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Direct Caregiving in Older Adults: How Systems of Care Perpetuate the Grand Challenges and
What Social Workers Can Do about It

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Abstract

Direct care workers (DCWs) provide personal care, emotional support, and companionship, helping older adults maintain quality lives (Phillips, 2016). DCWs earn low wages, have little training, and experience high turnover rates (Dawson, 2016). While the demand for DCWs grows, real wages continue to fall. Undervaluing DCWs threatens the continuity and quality of care older adults receive (Espinosa, 2017). Through the social work grand challenges lens, this paper discusses two qualitative studies, in home care (n=24) and in nursing homes (n=23) that demonstrate that while DCWs help *advance long and productive lives*, they experience *extreme economic inequality* and *lack equal opportunity and justice*. We conclude with a discussion of social work's role in advancing opportunity and justice.

Keywords:

Low wage workers, direct care, organizational structure, disempowerment, social work grand challenges

Introduction

Long term services and supports are provided in the community or in institutional settings to older adults and persons with disabilities who receive the majority of their daily care from a direct care workforce that is paid low wages and is often structurally disempowered by the agencies for whom they work. While titles vary, direct care workers assist individuals with activities of daily living (ADLs) such as bathing, dressing, grooming, and toileting. In home care, tasks may also include instrumental activities of daily living (IADLs) such as meal preparation, laundry, and light housekeeping.

These essential services allow some people with physical disabilities to remain in the community in good health. In nursing homes these services also maintain health and ensure that individuals remain clean and comfortable. In both settings direct care workers face the competing demands of care recipients, families, and agencies and have little say in day-to-day routines. Since caregiving is a 24 hour/day industry and home care clients may go in and out of the hospital or die, workers also face unpredictable schedule changes. Low wages make these workers less able to absorb these changes and more vulnerable in other areas of life (Kusmaul & Waldrop, 2015). As a result, the long term care industry faces severe worker shortages and ongoing issues with recruitment and retention. This lack of a sufficient workforce threatens the health of all individuals in need of care and risks the ability of homebound individuals to remain in the community.

This article will discuss findings from two studies **conducted by the authors**, one with home care workers **(led by second author)** and one with certified nursing assistants in nursing homes **(led by first author)**, the challenges of low-wage work, structures that maintain challenging conditions for low-wage workers, and implications for micro and macro social work.

Background

The Direct Care Workforce

Direct care workers (DCWs) in the US work in multiple settings, including home care, nursing homes, assisted living, group homes, and hospitals. According to the Paraprofessional Healthcare Institute (PHI) there were 4.3 million direct care workers in the United States in 2017 (Espinosa, 2018). Home care is one of the fastest growing occupations of all industries, expected to add more than one million jobs between 2016 and 2026 (Espinosa, 2018), in addition to job vacancies created by turnover. Turnover is a major concern: up to one in two direct care workers will leave a job in any given year, often citing low wages as the reason (Espinosa, 2017).

The Bureau of Labor Statistics divides DCWs into three groups (PHI, 2018). Personal care aides (personal care attendant, personal assistant, or direct support professional) work in the home, assisting with ADLs, meal preparation, housekeeping, and medication management. They may also help younger disabled clients navigate the community. Clients may hire a personal care aide through an agency or directly. Home health aides also assist with ADLs, but may provide wound care, blood pressure monitoring, and range-of-motion exercises under the supervision of licensed nurses or therapists. Nursing assistants (Certified Nursing Assistant, Certified Nursing Aide, Nursing Attendant, Nursing Aide, or Nursing Care Attendant) perform similar tasks to personal care aides and home health aides, in settings such as assisted living or nursing homes. Licensure and training requirements vary by state. In many states, certified nursing assistants can also work in the home performing the same tasks as home health aides (PHI, 2018).

Direct Care Workers: Social Justice Issues

Direct care worker wages, titles, and roles vary significantly by state and payer source. In general, wages are lowest for home care workers, with a median wage of \$11.03 per hour in

2016 (Espinosa, 2018). Home care workers (HCWs) face challenges with getting enough hours, often needing to take clients from multiple agencies to make ends meet (Butler, 2015). Since home care workers are also responsible for their own transportation between clients; the cost of car ownership and gas is often an issue, particularly in rural areas, which causes workers to be selective about the clients they will accept (Butler, 2015). Home care workers who provide end-of-life care, such as hospice or palliative care, often have the most contact with patients and/or families of any of the members of the interdisciplinary team. However, DCWs often receive little respect and are not considered part of the medical team (Osterman, 2019). Through providing physical care, they develop emotional connections with patients and caregivers (Wholihan & Anderson, 2013). Yet following the death of a client, agencies provide little support to help staff cope (Boerner et al., 2016) and DCWs are expected to work with new clients immediately following client death, with little or no time to grieve (Ghesquiere & Bagaajav, 2018; Staley et al., 2015).

One survey of home care workers (n=80) and certified nursing assistants (n=140) found that DCWs experience grief symptoms similar to family caregivers (Boerner et al., 2015). Further, a study of 78 home health aides found decreased job satisfaction and less opportunity to process their grief in agencies with restrictive or no contact policies (Boerner et al., 2016). With a high turnover rate for DCWs, identifying and implementing supportive policies could minimize the disruptions of care for patients and increase stability of the DCW position. Despite these emotional connections, work structures maximize productivity, not continuity of care (Wholihan & Anderson, 2013). When care is disrupted, agency policy may be unclear or prohibit follow-up contact with families post-discharge or care transition (Boerner et al., 2016; Staley et al., 2015). The impact of limited or unclear support with care transitions is not well understood, but home

health aides who feel supported may be more likely to remain at their jobs offering greater consistency in care for their clients (Gleason et al., 2016).

In nursing homes, direct care is provided by certified nursing assistants (CNAs) whose training is regulated by federal minimum standards that states are able to supplement if desired (Kusmaul, 2016). Facility based workers face fewer challenges with inconsistent hours than home care workers do. Three quarters of nursing home aides work full time, as compared to less than two thirds of home care workers (Espinosa, 2018). Nursing assistants are generally better paid than home care workers, with median wages of \$12.84 per hour in 2016 though these wages have remained stagnant over the past decade (Espinosa, 2018). Osterman (2019) uses data from the 2016 American Community Survey to demonstrate that DCWs are overwhelming women and disproportionately persons of color with 32% being Black, 17% are Hispanic, and 6% are Asian. In addition, nearly one in four direct care workers are immigrants (Espinosa, 2018). A culture that supports low and stagnant wages, inconsistent hours, and marginalization, limits upward progress to higher wage positions or leadership opportunities (Osterman, 2019).

Older Adults and the Need for Direct Care Workers

Older adults in the community are often cared for by family members and for these families, the financial and emotional cost of caregiving is a large consideration (Tang & Lee, 2011). When family members are unable to provide care, or as a supplement to family care, home care professionals are employed. By 2030, more than 20% of the US population will be over the age of 65 and DCWs will be a key component for individuals to stay at home (Phillips, 2016). Paid caregivers can significantly improve the lives of older adults and their families (Spillman, 2016) by preventing institutionalization, meeting daily care needs, providing family caregivers with respite and relief, and providing companionship and socialization. Yet the

unstable workforce leads to uncertainty in care which is challenging for older adults and their families (Dawson, 2016). Some family caregivers rely on professional care to be able to work themselves. Almost 2/3 of American workers have taken time off to care for a family member, and very few have access to paid leave (Greenfield et al., 2019).

For all of the reasons mentioned above, DCWs provide intimate and personal care for older adults when family members are unable to. Through this intimate care they develop close interpersonal relationships with their clients, a closeness that is unrecognized by organizational structures. Ultimately this closeness contributes to their grief experience when a patient dies (Boerner et al., 2015).

Social Work Grand Challenges: Understanding Systems of Care

In 2012, the American Academy for Social Work and Social Welfare (AASWSW) identified grand challenges for social work, “deeply significant problem[s] widely recognized by the public whose solution is within our grasp in the next decade, given concentrated scientific and practical attention” (Padilla & Fong, 2016, p. 133). The twelve grand challenges address social problems at all ages and all levels of society. The social problems facing the direct care workforce cut across grand challenges. We focus on challenges of “Reduc[ing] Extreme Economic Inequality and Achiev[ing] Equal Opportunity and Justice” (AASWSW, 2019).

Reduc[ing] extreme economic inequality. The AASWSW describes this challenge as being about causes and solutions. The current state of inequality in the United States has been caused by “a confluence of macroeconomic, demographic, and political forces” (Elliott et al, 2016, p 1), but “thoughtful and purposeful action” (Elliott et al, 2016, p. 1) can reverse it. The entire system of low wage home care work is detrimental to the income potential of the workers and contributes to the economic insecurity of workers and their dependents (Elliott et al, 2016).

Achiev[ing] equal opportunity and justice. McRoy et al (2016) describe this grand challenge as: “In the United States, some groups of people have long been consigned to society’s margins. Historical and current prejudice and injustice can bar access to success in education and employment” (p. 1). This injustice is found in the identities of DCWs themselves, where marginalized groups such as women of color and immigrants are significantly overrepresented, and they continue to be marginalized by the work itself (Espinosa, 2017; Espinosa, 2018).

We present findings from two studies of direct care workers, which illustrate structural challenges facing the workers and suggest, based on our findings, ways to improve these structures. Structurally improving direct care jobs will improve the lives of workers and their families, as well as the lives of care recipients and their families.

Study 1: Home Care Workers

Home care agencies seldom notify DCWs when patients die, are discharged, or transfer between settings and may lack policies about post-transition contact (Staley et al., 2015). Study 1 looked at home care workers who care for individuals at end-of-life, including DCWs who work in hospice, palliative care, long-term care, and home health agencies with a job title of Home Health Aide (HHA), Certified Nursing Assistant (CNA), and Hospice Aide (HA).

Methods Study 1

A non-random, purposeful, convenience sample of DCWs was recruited over 6 months through hospice and home health care agencies, and personal and professional contacts in a Midwestern state. All HHAs, CNAs, or HAs with at least 3 months experience working with individuals at the end of life were eligible. Participants were given a \$25 gift card to a local grocery store. The Institutional Review Board (IRB) of a Midwestern university approved this project.

Semi-structured in-person individual and focus group interviews were conducted by the PI. A research assistant was present and took de-identified notes during all interviews. Five individual interviews (average length of 28 minutes) were completed in public spaces of the participant's choice. Privacy and confidentiality were discussed prior to consent. Four focus groups [3, 4, 5, 7 participants] were conducted during one home health agency's professional development day. Staff were notified of the option to participate in the focus groups. Participants were already coming to the site for scheduled training sessions and chose to arrive earlier or stay later to participate in a focus group. Focus group sessions lasted an average of 49 minutes.

Interviews were recorded, transcribed verbatim and both authors independently coded 3 individual interviews in Microsoft Word to create a codebook (Creswell & Poth, 2018). Following Braun & Clarke's steps of thematic analysis (2006), the authors continued to search and review themes while defining and naming themes. After initial coding, each transcript and its codes were reviewed against the initial framework. Throughout each stage of the analysis of searching for and reviewing themes, the codebook was modified or adjusted as needed through meetings and discussion between authors until consensus was reached.

Findings Study 1

Twenty-four home care workers participated in this study. A majority of study participants were female (96%), Caucasian or White (67%), with a mean age of 36 years old. Most worked as Home Health Aides (83%), and worked with clients in private residences (98%); assisted living facilities (67%); and/or independent living facilities (54%). A quarter of participants (25%) worked full-time (over 32 hours a week), 29% part-time (20-32 hours per week), and 29% less than 20 hours per week. Others (8%) worked per diem hours (more than 20 per week) or on-call only (4%).

Three themes emerged from the data. The first theme, agency practices, included (n=20) perceptions about the need for psychological support for DCWs and how communication (n=10) problems added challenge to care transitions. The second theme included DCWs' views of their roles (n=22), particularly the value of their work, such as helping people, the rewards of learning from clients, and pride. Finally, participants provided suggestions (n=14) to better support care transitions for DCWs, both when changing schedules and/or following the death of a client.

Agency Practices: The Need for Support and Communication

Many participants (n=20) expressed a desire for psychosocial support related to their grief needs, which they did not feel they received from their employers, such as, "... *We don't get any debriefings or anything afterwards [client's death].*" Most found this support through friends and family. Another participant illustrated their reluctance to reach out to agency staff:

... I'm sure I could call the office and our social worker would answer any questions or talk me through anything I was havin' trouble with, probably anybody in the office staff but, they're not necessarily my favorite people, so ... I'd rather go tell a friend or family member about my day than the office staff.

Where communication from the agency about care transitions might have eased the psychological burden, this communication (n=10) was inconsistent and the responsibility of the DCW. One participant said, "*I have to check on my email and then we have like an on call in the morning.*" Another illustrated the challenges of being responsible for schedule changes saying,

... if you're being taken off a client, they'll let you know, but a lot of the times for your consistent clients, my schedule will just change and if I don't see my calendar it's like, "Oh, I'm working late tonight." That can be a little frustrating. There definitely could be more communication.

Overall, psychosocial support related to care transitions was perceived as minimal and solely the responsibility of the direct care workers.

View of Role

The second theme was how direct care workers view their roles (n=22). Despite challenges, many workers found rewards in their work such as helping people (n=12), learning from their clients (n=9), and taking pride in their work (n=9). For example, many shared sentiments similar to this participant who said her role is to, *“Help people! That’s simple. Help people. And earn a few bucks on the side.”* Another shared how she benefits from her role by, *“... practicing kindness, learning from, learning and gaining knowledge from my elders ...”*

One participant described the perceived contribution they provide to their clients:

... being able to care for those who cannot care for themselves. ... helping them stay in their homes without having to go to another facility to live. It’s the joy just to see them be ... comfortable. You can tell the difference in them. You really can.

Overall it was clear that the workers found their work meaningful and cared deeply for their clients, suggesting they found value in their work despite a lack of support from their agencies.

Suggestions to Improve Care Transitions

In the third theme, direct care workers identified specific improvements to structural support that could help them with care transitions (n=14). Several participants (n=9) suggested that agencies provide someone to contact by phone, peer or group support. One participant said, *“I think a hotline would be great. ... You know how they have like suicide hotlines?”* Another agreed that sharing their experience with others would provide support:

... having like a group setting I think would be helpful. Not only is it good to talk about what you're experiencing, but it's also comforting to hear other people going through similar situations ... being able to relate to people can be really supportive..."

The DCWs specifically noted a lack of bereavement support when clients died and requested interventions such as someone to call, peer support groups, or simply **acknowledgement of their** grief.

Study 2: Certified Nursing Assistants

Study 2 explored the experiences of CNAs in one northeastern state. CNAs provide the majority of hands-on care in nursing homes yet experience an array of structural disadvantages. U.S. federal regulations require a minimum of 75 hours of training for these workers. Most workers in this role have a high school education or less and are female. The racial and ethnic breakup of CNAs has regional variation, with rural areas in the northeast and Midwest being majority U.S. born whites, more African Americans in large cities, and immigrants in coastal/large cities. Nationally, roughly 25% of this group are immigrants (Espinosa, 2018). Within these jobs there are structural barriers to economic equality, opportunity, and justice.

Methods Study 2

This was a secondary analysis of interviews collected **by the first author** for a study on CNA perceptions of care (Kusmaul & Bunting, 2017). This analysis explored the concepts found in study 1: agency practices, roles, and structural support. Individual interviews were conducted with (n=23) CNAs currently working in that role. Detailed recruitment procedures are described in Kusmaul and Bunting (2017). Briefly, sampling was purposive to access the employed CNA population. All nursing homes in the county were asked to advertise the study and about 25% agreed. CNAs at the participating facilities received a study description and the PI's contact

information. Interviews were conducted in public areas of the participant's choice and included public libraries, fast food restaurants, and in one case, the library area of the long term care facility. Like in study 1, privacy in a public area was discussed prior to consent. Interviews were recorded and transcribed verbatim. The two authors of this paper analyzed the interviews using the deductive content analysis process outlined in Elo and Kyngas (2008) with a framework of structural organizational characteristics to describe participants' experience of the work environment.

Findings Study 2

Twenty-three CNAs participated in this study. Descriptive characteristics included sex and years of experience. Participants were majority female (91%). Most participants had either less than 5 years' experience (30%) or more than 20 years' experience (26%). The remainder had 5-10 years' experience (17%), 11-15 years' experience (9%), or 16-20 years' experience (17%).

Three themes emerged in Study 2 within the structural organizational characteristics: responsiveness of individual supervisors (n=12), structures which provided or took away voice (n=6), and wages (n=6).

Responsiveness of Individual Supervisors

The first theme, the responsiveness of supervisors (n=12), describes times when participants' experiences were defined by specific people with whom they worked. Particularly in settings where CNAs had little structural power, the absence or presence of responsiveness by individual people made a difference as to how much they felt they were able to make change. One CNA, employed in a facility where she did not feel like supervisors were responsive to her input said, "*Sometimes they don't take what we say seriously enough to change things.*" Another CNA described both good and bad interactions with supervising nurses: "*I have been fortunate*

to work with some good nurses but some of the nurses, they can be real nasty.... they feel that they are higher than the CNA. I feel like some of the nurses aren't on board."

Structures that Provided and Took Away Voice

The second theme was about agency characteristics that contributed to the presence or absence of voice for workers (n=6). CNAs often lacked formal input into the system and these participants desired it: *"I felt that as we are the ones who do the physical part of that, that we should be consulted about certain things."* None of the CNAs in this study worked in organizations that gave them a consistent voice, but some had nurse managers who created space for their input. One said, *"At our care plan meetings they do now include us. Our nurse manager has made sure of that."* Receiving information was an important structure of opportunity: *"We have a new nurse manager now and she tries to do a weekly meeting to keep us informed of things, the changes, whatever, tell us we're doing a good job."*

Wage Structure

The third theme was around wages (n=6), and the ways low wages reflected the structural lack of respect for the importance of their roles. One said *"I'll tell you my salary because I don't care. It is \$14.71 and I have been there for 21 years."* Some CNAs relied on other family members or worked multiple jobs in order to be able to do this work. One CNA said she needed a second job because of *"having to make ends meet. Have to pay the bills."* When asked if CNAs should be paid more, she went on to say, *"Oh, definitely. We don't get recognition and appreciation from the companies for the work that we do. We are the backbones."* Yet, despite low wages, one respondent found more opportunity as a CNA than in home health, *"The pay was higher [than home health aide] and it was free training, and it was three minutes from my house ... so I did it."* Participating CNAs did the work despite the low pay, but the wages created

challenges in other areas of their lives. Participants were currently working in their CNA role, so this study could not capture the experiences of those who had left because of wages.

Discussion

DCWs are integral to our healthcare system. Both studies suggest high-quality compassionate care requires greater communication with and decision making by DCWs. Yet organizational structures fail to give a voice to DCWs; provide adequate support for workplace challenges, such as patient loss; or to pay living wages. Voice is necessary for achieving equal opportunity and justice. These findings have implications for the future of care across systems and progress towards the social work grand challenges goals of reducing extreme economic inequality, and achieving equal opportunity and justice for direct care workers. With growing concerns about an adequate labor force to care for older adults, to truly address social inequality, social workers must advocate for both low-wage workers and vulnerable clients.

Wages and hours create extreme economic inequalities for DCWs. The \$14.71 an hour one Study 2 participant earned would be \$30,568 per year for full-time work, less than 200% of the federal poverty line for an individual. Some DCWs work more than one job, which impacts their fatigue, self-care, work-life balance, and potentially their ability to provide care. Only a quarter of the participants in Study 1 worked full time, which raises the question of if they worked other jobs, had personal obstacles to working more hours, or if the agency was limited in the number of hours they can provide. The study did not ask these questions but the literature suggests that all three of these are realities for home care workers (Osterman, 2019).

Psychosocial support would improve opportunity by reducing burnout, allowing workers to continue caregiving. Both groups of DCWs lacked support from agencies and supervisors. Study 1 participants offered low-cost solutions, such as group meetings or a telephone hotline to

process grief and/or cope with job demands. Yet DCWs are only paid for time with clients; such support might be on their own time. Study 2 participants wanted more supervisor support, which suggests a place for leadership development for the DCWs and their supervisors.

Despite the evident challenges and areas outlined for improvements, direct care workers describe finding joy and passion in their work and a sense of purpose in their role. The challenge is how to support DCWs in complex health systems, as in so many ways it is the employees who make a system successful or not. From a social justice perspective, viewing the satisfaction of DCWs with their work in contrast with the structural inequalities and lack of environmental supports can be viewed as taking advantage of an already marginalized population.

Structural inequalities call for structural changes. Study 1 suggests the need for specific policies to help DCWs manage care transitions and for psychosocial support for DCWs. Study 2 illustrates the role of supervision in DCW disempowerment. Larger structural factors also contribute to the marginalization of this worker population. For example, many home health agencies (including hospice and palliative care) and nursing homes rely on fixed rates from Medicare and Medicaid for their services. **This reimbursement model contributes to structural inequality because the fixed rates leave little room for agencies to control client revenue, and can only pay wages that are relative to the reimbursement rates determined by Medicare/Medicaid (Osterman, 2019).** Reimbursement is only partly responsible for low wages, but does illustrate the health care delivery structures that must be addressed for improvement.

The anticipated growth of the older adult population is expected to outpace the availability of a trained workforce. Stone and Harahan (2010) outline key items that must be addressed at an individual and systemic level. For example, employers in long-term care need to attract a more diverse base of potential workers, provide fair wages and supportive work

environments. We also recommend recognizing nursing homes, residential care settings, and home health as distinct components of the health care system, thereby lifting the status of workers across the continuum of care. We concur with Stone & Harahan (2010)'s recommendations for training, supervision, and general oversight to DCWs to enhance worker competence and improve the safety of workers and older adults.

Implications for Social Work Practice

Supervisors need training on how best to support DCWs in carrying out their job duties and coping with the psychosocial impact of caring for those who are frail and/or at the end of their life. DCWs demonstrate incredible dedication to a difficult job with minimal agency guidance. Grief support is also needed for DCWs who are often closest to the clients but not a recognized part of the team. Social workers are well positioned to provide both this training and this additional support.

In end-of-life care social workers are particularly concerned about vulnerable individuals (NASW, 2004), and can be key supports to DCWs as interprofessional team members. Social workers should consider the needs of DCWs when advocating for patients. Additionally, social workers currently have a voice on most interdisciplinary teams and can amplify the positive impact DCWs provide in their relationships with patients and families to their team members. They can also use that voice to empower DCWs where structural barriers silence them and seek opportunities to promote agency policies to provide grief support. The additional support may help to decrease staff turnover and increase job satisfaction for DCWs (Boerner et al., 2016).

Social workers should incorporate macro advocacy strategies to support DCWs and their patients. Elliott et al (2016) outline many ways social workers can reduce economic inequality by advocating in government and with employers. Specifically, social workers should fight for

fair employment practices that include sick time, work-hour standards, and advance notice of schedule changes. They should work with employers to identify effective program interventions to improve jobs for employees, employers (Elliott et al, 2016), and the older adults and their families who rely on DCWs. Social workers can help ensure that psychological support is a part of an agency's services. Finally, all policies that impact direct care workers, clients, and the interactions between them should be examined to ensure they are clear and fair to both parties.

Finally, if we Reduce Extreme Economic Inequality and Achieve Equal Opportunity and Justice for DCWs, we can address another grand challenge- Advancing Long and Productive Lives. Morrow-Howell et al. (2016) argue that we need policy solutions that include all older people. The older adults served by direct care workers, those who require care, are often excluded from societal consideration. As DCWs report strong interpersonal relationships with their older adult patients (Boerner et al., 2016), collecting their input can provide the perspective of these marginalized individuals. Improving work conditions for DCWs will allow them to help frail older adults live long and productive lives.

Conclusion

The elder care workforce faces many challenges in the coming years to meet the needs of the growing population of older adults. DCWs will continue to be the backbone of this workforce, yet the jobs pay low wages, lack adequate worker protections, and do not provide structural, organizational supports for doing this difficult work. It is only through addressing this economic inequality and structural injustice that US society will truly advance long and productive lives for older adults through an economically and mentally healthy workforce.

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