caregivers during the transition back into the workforce, but would also meet the growing demand for caregivers and allied health professions. Many patients need care, but either do not want or do not have a friend or relative to provide the services. The Bureau of Labor Statistics projects that the number of personal care aides will grow by 48.8% between 2012 and 2022 [23]. This growing demand demonstrates a job market opportunity for past caregivers with transferable skills. Our paper supports pilot implementation of such a training program for informal caregivers in a community like DuPage.

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Table 1

Sample characteristics

Caregivers (N=25)		Stakeholders (N=37)	
<i>n</i>	%	<i>n</i>	%
Age			
21–30	-	2	5.4%
31–40	-	4	10.8%
41–50	5	7	18.9%
51–60	8	17	45.9%
61	12	7	18.9%
Gender			
Female	19	33	89.2%
Male	6	4	10.8%
Education			
5–8 years	1	-	-
9–12 years	3	1	2.7%
13–16 years	18	12	32.4%
17+ years	3	24	64.9%

Table 2

Suggested target components/skills for a potential formal caregiver training program

Components	Responses (freq.)	
	Caregivers (n=25)	Stakeholders (n=37)
* Social & emotional skills	15	12
+ Transferring patient	13	10
+ Basic ADLs	10	13
* Knowledge of medical conditions & processes	8	9
+ Administering medications & injections	7	8
* Decision-making & problem solving	8	6
+ Basic medical skills (CPR/first-aid)	4	10
* Cultural competence	2	10
* Communication & patient advocacy	2	6
* Caregiver self-care & coping	3	4
+ Physical & functional rehabilitation (PT/OT)	6	1
+ Phlebotomy	5	1
+ Technical safety	2	3
+ Respiratory care	3	1
* Resource utilization	1	3
* Mental health knowledge/awareness	2	1
* Financial & legal management	1	2
+ Catheterization	2	0

Notes:

+ denotes technical skill,

* denotes intangible skill