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“I Know Best:” Women Caring for Kin with Dementia

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Introduction

The care literature on Alzheimer’s disease and related dementias in the home is vast, particularly in the health sciences. There are over four decades of research in nursing, medicine and psychology focusing on interventions to “improve” dementia kin carer health outcomes. However, as I have suggested elsewhere (Apeso-Varano et al., 2015b), these interventions have shown limited effects, especially longitudinally. The health science approach to the “problem” presupposes a paradigm that pathologizes (or medicalizes) responses to the challenges of dementia care in the home as a carer’s incapacity to cope with its demands (Gitlin et al., 2003). Likewise, this approach assumes that kin carers lack the technical (or professional) knowledge and skills to care adequately; for if they had the knowledge and skills they would not experience as much stress (e.g. AARP training videos). Even for those in the health sciences who are critical of these medicalization and professionalization underpinnings, kin care remains essentialized as biological traits such as “emotional intelligence” (Powell, 2019). Paradoxically, this literature dismisses the fact that most dementia kin care is work performed by women in the home, where they must negotiate gendered expectations and household processes in caring for kin.

While the health sciences approach imposes on care an individualistic ethic of control, discipline, and rationality over the body of the care recipient and the psychology of the carer, a feminist/labor process perspective may reveal how kin care workers deploy skills and exercise autonomy over the care process. I show how Latinas caring for kin with dementia reject help from others because they hold a sophisticated skill set based on tacit knowledge developed over months and years of care work. This skill set is not easily transferable to others given the complexities of dementia care (often characterized by an unpredictable but progressive deterioration of the care recipient) and the time needed to develop it. Latina carers deal with the uncertainty of dementia care by engaging in strategic yet meaningful intimacy that calls for them to craft care work behaviors (e.g. giving a bath, feeding) based on acquired information, identification of patterns, and deployment of effective targeted labor to accomplish and maintain a care routine. Ultimately, what makes a difference is their well-crafted responses around unexpected and emergent characteristics of dementia

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deterioration. In this way care workers seek to preserve the dignity and comfort of the person with dementia as well as theirs.

Finally, the health sciences label care work as “caregiving” and primarily categorizes it into two types—formal (e.g. nurses) and informal (e.g. family). The following review of the health sciences literature thus utilizes this terminology given the field dominant nomenclature. However, as it relates to my work and the sociological and feminist literature on this topic, I characterize it as caring or care work and the individuals performing such tasks as kin carers or care workers to emphasize the valuable acquired skills that are deployed to accomplish labor rather than assume a set of gendered traits that one expresses.

Women and Dementia Care Work

It is estimated that over 34 million persons care for a family member who is over 50 years of age with a health condition and approximately one third of care recipients suffer from cognitive impairment. Among caregivers, about 67 percent are women, 20 percent are Asian Americans, 20 percent are African Americans, 21 percent are Hispanics, and 17 percent are whites (NAC, 2015). The health sciences literature defines caregiving for an ill family member as involving activities related to personal care, complex medical and nursing tasks, financial and instrumental assistance, and emotional and social support. Data show that providing in-home care to kin has changed due to longer life expectancy, more health complications and seriousness of disease in individuals with chronic conditions, shorter hospital stays, and limited access to health services, especially for socioeconomically and ethno-racially disadvantaged groups (Ortman et al., 2014).

Caring for a family member with dementia is associated with poor caregiver health (Pinquart and Sorensen, 2003). Prevalent neuropsychiatric symptoms (e.g. depression, agitation) in persons with dementia are associated with increased kin caregiver depression (Covinsky et al., 2003). Latinx caregivers, most of whom are women, provide more care to older adults with cognitive impairment (Weiss et al., 2005) and report higher levels of depressive symptoms (Adams et al., 2002). Latinx caregivers are also found to be less satisfied with formal support and have smaller and less supportive family networks compared to white non-Hispanics (Valle et al., 2004). Further challenges for Latinx dementia caregivers are related to difficulties in access to care services along with increasing geographic fragmentation and economic instability (Apesoa-Varano et al., 2015a). The loss of traditional inter-generational households has intensified physical and emotional burdens, putting Latina caregivers at high risk of adverse physical and mental health outcomes (Ortiz et al., 1999).

An ongoing concern in the health sciences is caregiver distress and burden. To date, there have been two dominant intervention models to improve mental health outcomes for caregivers (Thompson et al., 2007). The stress-appraisal-coping model (Chappell and Reid, 2002; Roth et al., 2009) focuses on psychological interventions at the intra-personal level targeted at increasing caregiver coping skills (Selwood et al., 2007). This model, developed for white populations, has been found to be only moderately effective at best (Thompson et al., 2007). The support group intervention model centers on formal “professional and peer

navigation” to provide knowledge to new caregivers (Toseland et al., 1989). The support group model, however, is always subsumed within a formal health care system in which a provider leads and peers share experiences, thus privileging the expertise of trained professionals and not of those doing the care (Apesoa-Varano et al., 2015b). While these two intervention approaches have been widely used (Belle et al., 2006), they have been found to be less effective among Latinx due to poor cultural congruence, accessibility, and sustainability (Coon et al., 2004; Napoles et al., 2010). In sum, the health sciences have narrowly focused on outcomes and interventions that fit biomedical assumptions of “abnormal” or “deficient” psychological function to increase carers’ coping with stress.

A Medical Sociology of Dementia Caring

There have been two major approaches to studying kin care work, primarily at the micro-interactive level and from a medical sociology perspective: a) the negotiation of illness disruption and losses model, and b) the medicalization of non-expert kin care model. The illness disruption and losses model, developed through the Straussian tradition (Strauss and Glaser, 1984), showed that much effort goes to managing the changes brought about by illness to redefine viable social identities. Charmaz (2002) proposed that home care work, while routinely carried out, reflect kin commitment toward the ill person. Negotiating fundamental disruptions and losses brought about by illness requires critical repair work in the physical and socioemotional sense to maintain legitimate identities and protect existing kin relationships (Williams, 2000). Care workers attempt to “restore” or salvage aspects of a pre-illness identity (Hayes et al., 2009). In advanced dementia, the carer becomes the proxy negotiator of the ill-person’s self by ensuring its continuity given the daily encroachment of impairment and uncertainty (Lyons et al., 1995). Even when carers act as a proxy for the family member with dementia, Karner and Bobbitt-Zeher (2005) have argued that this focuses on the care recipient and less so on the care worker, making the latter of secondary importance.

The premise of the medicalization perspective, building on Conrad’s (1992) work, is that the (bio)medical model dominates the home environment by pathologizing normative and normal processes such as aging (Goodwin, 1991). Scholars have shown how carers are viewed as experiencing “burden,” whereby biomedicine defines this as an abnormal response to challenging conditions in the home that must be “treated” (Bond et al., 2004). Further, Abel (1999) has posited that the biomedical model has led to the quantification of care work into discreet categories of tasks that only represent a superficial picture that aligns with intervention and treatment approaches. Gubrium (1986) and Downs (2000) have also demonstrated that once a person is diagnosed with dementia, family members reinforce biomedical assertions that symptoms of the afflicted person are related to the dementia-disease label (Hasselkus and Stetson, 1991). When behaviors are medicalized as pathological symptoms, biomedical treatment such as medications is justified. Kin care workers thus reproduce biomedical hegemony in the non-expert setting. However, Hasselkus and Stetson have shown that kin care workers can resist the infringement of biomedicine. They do so primarily by resisting disease-based definitions or questioning expert biomedical knowledge and by downplaying or dismissing the need for medicinal treatments (Miller et

al., 1992). Therefore, kin carers view the afflicted family member as having agency rather than being at the mercy of a deteriorating brain (Belgrave et al., 2004).

While this research documents the divide between medicine and the home, and the mutuality of the worlds of kin care worker and family member with dementia, it has not conceptualized the care worker's understanding of caring as a process of acquiring tacit knowledge and skills to be purposively deployed. Missing from this extensive literature is a feminist lens that conceptualizes dementia care work as *skilled work* where control and autonomy are exercised in a labor process. This could be considered what Quin and Toms (2019) in their meta-analysis of 53 studies on dementia care refer to as "positive aspects of caregiving." They show that "there is some evidence that reporting higher PAC is associated with higher competence or self-efficacy" (e593). Similarly, Cheng et al. (2016) found that "when caregivers were committed to the role, they wanted to do it well. When the CR [care recipient] responded well to something they did, they felt a sense of mastery and a confirmation that they were serving their purpose well" (454). This captures how women who care for persons afflicted with dementia enact agency within constraints by maintaining a care labor process and by upholding a modicum of dignity for care recipients and themselves.

Linking Dementia Caring to Skilled Work: Feminist Theorizing on Care Work

Feminist researchers have significantly advanced scholarship on caring, and they define care work as all activities that contribute to the maintenance of human wellbeing and human societal infrastructure. Care work involves a labor process between care workers and care recipients who are unable to care for themselves (England, 2005; Tronto, 1993). Theorizing care work pivots at the intersection of patriarchy and capitalism where it remains invisible and poorly remunerated but is central to much of what constitutes women's work in the private and public spheres (England et al., 2002). Paula England (2005) has aptly summarized this extensive work as advancing six theoretical frameworks, one of which is most relevant to my analysis: the prisoner of love framework.

Briefly, the prisoner of love framework is linked to Folbre's scholarship (2001) where care is conceptualized as the outcome of individuals' caring motives. Carers develop strong emotional bonds to their care recipients which validate their sense of reward, duty, and extreme sacrifice. These caring motives justify heroic commitment even when this is detrimental to them physically and emotionally. Care workers become "a kind of emotional hostage" who are unable to comprehend their best interests (England, 2005, 390). The underlining issue thus remains one of equity in which care workers' caring motives become a source of vulnerability and disadvantage.

Feminist scholarship has brought a critical understanding of care work in its many forms. However, there are three central gaps related to kin care work in the home. First, by focusing on the emotional bonding between the care worker and recipient the prisoner of love framework underappreciates the pockets of autonomy and control care workers exercise. Second, although this scholarship correctly highlights the need for a welfare state that values and supports care work as "economic and ethical imperatives," it has less consistently

focused on the implications of kin unpaid care work in the home, especially around older age illness. That is, scholars have increasingly moved toward theorizing care work as an “economic sector” (e.g. Duffy et al., 2013), while inadvertently the home as a central site of care work remains invisible and marginalized. This takes on theoretical and empirical significance when examining the illness care work of non-white and ethnic, poor and working-class women who do much of this invisible labor on behalf of their families and communities (Glenn, 2010). Lastly, and contrary to so much feminist scholarship that highlights the collectivist struggles of women, neglecting this invisible labor individualizes illness care work as if by default. Here, the collective obligations of family members recede behind “women’s work” leaving, what I will argue, is more than an “emotional hostage.”

I analyze kin unpaid dementia care work to advance a feminist/labor process perspective by theorizing it as valuable and meaningful activity carried out at the juncture of illness and the home. I ask, why may it be that kin care workers are unable or unwilling to cede care to others? Contrary to the “prisoner of love” perspective, I argue that kin care workers are as much, if not more so, prisoners of their intellectual achievements. I show that Latina kin care workers exercise a degree of mastery over the care process because they have developed knowledge-based skills about how to best achieve care. In this context, they enact degrees of agency vis-à-vis their families and health care professionals, perhaps in ways that might alter the face of medicine through highlighting their lay expertise. A nuanced understanding of dementia care work from a feminist/labor process perspective reveals how women achieve dignity and comfort for the family member and themselves through work that has been devalued and essentialized as a “female problem.” But I move beyond the findings of Quinn and Toms (2019) and Cheng et al. (2016) by arguing that this “positive aspect of care” makes it much harder for the kin care worker to relinquish care over time, and this dilemma paradoxically reinforces the very essentialist stereotypical characterization that women are the best carers.

Methods

This study involved seven waves of in-depth interviews over approximately five years with Latinas caring for a family member suffering from dementia at home. This multi-wave study design offers advantages over the cross-sectional one-time interview design most typical in dementia and care work research because it allows for rapport-building with participants and opportunities for verification over time (Berry and Apesoa-Varano, 2017; Berry et al., 2015). Likewise, longitudinal interviewing enables one to identify change and long-term processes in household dynamics and carers’ views. My grounded theory approach (Charmaz, 2014; Morse et al., 2016) relied on extensive field notes during and after interviews that were critical to analyzing my interviews but also adjusting my questions for subsequent interviews. The study was IRB approved.

Sample

I recruited a non-probability purposive sample through a large health system that provides dementia clinical services and community-based senior centers around the region. Given my interest in Latina kin carers, I selected female participants who self-identified as the primary

carer (whether or not she resided with the care recipient), had been providing care within the year of recruitment, and who spoke Spanish or English. The original sample included 15 Latinas, with three of them declining to continue in the later waves of interviewing (waves 1–4, N=15; wave 5, N=14; waves 6–7, N=12). Of the participants who left the study, one said she was moving while the other two simply stated that they were no longer interested without offering further reasons when asked. Twelve participants were the adult-children of an elder with dementia and three were their spouses. At wave one, participant ages ranged between 44 and 77 years old and the ages of elders with dementia were between 67 and 96 years old. Participants estimated the time since diagnosis from one to 12 years with a mean of 3.73 years at the outset of the study. Participants reported sharing households with the ill family member either part time (5 of 15) or full time (7 of 15) and three did not cohabitate with the care recipient.

Data collection

A total of 98 interviews with kin carers were conducted over the study period. Participants were interviewed seven times at approximately six-month intervals. Interviews averaged two and half hours each and were conducted in person (35) or by phone (63) in English or Spanish per participant preference. I did not notice any meaningful nuance or difference in the interviews whether conducted in Spanish or English. Interviews were equally lengthy and detailed, and Spanish and English speakers appeared equally engaged in every interview. The in-person interviews were conducted in a medical center office without the presence of the afflicted family member, while some care recipients were present in the home during the phone interviews. Carers frequently arranged interviews when the family member with dementia was not at home or was sleeping. Though it is possible that in-person interviews might have yielded more detailed information, there is no indication from my data that the interviews varied depending on context. All participants received a \$40 gift card after each interview. I elicited accounts of care work-related activities and interactions between family members and the family member with dementia since the moment the first signs of the disease were recognized, whether this awareness coincided with the care recipient's formal dementia diagnosis or not. Interview guides for the first two waves of data collection were more general and sought history and context about the care worker, family, and the family member suffering from dementia. During subsequent waves of interviewing, the interview guides focused more on emergent topics and pursued additional details informed by the ongoing analysis and data interpretation. When participants provided generalizations in answering a question, I asked follow-up questions encouraging them to think about who was involved and what, when, how, and why something happened. Besides myself, participants also developed a relationship with research assistants and a post-doctoral scholar who were trained in qualitative research and participated in recruitment activities, project management and the data collection process. During this period, we all met regularly to discuss the status of each participant, resolve emergent issues, and refine the data collection process.

Data analysis

The data analysis began during the first interviews and extended after the data collection was completed. I analyzed the interviews from a social constructionist perspective that holds that

the researcher's subjectivity and positionality always enters the analytical process (Charmaz, 2014; Morse et al., 2016). I utilized a constant comparative method by which coding and analysis generated a substantive level explanation of why care workers typically end up not sharing the burden of caring for a family member with dementia. This meant that categories of analysis were compared within each transcript and within and across waves of interview transcripts. I coded the transcripts line-by-line with the assistance of qualitative software (Deedose) for data management purposes.

As the analysis advanced, I identified patterns in the data and I sought to limit potential misinterpretations of participants' accounts by verifying and validating the findings through probing and further data collection (i.e. theoretical sampling). Achieving validity meant addressing apparent contradictions and negative cases, and at times this required that I look for more contextual information around a specific account or occurrence. Other times, this required that I listen to the interview audio recording to reexamine emotional tone, nature of the exchange or other verbal cues to ascertain meaning. In sum, my grounded theory approach involved simultaneous data collection and analysis with recurrent modifications of interview questions as appropriate to the changing context of the carer and the family member with dementia.

Finally, cross-ethnic comparisons must be speculative in the absence of in-situ additional groups in the study. Part of my analytic reflexivity involved asking whether my results would be different without knowing the care workers' ethnic background. Thus, when the analysis suggests that a finding appears to be ethnic-related I refer to existing literature supporting it.

Findings

As context, it is important to know how carers assumed this role in the first place and I identified three paths to the kin care worker role. The first path involved holding spousal status and a degree of good health (physical and mental) whereby wives (three participants) were the first people to assume the role of care worker. Two other paths were contingent on geographic proximity of children to the home of the afflicted family member. One of these secondary paths involved the intersection of gender and marital status, whereby an unmarried, widowed or single daughter becomes the carer (three out of the 12 non-spouse participants). The other path involved gender and socio-economic resources, whereby the daughter with more education, a better job, and/or more resources assumes the care worker role (nine of the 12 non-spouse participants). Consistent with the literature, care work for my participants was a gendered activity which resonated strongly with how Latinas viewed the role of women in general (Flores et al., 2009; Henderson and Gutierrez-Mayka, 1992). Nonetheless, I would expect that the themes I discuss below are more common than not to women across ethnic groups.

Apart from two care workers who spoke approvingly of how family members had eventually "come together" to help, I found that carers during all phases of interviewing described tense or compromised relationships with other family members. Daughters (whether married or single) spoke of feeling dissatisfied with the quantity or quality of support from others,

especially when it came to siblings. Noticeably, spouse care workers (three participants) were more likely to justify the inconsistent or miniscule help they received from their children or grandchildren as a function of them “having their own lives,” “they have busy lives with work and children,” or “they just live far” but “they do what they can.” In this context, the collective effort so critical to less demanding and less stressful caring is fleeting and tenuous when it needs to be available, stable, and durable. As women whose gender socialization most likely prioritized relationships over individualism (Gilligan, 1982) and whose ethnicity surely reinforced this relational orientation (Gil and Vasquez, 1996), they now found themselves practically alone in caring for their loved one.

Similarly, participants described doctors (and sometimes nurses) as unhelpful. Whether a spouse or a daughter carer, I found three main sources of dissatisfaction with physician help. Participants reported doctors a) not accurately diagnosing the family member or “getting it wrong,” b) not understanding what being a care worker is like or “they don’t get it,” and c) being unable to provide tangible help beyond “just give [him/her] this medication.” Over study phases, participants’ views of their interactions with physicians remained mostly unchanged, except for three carers who in later waves thought they were better prepared to ask the right questions and know how to get physicians to be more helpful or responsive to them. Still, the implication seemed to be that clinical encounters had improved slightly because the carer had figured out a strategy to work with the physician rather than the obverse. Furthermore, as I noted above, formal support groups have been found to be less effective among Latinx (Coon et al., 2004; Napoles et al., 2010), and the women I interviewed who did attend some meetings said that they found them unhelpful and stopped going.

I begin by describing how Latinas acquire tacit knowledge, primarily from family and friends and from caring for their loved one over the years. I then explain how they craft care work by deploying various skills, tactics, and strategies. I then conclude by discussing how the dilemma they face of relinquishing care paradoxically arises from the very knowledge and skills they have acquired over time.

Acquiring and Developing Dementia Care Work Tacit Knowledge

In interview waves 1–2 participants talked about the challenges of their work, often describing in detail the daily conundrums of ensuring the wellbeing of their loved one. With few exceptions (3 of 15), participants expressed feeling at a loss about what to do, not knowing how to accomplish a specific task, doubting their ability to problem-solve, and “shooting from the hip” or “trying something to see if it works.” While there was a range of experience among participants, by and large, early interviews depict a landscape of trials and errors as well as seeking information about how to best care given unanticipated changes in their loved one. Participants also spoke about having trouble accepting their negative emotions upon realizing that things would get progressively worse. Fearing the unknown or the unpredictability of dementia progression was a source of stress and concern (e.g. “some days he knows who I am and other days he doesn’t”). However, this orientation changed over time.

In mid (waves 3–4) and late (waves 5–7) interviews participants began speaking about what they had learned to accomplish care in the home. This shift was even apparent among participants (6 of 15) whose loved one passed away during the study. I found that carers described two ways of learning: from friends and family and from observation and hands-on caring. Often, what participants learned through these different means was congruent. Other times, what they learned from family and friends differed from their own observations in the home, in which case they “tried things” to determine what worked best.

Learning from Friends and Family

Over half of the participants spoke of learning how to care through others such as friends, spouses, or family members who had cared for someone themselves. As Dorita said:

I learned a lot from my husband because [I] trust his experience. He explained about it [dementia] a lot more than a doctor would have... [husband] advised, ‘just trying to get her ready in advance.’ Not to wait because she [mother] can get a little stubborn and don’t want to do things, and let her [mother] take her time. So, we need to allow extra time for getting ready if we want to go somewhere with her [mother]. (Wave 7)

The casual exchange of information among friends was also an important source for comparing how the dementia was progressing or what could be anticipated. Rosa expressed:

In fact, one of his [father’s] younger sisters [aunt] had it and she was diagnosed before he was... And, then a friend of mine had it and it’s just like, everybody I knew had it but you never expect that it’s going to land at your own home... Everybody was complaining about their spouses or their mothers not wanting to take a shower when he [dad] was taking three showers a day. (Wave 7)

In the end, this process of informal teaching would come full circle for some carers as they too found themselves having the experience and knowledge to advise friends. As Gloria shared:

Yeah, so that I got loud and clear from my experience with my mother. So now I can really let other people know... Also, she [friend] has to realize that the advice she gave me is now the one she needs to take for herself. (Wave 7)

For carers, these other individuals were more readily accessible for advice or as a sounding board than resources associated with a health system (e.g. physician, nurse, formal support group). These informal “teachers” or “advisors” were easily reached and more easily understood in the lay context and language of the care workers. Finally, the women consulted these individuals because they had a preexisting relationship based on rapport and established trust. All of these features of learning are most likely absent in the health science intervention models referred to above.

Learning by Being With: Observing and Doing

Carers also describe learning from spending time with their loved ones, observing his/her behavior and trying things to accomplish the care routine. This meant gathering information about what was most effective for completing basic tasks of daily living such as feeding,

bathing, clothing, sleeping, ensuring safety and administering medications (for the latter, see Berry and Apesoa-Varano, 2017). In reflecting upon what she had been told by a friend and her own observations, Nora said:

This lady was telling me that her mother tried to choke her. I thought, ‘oh my God! If he does that to me I won’t be able to defend myself.’ But I found out that not trying to argue with him, not going against his will, if he doesn’t want to eat, I leave it there. Then he’ll sit down and I’ll go over there, ‘let me warm it up a little bit because I think it got cold.’ So, I warm it up a little bit because I hate cold food. So, he’ll be okay with that even though it was 10 minutes ago he didn’t want to do it. (Wave 6)

Likewise, Sonia detailed the changes in her husband and how she has dealt with them:

It used to be more difficult like last year... I sit to eat early because then he gets up real early. He goes to bed at around eight o’clock because he’s tired... He doesn’t get up until around four o’clock and then I’ll take him to the bathroom and then he comes back. But years ago, he was up and down, up and down, sometimes not all the time but sometimes he does that, he gets up and he’s looking for something and he mumbles. ...He doesn’t talk. I mean sometimes we get so excited because he talks.... Not everyone can understand him but I do. (Wave 7)

Spending time with the afflicted family member allowed carers to learn patterns of behavior and try things that might work in achieving a specific task. Recognizing the patterns of behavior and anticipating responses to carer prompts required ongoing engagement and attention to subtle clues and signals.

Even when carers thought they had learned a good deal about their loved one, they also spoke about being puzzled by emergent patterns of conduct that defied their sense making. Luisa expressed curiosity and incredulity around her mother’s apparent contradictory behavior:

She won’t let me take her places... to places that I know will get her out of the house, she won’t do that but she loves to just take off across the street. I can’t figure that out. ...but I try to put myself in her shoes and I can’t even imagine. She’s thinking everything’s okay and nothing’s wrong with her but I see that there is a problem and I’m just trying to deal with it day-by-day. (Wave 6)

Building a deep knowledge of the afflicted person was central to care workers’ accounts of caring. In this sense, participants had two major domains to master—they had to observe and collect information to develop an intellectual and emotional repertoire of strategies to deal with the vicissitudes of degenerative disease, and they had to effectively apply such strategies in doing the hands-on work of daily care.

Crafting Dementia Care: Deploying the Skills of Persuasion to Accomplish Work

Over time, all participants depicted in detail the “games,” “strategies” or “approaches” they used during hands-on care where they applied the knowledge they had about the likes, dislikes, triggers and behavioral vagaries of their parent or spouse. It was while fulfilling

mundane maintenance tasks that women crafted care provision to emerging conditions such as shifting moods, momentary changes in cognition, and physical functioning. For example, Marta explained:

Like he said I lied to him... because you're not really lying. You're just trying to make it easier for him and for you. That is true because if you're arguing it's not going to work. When you get mad it's going to get worse... In the beginning he would say to me, 'did you give me my medications?' And I would say, 'yes, I did.' ...but now he gets upset because I want to give him his medication and sometimes he spits them out. So, again, I have to fill it. If he does that then I wait and put in the medications again and I say, 'honey, you had a terrible headache, you told me so I'm giving these. This is what the doctor wants you to have.' And he'll take them. (Wave 6)

Carers spoke about moments when after much observation and trial and error something "clicked" in their understanding of their loved one. This led Salma to connect knowledge of past behavior with current care.

Her nails are long... she doesn't let me cut them... so I like to have her in her recliner with her feet up, and I bring like a little table and a tray on wheels, and I make it look like spa like. Bring out the white towels, and the towel is in my lap, and then all the cotton balls and sponges. I bought her very own mani-pedi cutting set. So now I try to make it resemble as much as, so she can get the feel of, the ambiance of going to get her nails done. I'll have the nail polishes all set up, and she just smiles, and giggles, and she takes it all in like a sponge. She used to be a model when she was young. She used to have her own consignment store... she [was] into fashion. (Wave 7)

Carmen described how she signed to feed her mother and her novel approach when her mother refused to nap:

Looking her in the eye, mostly by body language. When I tell her it's time to eat, I point to my mouth, and eat. When it's time to take a nap, I just fix the bed. She doesn't want to take a nap, so it occurred to me that if she is not going to take a nap, then I went to the garage, because I do yard sales, and I pulled out the Barbie dolls, and I pulled out this one big, it's called Sleeping Sally, she's like the size of a newborn baby with fake hair and everything. She had blankets and bottles, and clothes to wear. So, I gave that whole box to my mom, and she spent an hour and a half sitting there, just mumbling to the doll, and combing her hair, and changing the clothes, holding the baby. (Wave 7)

The crafting of care meant picking up on behavioral clues, deploying what the carer knew had been effective in the past, and, when faced with a new challenge, creatively using available resources to affect behavioral compliance.

As she reflected on the last few years, Angela spoke about crafting care for her mother:

...[things] are getting better, getting easier. [Mom] doesn't want to do things when I ask, but it doesn't bother [me]. I try to understand, and then we talk to her nicely

and say this is why we are going to do it, and then she changes her mind. You just have to kind of play and know her way. (Wave 6)

As was evident in latter interviews, expanding and deepening of tacit knowledge took time, often years. This knowledge enabled carers to refine their care in ways that achieved desired results in ways that were more relaxed and humane for their loved one without carers incurring the stress and frustration normally documented in the health sciences literature. But if this can be considered an achievement or “positive aspect of dementia caregiving” (Quinn and Toms, 2019; Cheng et al., 2016), it is also a catch twenty-two.

The Dilemma of Relinquishing Control of Dementia Care Work

Over later interviews, a pattern emerged whereby women were reluctant to include others in care provision of their steadily declining family member. While contrary to earlier interviews where carers expressed disappointment about not receiving help from family members, this was merely an apparent contradiction. For women’s views of wanting or needing help must be contextualized in terms of their increasing tacit knowledge and their improving ability to provide what they perceived as quality care compared to others. Maria shared her frustration regarding the help she receives from her sister:

When I take care of her I know what to [do]... right now my sister is taking care of her because of this [interview]... I hear her complaining a lot of mom having messy bowel movements. She had to clean up the bathroom, the floor. She was on her way out the door to bring mom to visit dad on a Sunday. Come to bring her here. She said, ‘Oh, we’re going to be another hour late, two hours late, because mom messed in her pants again.’ I try to teach her how to deal with her but she just... [is] not learning it. (Wave 7)

Likewise, Estela confided her concerns about how her grandson deals with her husband:

One of my grandson’s he’s always trying to force him. I said, ‘no, no. You cannot force him. He’ll get more agitated and he’ll hit you. And you can’t hit him back,’ I said, ‘if he hits you, you cannot hit him back.’ I said, ‘no, just be calm with him and if he doesn’t want to okay. If you just wait a few minutes and then come back and say, okay, let’s go pops and then he’ll go.’ ...but I have to do it, he [grandson] doesn’t learn... (Wave 6)

Having to instruct others in how to care for an afflicted parent was also perceived as a frustrating for carers. “I’m off because it’s technically my day off, but I’m still on. I’m never really off” Angela said, “it is just a constant 24-hour thing... ‘cause I know what’s going on with her [mom]” (Wave 7). One husband with dementia had passed away during the study but Sandra continued doing interviews. Reflecting on having people involved who would not provide adequate care to her husband, Sandra said:

I didn’t want him to get the wrong care, that was my motivation. My brother told me, ‘oh, get a part time person’ and... I’m honest with you, I didn’t like it. As his disease progressed, more years had gone by... and I knew what [was] good for him... (Wave 6)

Whether hired help or a son, the worry persisted, fueled by the sense that only the carer was knowledgeable and provided quality care. In Marta's words:

...when I go out, I do it in a hurry. My son says, 'Mom, why do you hurry? You go and don't worry, I take care of him here.' 'Oh my son, I do worry.' 'No, no.... you don't know how [to] do it' ... Because there's no one else who can take care of him but me, no one else but me. ... And then they even told me 'no, you are the spouse, it's your obligation.' I know that it is my duty. But, you know, I am the only one who know[s] him ... (Wave 6)

This dilemma of whether to relinquish care to others who know much less than the care worker was not lost on carers. Recognizing her emotional ambivalence and the irony of wanting help but not always letting others help, Clara's reflection is representative of others:

I think [I'm] trying to be more strategic. ... Trying to be smart, strategic about what I take on, and when I take it on, and how I react to some of the communications and things that I felt were stressful, stress-inducing, from my brothers and sisters. I am sure when I look back on this whole experience, I might have some insight into what I could have done differently, but when you are going through it, it's kind of hard because you want to take some of the things that your brothers and sisters don't take seriously, to get through underneath what they are saying [about] knowing how to do this work. But it doesn't make it any easier emotionally. (Wave 7)

In the end, though accomplishing daily care was undoubtedly challenging, women kin care workers had too much invested in it, including having learned to understand dementia and figuring things out. But rather than viewing this as congruent with the "prisoner of love" perspective, I propose that these women were more likely "*prisoners of knowledge*." Their love of the afflicted family member was always there, but what had changed was their acquisition of a knowledge base. The skill set that enhanced the dignified self of both carer and parent/spouse was hard to relinquish to novices after years of steady deterioration. For Blanca, the intellectual investment and emotional attachment became fused, making it hard to cede control of the care routine.

It has its moments. I wouldn't have it any other way, I wouldn't want to bring in a care home person you know I'd rather take care of her 'cause I know her... Just seeing her here there [is a] reward. These moments that I have whether they're good or bad, they're my moments. (Wave 6)

Care workers thus struggle with relinquishing control of care. Knowing the "ins and outs" of their loved ones may allow them to teach others but the catch twenty-two is that they believe others "never learn" and they are the only ones who can deal with the intricacies of daily care. Other family members do not contribute because eventually they too see the carer as the "knowing one" – they see *her* as the knowledgeable person to provide care. While a gender and ethnically salient norm holds that "Latinas are always there to care for their families" (Flores et al., 2009), over time it was their recognition that "she knows best" which ultimately justifies family members' reticence to become involved (Guberman et al., 1992; Mendez-Luck et al., 2016). The tacit knowledge that allows carers to enact some agency and

an identity worthy of respect becomes both liberating and oppressing as there is no one else to rely on for skilled dementia care work.

Discussion

That kin carers view the absence of effective help from family members and the health system constitutes the backdrop for what I argue here. Latinas caring for a family member with dementia find themselves with little time and few resources to navigate the daily demands of caring. Given the deterioration of their loved one, they learn the job on the go and do so remarkably well as they develop a deep knowledge of the routines and life of the afflicted family member. It is at this inflection point—developing tacit knowledge to craft care—that kin care workers also find themselves in a conundrum. The longer they provide care, the more they know about how to deal with the ill family member but also the more intellectually invested they become. This investment makes it harder to relinquish care to others, not because it is an “abnormal” psychological state requiring intervention *but because it pays off*. I do not argue that carers’ knowledge or skills are always effective (though they most likely are compared to accessible others). Rather, I propose that given perceptions of others’ pronounced ineffectiveness and lack of knowledge of the afflicted family member, kin carers hold a reasonable edge over others. This situated advantage is developed over time in hands-on care work. Hence, they are reluctant to cede care work to family, friends, even trained nurses, who they understandably perceive as novices and/or transitory care workers who could not possibly acquire the necessary skills in time to provide what they deem adequate care.

Consequently, kin carers “learn” their way into the very stereotype that reaffirms and reproduces the gendering of care work in the Latinx home, and I would argue in most families regardless of ethnicity. However, women kin carers exercise some degree of autonomy to determine when and how to care and, equally important, when they forgo available help. The dilemma of women caring for afflicted kin pivots on becoming “prisoners” not of their love but of their intimate *knowledge* of the care recipient and their *skills* to accomplish care routines that others “just don’t learn.” Moving beyond the medical model that individualizes carer physical and mental states to biological dysfunction, I re-conceptualize these women as competent rather than inadequate carers. Instead of personalizing carers as victims of their fateful love, I argue that it is their knowledge acquisition that is double-edged.

Yet leaving them to care alone is not the answer. If, as feminists contend, “it takes a village to raise a child,” perhaps it takes a village to help a family member with dementia live in a peaceful and dignified manner. Family, welfare institutions, health care systems and practitioners could provide more support by recognizing what carers know and follow their lead where and when it is reasonable (Prior, 2003; Britten and Maguire, 2016). For can any of these other stakeholders know or do better (even with the advantage of the best “scientific” training and knowledge) considering the challenges posed by the progression of cognitive deterioration? At a minimum we can validate dementia kin care work in the home symbolically, and, at best, economically. If “village care” were to start at the onset of dementia, then perhaps acquiring knowledge and skills would be more collaborative, thus

alleviating the dilemma afflicting women carers. Instead of individualizing their struggles, we would do better by defining and making care a collective project.

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Highlights

- Carers perceive providers as lacking understanding of what happens in the home.
- Carers develop knowledge and skills over time which allows them to craft care.
- Carers experience a dilemma about relinquishing care responsibilities to others.
- Carers are “prisoners of knowledge and skills” rather than “emotional hostages.”
- Carers reject help to maintain care quality and protect dignity.