“They Expect You to do a Lot for Very Little Money”: Compensation Concerns of Home Care Aides

Sandra S. Butler*
School of Social Work, University of Maine, USA

Abstract

As our population ages, there is increasing demand for personal care assistance at home. The personal care aide position is projected to be the fastest growing occupation in the United States between 2010 and 2020, despite its very low pay. Low compensation contributes to high turnover rates, which are costly to employers, society and elders needing care. This article reports on a thematic analysis of interviews with 252 home care aides—employed by agencies throughout a rural state—whose employment status was tracked for 18 months. “Leavers” (n = 88, 34.9%) were interviewed at the point of termination regarding reasons for job separation; “stayers” (n = 164), interviewed at the end of the study period, were asked what might cause them to leave their jobs. The issue of compensation was central to both groups, with low pay; insecure hours; and lack of health insurance, mileage reimbursement, and paid holidays and sick days emerging as themes in most (82.3%) of the interviews. While low pay and lack of health insurance were equally important reasons for terminating for both groups, insecure hours (p < .001) and lack of mileage reimbursement (p < .05) were of greater concern to “leavers” and lack of paid sick time (p < .05) and paid holidays (p < .1), for those who stayed. Themes are illustrated through quotes from study participants. Implications are explored within the context of improving job conditions and increasing retention of this critical component of the long-term care workforce.

ABBREVIATIONS

FLSA: Fair Labor Standards Act; DOL: Department Of Labor; HCWRS: Home Care Worker Retention Study; ACA: Affordable Care Act

INTRODUCTION

Personal care aides—sometimes called home care aides—are essential to community-based, long-term care services. The demand for personal care assistance is expected to double in the first half of this century, rising from 13 million in 2000 to 27 million in 2050 [1]. Four out of five older adults that need long-term care, live in the community, and most prefer to remain at home as long as possible [2]. Although, most personal assistance services are provided by unpaid family caregivers, the large majority of whom are female, the availability of these informal caregivers is decreasing [3,4]. There are several factors contributing to this decline, including rising employment rates among women, smaller family sizes, increased childlessness, and higher divorce rates [4]. With this decline will come a greater reliance on paid personal care. Given this situation, it is perhaps not surprising that the position of personal care aide is predicted to be the fastest growing occupation in the United States, increasing at a rate of 70.5% between 2010 and 2020 [5].

Despite the high demand for these workers, they face difficult work conditions including low pay, inconsistent hours and few, if any, employment benefits. These factors impact home care aides’ ability to stay in this line of work [6,7,8]. Job turnover, which has been estimated to range from 44% to 65% annually [9], can result in compromised care for older adults and increased direct cost to agencies. Turnover also increases indirect costs to taxpayers as personal care work is often financed by Medicaid and state-funded programs. Costs increase when turnover leads to poor quality community care, resulting in expensive hospitalizations and high levels of institutionalization [10]. While the rewards of the job have also been well documented [8,11,12,13], for some workers, particularly those who are younger and raising families, poor compensation may ultimately drive them to leave the work they love [14].
The work done by home care aides is generally considered to be “women’s work” and, like other caring professions, it is devalued by U.S. society. According to the Institute for Women’s Policy Research, poor wages have been justified because workers perform services that women have traditionally provided in the home for free; the work is seen as different from other paid labor, and thus, undeserving of the same monetary rewards [15].

Attention to issues of compensation for home care aides has received attention recently as the “companionship exemption” was finally removed from the Fair Standards Labor Act (FLSA). In 1938, when the FLSA was first passed to provide wage and overtime protections, many jobs held primarily by women were not covered. In 1974, the FLSA was amended by Congress to include domestic workers—such as maids and cooks—but people providing “companionship” were excluded. At the time, the Department of Labor (DOL), charged with writing regulations to implement the new law, interpreted the “companionship exemption” quite broadly. The intention of Congress had been to exempt the babysitter or neighbor who provided occasional support, but the DOL chose also to include under the exemption umbrella professional home care aides employed by third party agencies.

The “companionship exemption” came to the public’s attention when a home care worker named Evelyn Coke sued her employing home care agency for not paying her overtime; the Supreme Court heard her case in 2007. Coke was a single mother of five who worked for decades providing care for others. She earned $7 per hour and received no overtime pay, even when working up to 70 hours per week, sometimes putting in three consecutive 24-hour shifts [16]. The court ruled that the exemption was valid suggesting it was not the Court’s role to change the law, but rather that any change needed to come from the DOL or Congress.

This decision led to four years of advocacy to change this rule, providing considerable exposure to the issue of compensation for home care workers and bringing it into the public eye. While 20 states had their own wage and/or overtime protections for home care aides, 30 did not, leaving many workers facing conditions similar to those of Ms. Coke. Under President Obama’s administration, the DOL proposed a rule to eliminate the exemption in 2011. During the public comment period, 26,000 comments were received, 19,000 of which were in favor of the change [17]. In 2013, the final rule passed, although at this writing there have remained delays in its implementation.

Compensation remains a key concern for home care aides. In 2012, personal care aides had a median hourly wage of $9.57 per hour. In inflation-adjusted dollars, this average wage has declined over the past ten years. Further reducing their overall earnings, 59% of personal care workers were employed part time in 2011. Moreover, in 2011, over a third of agency-based home care aides lacked health insurance coverage [18].

While the reasons personal care aides leave home care work are as varied as the individuals making up the workforce, issues of compensation, benefits, and hours often surface as primary factors for termination or intended termination [7,8,9]. The Home Care Worker Retention Study (HCWRS) described herein sought to gain a better understanding of how issues of hours, benefits and wages impact job experiences both for workers who choose to leave their home care jobs and for those who remain employed. Earlier analyses from the study have shown that compensation issues are of concern not only to workers who terminated employment [6,12] but also to those who remain on the job [19], although, perhaps to a lesser degree [14]. This article explores compensation issues more directly and seeks to address the following research questions:

1. How do issues of wages, hours, and benefits affect home care aides’ job experiences and decisions to terminate employment?
2. How do perceptions of compensation differ between workers who terminate their employment compared to those who do not?

Through use of qualitative data analysis, this study provides a richer examination of the experience of poor compensation than is possible in studies restricted to quantitative data. Furthermore, the study examines not just those workers who leave the field or intend to leave the field, but also those who remain in their jobs, thereby providing potentially useful information in targeting retention efforts for specific groups of workers.

MATERIALS AND METHODS

Methods

After approval from the Institutional Review Board of the University of Maine, the longitudinal HCWRS was implemented in October 2008 in order to study the dynamics of turnover among personal assistance workers employed by home care agencies in Maine. The study involved both mail surveys and telephone interviews. Information on the survey questions, reliability and validity may be found in previously published reports on the HCWRS [12,14]. Data from the telephone interviews are the focus of this article. Eleven home care agencies/companies participated in the study. All counties of the state were served by the 11 agencies in the study whose home care aides provided personal care to individuals in their homes. Personal care workers in Maine are called Personal Support Specialists and they complete a variety of tasks including personal care, light housekeeping, and meal preparation depending on the needs of individual clients. They will be referred to by the more general terms of personal care workers and home care workers in this article.

Clients receiving care were predominantly frail older adults, but also included some younger adults with physical disabilities. Agencies agreed to send a mail survey (Time 1) to all their personal care assistants (n=496) in October 2008; over half of the workers completed the survey (n=261), giving a response rate of 52.6%. Participating agencies provided the study team with regular reports of study participant terminations in the 18 months after completion of the first survey. Workers who left their employment received a second mail survey and completed a telephone interview lasting between 15 and 30 minutes soon after their termination (n=90); workers who remained employed throughout the 18-month study period (n=171) received the second survey and completed the telephone interview during the spring and summer of 2010 (Time 2); 252 interviews...
were completed giving a study retention-rate of 96.2%. Study participants received $20 grocery gift cards at both Time 1 and Time 2.

The telephone interview completed by study participants was composed of 18 open-ended questions. Questions covered topics such as what about the work appealed to the workers in the first place, what parts of the work were satisfying and what parts were draining, how they felt the work affected their health and safety, whether they felt prepared by the training they had received, how involved they were in decision making at their agency, and what they would like society to know about their job. The four questions of particular focus in this article asked participants about what they found draining about their work, what caused them (or could cause them) to leave their job, why they thought others left home care work, and what they thought agencies could do to keep their workers from terminating. Telephone interviews were tape-recorded and transcribed verbatim. Using the constant comparison method of grounded theory, a systematic thematic analysis was performed on all interview transcripts [20,21].

Previously published analyses of the HCWRS survey data utilized multivariate statistical methods to determine factors predicting termination [6,12] and increased job tenure [14]. For this article descriptive statistics and bivariate analysis including chi-square analysis and t-tests were utilized to determine differences between groups.

Earlier thematic analyses of the qualitative data provided rich description of the job experiences of study participants, including areas of satisfaction, dissatisfaction, and reasons for leaving the work. For each of these analyses, transcripts were examined line-by-line to inductively identify emerging themes. When more than one reader was involved, inter-rater reliability was calculated through percent agreement between readers’ coding [20]. When agreement fell below 80%, differences were negotiated [6,11,12,14,19].

Compensation issues arose as a key issue in previous thematic analyses of the interview data, though, other than access to health insurance, issues of compensation were not predictors of termination in the multivariate models. The two research questions for this study arose from these earlier thematic analyses and were identified in order to more fully understand the power of these compensation issues both for workers who stay on the job and those who chose to terminate. Among the 18 interview questions asked, the above-listed four were chosen because compensation concerns emerged most frequently in study participants’ response to these particular questions.

Six themes related to compensation surfaced in the responses to the four interview questions. These themes were coded in all interview transcripts. NVivo 9 was utilized to facilitate data management and analysis. Chi-square analysis was performed to distinguish differences between those study participants who terminated their employment (“leavers”) with those who did not (“stayers”).

RESULTS AND DISCUSSION

Findings

Sample description: The sample of home care workers interviewed in this study ranged in age from 19 to 82, with an average age of 46. As is true of the profession nationally, the vast majority was female (Table 1). Reflecting the racial composition of the state (97% white) [22], the sample was largely white (Table 1). Although unusual for an occupation that attracts many immigrant women on that national level, this sample had only nine individuals who had been born outside the U.S.; again this reflects the population of the state where the study took place, which has a very small immigrant population (3.3%) [22].

Nearly half the study participants were married or partnered and about a quarter were divorced or separated. The highest degree obtained by half the study participants was a high school diploma (Table 1). The study participants reported very low incomes, with nearly two-thirds indicating a household income below $20,000 (Table 1). Among the demographic variables, there were no statistically significant differences between stayers and leavers other than for age. Stayers were on average older than leavers (47.9 vs. 43.3, p < .05) and, as indicated in previously published findings, younger age predicted termination [12]. Stayers were also more likely to have health insurance than leavers (76.8% vs. 62.5%, p < .05). Not having health insurance also predicted termination [12].

Compensation themes: Six themes relating to compensation emerged from the interviews with study participants in their responses to questions about what they found challenging about the job; what made them, or could make them, leave the work; why they thought other home care aides left the field; and what they thought their agencies could do to reduce worker turnover. These themes were: low pay (n = 163; 62.5%); inadequate mileage reimbursement (n = 79; 30.3%); too few and unreliable hours (n = 77; 29.5%); and lack of benefits, including health insurance (n = 66; 25.3%), paid holidays and vacation (n = 36; 13.0%), and paid sick days (n = 27; 10.3%). These concerns were raised by both workers who terminated their employment during the study (the “leavers”) as well as those who stayed on the job (the “stayers”), with at least one compensation theme being mentioned by 209 (82.9%) of the study participants.

Low pay: Low pay appeared to be of equal concern to both the “stayers” and the “leavers”, with nearly two-thirds of each group mentioning it in their interviews (Table 2). Interestingly, although also earning very low wages, on average, those who stayed on the job made slightly more per hour than those who left ($9.30 vs. $8.98, p < .05). Nonetheless, the issue of low pay was mentioned by more than six out of ten workers whether they left the job or not. For example, a “stayer” in her early 50s, single and with a child, said the following about her home care agency where she had worked for over four years:

I’ve had a couple raises there of maybe ten cents or fifteen cents, I only make $8.15 an hour and I’ve been doing this type of work for ten years, that’s kind of sad. I haven’t had a raise from them in a couple of years. And it’s not that I miss work, I always go to work, I always get there on time unless I’m sick and I haven’t even had that.

Another “stayer,” also in her early 50s, divorced and without children, who had been at her agency more than six years at the time of the interview stated, “It’s too bad that we don’t get a little more money ’cause it’s hard to survive in this world. Money is important, and benefits are nice. So, it’s too bad we don’t get a
Lack of health insurance: Although mentioned far less frequently than low pay, lack of health insurance was also mentioned as a concern by about the same proportion (one quarter) of workers who stayed on the job as those who terminated. Nonetheless “leavers” were significantly less likely to have health insurance than “stayers” (37.5% vs. 23.1%, p < .05), and previous analyses of the sample data have indicated this to be one factor contributing to job termination [6,12]. A 52-year-old “stayer” whose family had health insurance through her husband’s employment discussed the health insurance situation at the home care agency where she had been working for six years.

They just started offering medical but that’s almost ridiculous. I’m glad my husband’s got it. Because I’d take home every two weeks a hundred and something dollars, you know, after paying my health insurance for my husband and me.

A 40-year-old, married “leaver,” who had left her original home care agency after three years, was unable to afford the insurance offered at her new agency. She recounted: I started getting medical there and it was costing me one hundred-and-something every two weeks. They were taking it out of my check and it’s like “holy crap”. That’s why I don’t have a medical right now. I’m struggling because I take depression pills and cholesterol pills. All this time I’ve been having my doctor give me samples because they know my situation. Now I can get my depression pills for $4 at Wal-Mart. Other than that they are not covered. So, it’s been hard.

A 39-year-old, single mother described the irony of being a health care provider without health insurance:

Well, you work hard and you don’t get compensated for it. You care for someone who is ill and when you need care and need to stay home you’re not being taken care of. If you get sick, you don’t have health care. So, unless you have state issued healthcare and you’re sick, you are in trouble because your company doesn’t offer you any benefits to take care of you, but they ask you to take care of others. Really weird, I don’t get that. She terminated her employment after three and a half years.

No mileage reimbursement: Two of the themes—no mileage reimbursement and too few hours—appeared to be significantly more important to workers who terminated than to those who stayed on the job. Over two-fifths of workers who terminated mentioned the difficulty of not receiving reimbursement for miles driven on the job, while only about a quarter of those who stayed discussed this issue in the interviews (p < .05; Table 2). On average, workers in the rural state where this study took place estimated that they drove between 40 and 45 unreimbursed miles a week for their home care work. There was no significant difference in the number of unreimbursed miles driven by “leavers” as compared to “stayers”, though “leavers” were more likely to mention this as a problem in their interviews. A 58-year-old, married “stayer” who had been working at her agency for six years described how lack of compensation for mileage drove some workers to quit their home care work:

I think a lot of them, for the most part, have left our agency a little bit more for what we do.”

A 60-year-old, married woman who left her home care agency after 18 months noted the discrepancy between what she earned and what she believed her agency received for the people for whom she provided care.

They expect you to do a lot for very little money. And the thing I found out when I was working up here is that they get the same amount per case, like [when] they go into somebody’s home they get $40 an hour. But you only see $8.36 of that.

Typical of many of the “leavers,” a divorced woman in her late 40s, who left her agency after two and a half years, said, “Had the pay been better, I probably wouldn’t have looked elsewhere.”

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>238</td>
<td>94.4</td>
</tr>
<tr>
<td>Male</td>
<td>14</td>
<td>5.6</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>236</td>
<td>93.7</td>
</tr>
<tr>
<td>Native American</td>
<td>9</td>
<td>3.6</td>
</tr>
<tr>
<td>African American</td>
<td>1</td>
<td>0.4</td>
</tr>
<tr>
<td>Multiracial</td>
<td>6</td>
<td>2.4</td>
</tr>
<tr>
<td>Latino/a Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3</td>
<td>1.2</td>
</tr>
<tr>
<td>No</td>
<td>249</td>
<td>98.8</td>
</tr>
<tr>
<td>Born in the US</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>243</td>
<td>96.4</td>
</tr>
<tr>
<td>No</td>
<td>9</td>
<td>3.6</td>
</tr>
<tr>
<td>Family Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/partnered</td>
<td>125</td>
<td>49.6</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>62</td>
<td>24.6</td>
</tr>
<tr>
<td>Widowed</td>
<td>15</td>
<td>6.0</td>
</tr>
<tr>
<td>Single</td>
<td>50</td>
<td>19.8</td>
</tr>
<tr>
<td>Dependent Children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>86</td>
<td>34.1</td>
</tr>
<tr>
<td>No</td>
<td>166</td>
<td>65.9</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;HS graduation</td>
<td>10</td>
<td>4.0</td>
</tr>
<tr>
<td>HS grad or GE</td>
<td>126</td>
<td>50.0</td>
</tr>
<tr>
<td>Some college</td>
<td>97</td>
<td>38.4</td>
</tr>
<tr>
<td>4-yr degree</td>
<td>11</td>
<td>4.4</td>
</tr>
<tr>
<td>Post college</td>
<td>8</td>
<td>3.2</td>
</tr>
<tr>
<td>Household Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$1,000</td>
<td>64</td>
<td>25.4</td>
</tr>
<tr>
<td>&lt;$10,001-$20,000 &gt;</td>
<td>92</td>
<td>36.5</td>
</tr>
<tr>
<td>&lt;$20,001-$30,000 &gt;</td>
<td>29</td>
<td>11.5</td>
</tr>
<tr>
<td>&lt;$30,001-$40,000 &gt;</td>
<td>36</td>
<td>14.3</td>
</tr>
<tr>
<td>&gt;$40,001</td>
<td>29</td>
<td>11.6</td>
</tr>
</tbody>
</table>

Table 1: Demographic Characteristics of the Sample.
because they cut the mileage back. There's no mileage. And I think they [the workers] went to nursing homes or whatever and filled [those open] positions. They just can't be traveling 200-300 miles a week and not be taken care of with that.

A 58-year-old, married "leaver" who left her agency after a year, explained her decision by saying, "It cost me to work for them because they didn't pay any mileage whatsoever. Gas was over four bucks a gallon. It was costing me [and I said], 'I can't afford to work for you!'"

**Unreliable and too few hours:** Half of the workers who terminated their home care work during the study reported that having too few hours was one of their main reasons for leaving; among those who did not terminate, only one-fifth mentioned this as a problem (p < .01; Table 2). On average, those who did not leave their jobs during the study period had slightly more hours per week than those who terminated (16.5 vs. 13.4, p < .1). Nonetheless, even those who remained on the job found the unstable hours to be problematic. For example, a 34-year single mother, who had worked for her home care agency for over four years, thought the erratic hours caused some workers to leave the work. She said:

It is hard to get hours. You know you can get a few here and there, but they're not guaranteed. That's the thing. They're not guaranteed. You never know...I mean like I've got one that went into the hospital, and one that they had to put her in the nursing home because they were going on vacation, and I didn't get any type of notice or anything.

A 57-year-old married woman who left her home care agency after one year said the unreliable hours contributed to her decision to terminate. She explained:

There was 20 [hours] in the beginning. And that was about what I wanted. And then, one lady went to a nursing home and another one, you know, this and that, and then all of a sudden I was down to ten hours. And driving long distances for two hours here and two hours there. And when you really stop and think about it, with the price of gas and my time invested in driving, I was making only three, four, and five dollars an hour, maybe even less...And that is part of the problem with this job. It is so unreliable. You know, because these elderly people never really get better, they only get worse. And they wind up in nursing homes or dying or in the hospital. And you've got to have a paycheck, especially right now and all of a sudden you only have ten hours a week at 8 dollars an hour. For two weeks pay, you are barely making a 100 bucks and that doesn't even pay for my groceries.

**Lack of paid vacation or sick time:** Workers who did not terminate their home care work during the study period appeared to be more concerned about the lack of paid vacation and sick time than were workers who quit; "stayers" were twice as likely to mention the desire for paid vacation as "leavers" (p < .1) and three times as likely to mention paid sick leave (p < .05; Table 2). Two "stayers" in their early 50s described how the lack of paid sick time and vacation felt unfair to them. The first, a widow who had been with her agency eight years, said, "If I'm sick, I'm sick. No pay. That's not right. Something should accumulate. Something over the time period even though you are part-time." The second, a single mother who had been with her agency over four years stated:

It is a rewarding job and I enjoy doing it, it's just the pay is not very good, and there's no benefits, we don't get any type of paid vacation, I've never had a vacation since I've been doing this work.

A 43-year-old, married woman, who left her agency after three years, lamented the lack of paid leave by saying, "There is no paid holidays. There is no sick time. There's no vacation pay. I want to take a vacation with my husband and I have go without a week's pay. There are no benefits."

**DISCUSSION AND IMPLICATIONS**

Clearly compensation issues were of great concern to the home care workers in this study. Low pay, in conjunction with unreimbursed miles driven for their work, and insecure hours made the job unsustainable for many. But, even for those workers who remained on the job throughout the 18-month study period, the poor remuneration and lack of benefits let them know society did not highly value their work. As one 52-year-old "stayer" said, "We shouldn't be taken for granted. We work very hard." Dawson and Surpin echo this woman's concern is their examination of workforce issues in long-term care:

The long-term care industry long ago structured itself on the presumption of a seemingly endless supply of low-income individuals (usually women, and disproportionately women of color). The industry presumed that these women would always be willing to provide care and companionship for our loved ones—despite jobs that kept them working, but poor [23].

Although there has been some relaxation of gender roles and expectations over the past 50 years, caregiving is one word—both paid and unpaid—continues to be performed primarily
by women in the U.S. and throughout the world [24]. Women are socialized to do caring work both in the home and in the workplace, resulting in a phenomenon well described by Boris and Klein: “The nonwage labors of the wife or mother, performed out of love, obligation, and duty, morph into the low-wage tasks of the housekeeper, personal attendant, health aide, and child or elder minder” [25]. The assumption that caregiving is one word is best performed by women and that they are naturally suited to it, relegates women to the domestic sphere and to a weakened position in the public sphere [26]. The job experiences of participants in this study reflect that weakened position. Given these deeply engrained societal assumptions about caregiving is one word, what might be done to improve the job situation for workers who provide care to the increasing number of frail elders in our communities? One seemingly obvious place to start would be to raise wages. While findings from this study are restricted to home care workers in Maine, low wages are a known concern for this segment of the workforce nationwide [9,18]. The current proposals in Congress to raise the minimum wage to $10.10 per hour would directly impact most personal care workers, whose average hourly wage falls 50 cents below that level [18]. A recent analysis by Traub and Hiltonsmith [27] reveals that millions of workers, paid through tax dollars collected from the public, are earning wages too low to support their families. Looking specifically at federal health care spending in 2011, they report that $552.4 billion supported an estimated 3.7 million private sector jobs, of which 1.2 were low-wage positions. These include home health aides paid through Medicaid and Medicare. Traub and Hiltonsmith report “when our tax dollars underwrite bad jobs, the economy as a whole is weakened and all of us are negatively affected” [27]; families earning low wages have little money to spend, thereby hindering economic growth. The authors recommend that President Obama should raise wages on these poorly paid jobs funded by federal tax dollars through a presidential executive order, given that the bills to more broadly raise the minimum wage currently being debated in Congress are likely to flounder in our current contentious partisan climate. Such an executive order would directly affect the wages of the many workers interviewed for this study, who were providing home care through programs funded by Medicaid. Barring such a dramatic change at the federal level, study findings underscore the importance of working to elect candidates at the state level who support raising the minimum wage. In 2013, Maine’s Governor Paul LePage vetoed a bill passed by the Legislature to raise the state minimum wage from $7.50 to $9.00 per hour, with links to inflation in years to follow. Such a policy would have directly impacted the wages of many study participants. The 2010 Affordable Care Act (ACA) was passed near the end of data collection for this study, so its impact is not reflected in the findings. Nationally, the ACA has had the potential to help thousands of home care workers gain access to health insurance either through expanded Medicaid—as many home care workers fall below 138% of the federal poverty level—or through subsidized health insurance purchased through the state health care exchange [28]. Unfortunately, the 2013 Supreme Court ruling in National Federation of Independent Business v. Sebelius has allowed states to opt out of expanding Medicaid under the ACA, and Maine is one that has chosen that option; to date Governor LePage has vetoed several efforts by the legislature to expand Medicaid coverage. Sadly, many of the uninsured home care workers in this study are likely victims of that decision, and if their incomes fall below the federal poverty level, they fall into a “coverage gap” which disallows them subsidies through the state health insurance exchange, as the ACA was written with the expectation that such individuals would be eligible for the expanded Medicaid [29]. Currently broad-based, grassroots efforts by organizations concerned about low-income, uninsured Maine residents are underway to elect legislators and a governor supportive of Medicaid expansion in the State. The unpredictable and unstable work schedules experienced by the home care aides in this study constitute a problem shared by many low-income workers. A recent report by the Center for Law and Social Policy, Retail Action Project, and Women Employed [30] describes both the consequences of erratic work schedules and recommends some potential solutions. In addition to not being able to count on secure income to pay their bills, workers with unstable hours are affected in other ways as well. “Workers experience adverse health effects, have difficulty finding and keeping childcare arrangements, face transportation obstacles, have trouble going back to school to advance their education, and experience considerable overall stress and strain on family life” [30]. Similar to the impact of low wages, the effects of unstable hours ripple out to the communities when workers cannot afford to buy groceries or other goods from neighborhood businesses. The authors recommend two policies to mitigate some of the harsh consequences of unstable work schedules: guaranteed minimum hours and reporting pay. Under the guaranteed minimum hours, employers commit to schedule employees for no less than a set number of hours each week. Under reporting pay laws, workers are compensated a minimum number of hours even when they are sent home or, in the case of home care aides, when their clients unexpectedly do not need them. Such practices would have helped the participants in this study, many of whom ultimately needed to terminate their home care aide positions in order to find work with guaranteed hours. Currently there is no federal law requiring employers to provide paid sick leave. Low-wage, part-time workers are the most severely impacted by this lack of labor protection, and women with children, in particular, face challenges in balancing their family and employment obligations [31]. Requiring employers to provide paid sick time—as is true in many industrialized countries—would benefit workers, families, and the larger community. In the field of home care, access to paid sick time would reduce turnover of workers who often need to make the difficult choice between staying at home when they or their children are sick or neglecting their family’s health in order not to lose much needed income. CONCLUSION Generalizations from this study must be made with caution due to the following limitations. First, the sample was voluntary, though it did not differ significantly from the population from which it was drawn. Second, the study took place in a state that is very rural, largely white, and with a particularly small immigrant population. The national direct care worker population is
composed of many more immigrants (23%) and people of color (53%) [32]. Undoubtedly, concerns and experiences of workers in more urban environments, which have public transportation and a larger pool of clients needing care, would differ somewhat from those expressed by home care aides in this study.

Nonetheless, issues of compensation are known to be of concern to direct care workers nationwide and the qualitative aspect of this study allowed participants to respond in their own words to open-ended questions regarding challenges in their jobs. This study provides an in-depth view of the nature of these concerns for home care workers in a rural state—both those who stay on the job and those who terminate. It is evident from the participants’ responses that we have a long way to go toward improving conditions of these jobs so that workers feel valued and adequately compensated. To meet the current and growing need for personal assistance as our population ages, we cannot ignore the needs of this workforce. As stated in a recent report from those expressed by home care aides in this study.

ACKNOWLEDGEMENTS

The author would like to thank the following individuals who participated in data collection and analysis on the HCWRS: Dr. Mark Brennan-Ing, Dr. Nancy Fishwick, Dr. Winston Turner, Alison Ashley, Sara Wardamasky, Nan Simpson, Julia Hewes, Meghan Wyman, Dawn Raven, Diane Holder, Meredith Wurpel, and Stephanie Allard

The HCWRS was funded through an R-15 award from the National Institute on Aging, 1 R 15 AG029599-01AZ

REFERENCES

17. Gerace A. PH: Millions of home care workers wouldn’t benefit from minimum wage increase. 2012.
30. Center for Law and Social Policy, Retail Action Project, Women
Employed: Tackling unstable and unpredictable work schedules. 2014.
