

# “They’re still in control enough to be in control”: Paradox of power in dementia caregiving<sup>☆</sup>

Charlotte Chorn Dunham<sup>\*</sup>, Julie Harms Cannon

*Department of Sociology, Anthropology and Social Work, Texas Tech University, Lubbock, TX 79409-1012, United States*

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## Abstract

Based on an interview study of 26 employed women dementia caregivers, we have found that caregiving involves a complex relationship that is characterized as a paradox in which the exercise of power creates an experience of powerlessness on the part of the caregiver; that the care recipients are not powerless, but encourage as well as resist attempts at providing care; and this relationship occurs in the context of a culture that influences and controls the family through the production of knowledge that is used to shape the caregiving relationship and give direction to the caregiver’s actions. The control achieved by the use of knowledge of medicine and gender is incomplete and is thus embraced yet resisted by caregivers who see the inadequacy of the knowledge for achieving the goal of loving, dignified care.

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## 1. Introduction

Research in gerontology has been limited in the range of its theoretical approaches, primarily focusing on theories that seek universal patterns and processes with which to describe and explain the aging experience. Theories such as disengagement, activity, and exchange seek to impose universal processes on an aging subject, all of which imply that aging involves the experience of decline. Postmodern theorists have rightly pointed out that rather than being objective and universal, the notion of decline comes from a biomedical stance that is part of

a broader cultural process of disciplining the aging body (Powell, 2006). Research on caregiving has been even less theoretically rich, in which the range of problems of old age are extended to the burden and stress imposed on family members who provide care in the face of decline (Berg-Weger & Tebb, 2003-2004). Much research on caregiving has focused on the individual caregiver, identifying factors that contribute to her experience of stress and burden. Fewer studies of dementia care have focused on caregiving as a relationship between two individuals characterized by issues of power and control. We will suggest that dementia caregiving involves a complex relationship that is characterized as a paradox in which the exercise of power creates an experience of powerlessness on the part of the caregiver; that the care recipients are not powerless, but encourage as well as resist attempts at providing care; and this relationship occurs in the context of a culture that influences and controls the family through the production of knowledge

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<sup>\*</sup> Corresponding author. Tel.: +1 806 742 2401x226.

E-mail addresses: [charlotte.dunham@ttu.edu](mailto:charlotte.dunham@ttu.edu) (C.C. Dunham), [julie.cannon@ttu.edu](mailto:julie.cannon@ttu.edu) (J.H. Cannon).

that is used to shape the caregiving relationship and give direction to the caregiver's actions.

## 2. Literature review

Research has focused on the impact of elder decline on caregivers by focusing on stress, burden and coping. The dominant paradigm in caregiving research is a focus on the individual caregiver and her well-being (Berg-Weger & Tebb, 2003) including studies of the effect of caregiving on physical health (Burton, Zdniuk & Schulz, 2003; Turner, Killian & Cain, 2004; Vitaliano, Zhang & Scanlan, 2003); emotional well-being and burden (Amirkhanyan & Wolf, 2003; Chappell & Reid, 2002; Pinquart & Sorensen, 2003; Wagner, Logsdon, Pearson & Teri, 1997); and quality of life (Karlavish, Casarett & Klocinski, 2001).

The underlying assumption of these studies is that caregiving is a difficult and demanding task, which has the potential to disrupt the health and emotional well-being of those providing care. This can be seen as an extension of the decline paradigm in aging because the decline of the care recipient is seen as creating difficulties for the caregiver, which result in compromised well-being. This paradigm further supports the general assumption that discipline and control of the aging body with dementia is best done at home by the family, with the concern of the research the reduction of caregiver strain so that care in the home can be supported (Biggs & Powell, 2001). This focus on decline and subsequent issues of well-being has shaped the kinds of questions asked about caregiving.

Research on care for family members with dementia that addresses issues of power and control often focus on the powerlessness of the care recipient. Higher levels of conflict between caregiver and care recipient have been found to be related to feeling dehumanized (Johnson, 1996). Kitwood (1990, 1997) suggests that dementia caregiving is often achieved using malignant social psychology, which are strategies for care that do not honor the dignity and personhood of the care recipient but are based on such practices as treachery, disempowerment and infantilization. He acknowledges that caregivers do not intend to be malicious, but adopt these strategies because they are often overwhelmed by the demands of the disease and lack sufficient support from the community. This approach does not acknowledge the ways in which care recipients influence their caregivers, relying on prior relationship dynamics and expectations for filial obligations as means of shaping care.

The cultural context under which this care occurs is best understood with the work of Michel Foucault. In his

book, *Madness and Civilization* (1988) Foucault discusses the way in which prevailing systems of knowledge are historically grounded, and have been used as systems of control. As changing meanings of madness occurred, so did the systems of control that conform to that understanding, culminating in the advent of the asylum in the 18th century in France and England. Foucault emphasizes the importance of knowledge as a means of shaping power relations and that "power and knowledge are joined together." (1978/1990, 100). Discourse can be used as "tactical elements or blocks operating in the field of force relations," which makes discourse "both an instrument and effect of power." (1978/1990, 100). Discourse about the nature of dementia, family and medical practices are used to affect the power relationship between caregiver and care recipient, shaping issues such as the kind of care given and who will provide the care.

Caregiving not only involves control over the behavior or actions of the person being cared for, but involves direct regulation of the body or the exercise of bio-power (1978/1990). Foucault referred to the exercise of bio-power as the outcome of the historical processes by which "there was an explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of populations." (1978/1990, 140). These techniques were a means of control that involved not just judicial punishment for wrong doing but the expectation that life itself would be regulated. He stated that "a whole different set of tactics that combined in varying proportions the objective of disciplining the body" emerged that shaped human relationships and provided social stability (1978/1990). He applied this concept to the increasing regulation of sexuality, criminality and mental illness in western societies, but it could be applied to any physical process that has the potential to disrupt social order, including dementia.

Research on aging from a Foucauldian perspective has focused on an analysis of the use of knowledge by gerontological researchers and social service professionals in the control of those with dementia (Biggs and Powell 2001; Katz, 1996; Powell & Biggs, 2003). Biggs and Powell (2001) suggest that the problem for the state is to "establish the health and development of family members who are 'dependent' while promoting the family as the 'natural' sphere for caring for those individuals and thus not intervening in all families." (p. 100). The implication of this statement is that the family caregiver is controlled by the same process of power/knowledge that disciplines the aging body with dementia. The person giving care is constrained as much as the person with dementia is being constrained

by their care (Tremain, 2005). Knowledge is communicated to family caregivers and/or care recipients by professionals who participate in the disciplining of old age. Physicians use their medical authority to explain the caregiving process to caregivers and suggest strategies of control. These formal means of disciplining coexist with societal and individual family expectations, which make the caregiving relationship much more contested and complex than individual theories of caregiving would predict.

These understandings of the way in which knowledge is used to control and shape families leads to a need to look at caregiving as a relationship of control. In this paper we will examine the ways in which caregivers discuss the issues of power and control. This will include an examination of the way they speak about control of the care recipient, their use of medical and cultural knowledge in that process, and the ways in which that knowledge is resisted.

### 3. Sample and methods

We conducted a series of intensive interviews with 26 employed women caregivers in the Panhandle and Western regions of Texas, including caregivers living in both rural and urban settings. Women were included in the sample if they were caring for a family member who had been diagnosed with Alzheimer's or an Alzheimer's like condition and who were employed in the labor force during some portion of their caregiving careers. Respondents were recruited in a variety of ways. Some were found through contact with a support group organized by the local Alzheimer's Association, through contact with individuals whose care recipients were involved in drug trials at the local medical school, through the media and through snowballing techniques.

We focused on women because research has shown that caregiving is gendered and that employed women caregivers have fewer resources yet are in caregiving relationships that place greater demand on the caregiver. This results in higher levels of strain, work interference and role strain than men who are caregiving (Fredricksen, 1996; Neal, Chapman, Ingersoll-Dayton & Emlen 1993). We used dementia as a criterion because it puts greater strain on caregivers that increases the likelihood of interference between work and caregiving (Ory et al., 1999) Research has found that behaviors often associated with dementia such as wandering, repetitive questions and body maintenance are related to greater caregiver stress.

Even though the caregivers' ages ranged from 29 to 74 years old, the mean caregiver age was 53. The caregivers had a variety of occupations but more than half were involved in caring professions, such as nursing, teaching and counseling. Of those in caring professions, eight were educators, five were nurses and three were school counselors. Of those in other professions, five were small business owners, two were secretaries, one was a banker, one was in public relations and one was employed in sales. Two homemakers were added to the sample for the purposes of this research. We interviewed individuals at a variety of stages in their caregiving careers. At the time of the interview, nine of the care recipients had been placed in nursing homes, seven were in the caregivers' homes, six were in their own homes and four were deceased. Most of the respondents were married and caring for their mothers. Eighteen women were married, four divorced, three single, and one was widowed. Twelve were caring for their mothers, three for their fathers, one for her husband and her father, five for a husband only, three for a mother-in-law and two were caring for a grandmother. All were caring for someone with some form of dementia, most often the care recipient had been diagnosed with Alzheimer's disease.

We conducted semi-structured interviews, usually in the homes of the respondents, which lasted on average about one hour. Open-ended questions were asked about the entire caregiving career on topics including emotional strains experienced, the benefits of caregiving, and the adjustments made in family and work life. Each interview was audio recorded and transcribed for analysis. The analysis involved a process of developing general topics then increasingly specific conceptual categories.

### 4. Findings

#### *Naming decline*

Caregiving for a family member with dementia must begin with a redefinition of the status of the care recipient from competent to not competent so that the caregiver believes she should intervene on his behalf. This occurred in our data when caregivers witnessed behavior that was not characteristic of the individual and they defined this as evidence of decline and the need for their intervention. A nurse caring for her mother describes a gradual process of decline in memory and cognitive abilities:

Uh, getting lost more and more. Misplacing things. Uh, not able to carry on a conversation that made

sense. So it was approximately eight or nine years ago that I recognized it and, uh, even family members and friends began to, uh, tell me they recognized something was wrong.

A teacher described an incident of confusion when her husband got lost coming home, which led her to realize that something was seriously wrong.

Well when he was getting lost coming in from the farm, wandering around, you know. I was in the yard and he went by and I yelled at him. He just kept a going up the street and pretty soon, I thought, 'He doesn't know where he is.' And I got in the car and tried to find him. Well then, I couldn't find him, so I called the law.

Caregivers described care as beginning with situations where family members who could no longer do for themselves. Examples include a mother who had her house foreclosed because she did not pay her bills. Another caregiver took over her husband's business affairs after his partner asked for her intervention because of a series of atypical and inappropriate business decisions.

Knowledge, especially medical knowledge, plays a major role in establishing the differentiation between competent and not competent care recipients and helped them to make sense of the changes in the family member. Women relied heavily on medical knowledge in the form of a medical diagnosis before assuming control over the affairs of a family member.

#### *Caregivers: knowledge and resistance*

##### *Medical knowledge*

Medical knowledge was used by caregivers to manage the caregiving relationship and the person with dementia. Medical knowledge provides caregivers with an answer to the question "what's going on," which allows them a sense of control in a seemingly unpredictable circumstance (Lyman 1993). One caregiver referred to the fear she experienced not knowing the reason for her mother's behavior and that the diagnosis was an important factor for relieving that fear. Referring to their physician, a teacher caring for her mother stated:

He conducted seminars, really explained a lot of things. He'd name these things. I'd say, 'He's talking about mother. But, he's talking about all of them.' And then we began to realize that this was the disease. This is why she is sick.

However, an academic advisor who was caring for both parents expressed frustration with the limits of

medical knowledge in helping her exercise control over her parents.

Even the doctor out at the [medical center], when we brought 'em here, I'd go see him [the doctor] every six months or whenever we were supposed to go. One time he just said, 'You're doing real good. If you need me, call me. And I think you're doing alright.' I thought, 'Is that all you have to say? Thanks.' He says 'There's nothing I can do for you. So you're on your own.' (Respondent laughs)

She understood that medical knowledge can assist in the exercise of power and control by shaping her understanding of the problem, but that is not the same as providing the control itself. Another caregiver resisted the tendency of the medical establishment to dehumanize family members with dementia.

A nurse caring for her mother, referring to her care recipient's doctor, said:

Some of them, they just give up on people. Like they get to an age that, uh, should be in a nursing home or they should be in a different setting, like they wanna brush 'em aside and forget them. And you don't do that. You've got to deal with the problems here and now and treat 'em like human beings. And I, and you've got to find some help.

In statements like these, caregivers are showing their frustrations with the limits of medical knowledge and their resistance to certain aspects of medical control, especially when it affects their own ability to maintain what they define as the dignity of their family member.

These caregivers did use techniques of deception, but mostly in situations where it was necessary to protect the safety and well-being of their family members. Deceptive practices were used to keep family member from driving including hiding car keys, placing a pickup in the shop and not retrieving it, and disconnecting a car battery. Others types of manipulation that were described by caregivers included threatening to withdraw care or threatening the possibility of embarrassment by having an in-law provide direct body care. For example, the banker's mother-in-law was resisting receiving her required blood tests. She and their family physician:

just decided that she could stay by herself without any more help. And, I mean, she straightened up real quick. She's gonna give blood every two days if we have to drain it from her.

However, our results show that most caregivers are aware of the implications of using these techniques and try to find strategies to maintain a family member's dignity.

*Knowledge and the challenge of maintaining dignity*

Discourse about role reversal from the social and behavioral sciences helped to provide a meaning for the situation, yet created negative implications for maintaining the dignity of the care recipient. A teacher caring for her mother described advice given to her as: “But the doctor told me, he said, ‘you are now going to become a mother. And she’s going to be the child. And, he said, ‘and it will last longer than when you were a child.’ One woman referred to the care relationship as having children again. I have “two new kids.” Other women use the analogy of babysitting for their care relationships. A woman employed in marketing who was caring for her mother said:

It was kinda like babysitting in some respects. I keep her out of trouble. Don’t let her, don’t let her lose her purse. Don’t let her take everything out of the closet. Don’t let her turn the oven or the stove on. Watch out for her safety.

Caregivers resisted this understanding of their family member and the implications it had for their dignity. The care recipients were not children, but adults who deserved dignity and respect. A nurse caring for her mother referred to the stress of maintaining the dignity of the care recipient who has experienced a significant change in behavior.

It’s somewhat different than kids because you can discipline them (children). Adults you have to treat them with respect and try to use other methods than children.

Our analysis suggests that the effort that caregivers take to preserve the dignity of care recipients affects the way in which caregivers exercise control. Rather than being an absolute exercise of control once the caregiving relationship is established, control over the care recipient proceeds gradually as the disease progresses. For example, an elementary school principal caring for her mother described how as the disease progressed, she had to increasingly direct her mother’s bathing.

I used to call and just tell her to take a bath and now I go in and watch her. I make sure she really bathes ‘cause she doesn’t. I make sure she really gets in the tub. I probably watch her more ‘cause I know it.

Some caregivers discuss the ways in which they try to maintain their parents’ sense of dignity and sense of control even though care recipients are not able to make decisions themselves or control their own

behavior. A school counselor caring for her father described her caregiving strategy in the early stages as “A little bit of control over the situation but still trying to leave it basically up to them to be capable of meeting their own needs.” As stated by a nurse caring for her grandmother:

She’d forget how to do that or just wouldn’t do it or whatever and, um, we would kind of coax her along to take care of her personal needs, and well, she’d be real offensive about it. She’d be real angry most of the time.

A woman who works in sales who is caring for her father expressed her dilemma but saying “How do you make someone who can’t leave the house feel worthwhile? And how do you make someone who can’t tell time or the day of the week – and knows that something’s wrong with him – feel ok about himself?” These caregivers are aware of the challenges they face in preserving the dignity of their family members and must strike a delicate balance between control and dignity. These caregivers use strategies to avoid the practice of ‘malicious psychology’ as described by Kitwood (1990, 1997) when possible.

Caregivers rely on knowledge that implies that Alzheimer’s disease is a progressive loss of personhood, which reflected a loss of mind but survival of the body, which can challenge one’s attempts to maintain dignity of the person. The woman in sales caring for her father said “But you have to remember that body is not who the person is. The person is gone.” The woman working in marketing caring for her mother said “There’s no sense in asking her...she’s not there, as far as that part of her.” Another says that “I wasn’t dealing with a human. Isn’t that a terrible thing to say? I wasn’t dealing with a human being.” A poignant description of the feeling of loss and disconnection is illustrated in the statement of a school counselor caring for her mother:

I go every day to see my mother. You don’t really delve into the feelings and the emotions of what’s really going on and what shaped her and all of that. But there are times and a lot of times it’s at night when she’s in bed and then I start thinking about the woman she used to be, and the relationship we had. It’s very sad and it’s just sad to see her like that. I think about this almost daily, especially when I take her out and walk with her, that at least I have her physical being there. And when she’s not there, I don’t know what I’m gonna do ‘cause I talk to her all the time, even though she doesn’t say anything. She has no idea what I’m saying. I tell her about what

I've done during the day or the breaks that I've had or relationships I'm going through or whatever. And uh, she is just there to talk to. When I had my bad headache last week, I put my head down in her lap and put her hands on me. I'm gonna miss that.

In these statements, caregivers reflected the conflicted nature of their reactions to the medical community and the medicalization of care. While they may embrace the help with the caregiving task that medical knowledge can provide, they sometimes reject the depersonalization that can accompany medical definitions of care.

### *Gender knowledge*

The same embracing yet rejecting of knowledge occurs with women's use of gender knowledge in explaining care. Women referred to beliefs about differences between women and men to explain their caregiving responsibilities. A caregiver who works in banking who is caring for her mother-in-law revealed contradictory beliefs about the roots of gender differences: "I just don't think men have that caring. They, they, they just are not born with it. I mean they might be born with it. It's the way they're raised."

In many ways, women expressed this responsibility in gendered terms, as part of their identity as women. One of the school counselors caring for her mother said:

I don't do it for the other people that see me there but, you know, everybody (says), you know, what a good daughter and it's good that you come and everything.....it feels good when they say that, but I would do it even if they didn't."

A teacher caring for her husband stated:

You know, I just do what ... what a mother would do or a wife would do ... I tell you there are a lot of these girls is just too much social life where you get too far out and they don't stay in the [family] unit.

At the same time, women also show their ambivalence toward use of gender knowledge. Women express their disappointment that other family members, including men, are not willing to help them more than they do. They also express resentment that men may make decisions, yet don't have to participate in the hands on, difficult aspects of care. A nurse caring for her grandmother expressed her frustrations as:

Men that seem to make the decisions, when its time to do things, it's the women who have to do all of it.

And that what's seems to be done here. When it comes time to decide whether or not to put my grandmother on life support, you know...Well they're always quick to make decisions, but never quick to act...Oh my grandfather, my husband and my brother would all get together and they'd decide what to do... And none of them knew what they were talking about. They just knew whether to live or die. Not how to live or die.

Women described love and commitment to family as another motivation for care. As a self employed woman caring for multiple family members described, "the love there that one has for your family, and um, knowing that, uh, they are alone and you try to brighten their day just as much as you can." Others referred to the importance of caring for the elders in the family, especially keeping them from being cared for in nursing homes. Their expressions of love also involved a desire to repay family members who gave them loving care as children. As a public health supervisor who was caring for her grandmother stated:

My grandmother always took care of us when we were younger and, uh, she helped through college. So, yeah. It did. It helped me able to, gave me a, a sense of being able to give back that when she did to me.

### *Shaping their own care: demands and resistance*

Caregivers complained about care recipient's resistance to their care. It may not be possible to know the motives of the care recipients given their dementia and level of cognitive decline. However, it is important to stress that the caregivers often experienced their refusal to comply as resistance to their care. Resistance involved refusal to accept medical care. Caregivers would schedule medical appointments and procedures and have difficulty getting their parents to go to them. One caregiver, using the medical perspective of cognitive decline to explain her mother's refusal of surgery said, "she really was not able to make rational decisions."

Care recipients also refuse daily hands on care, such as dressing and bathing. A small business owner caring for her mother described an incident that she found particularly difficult as "bra wars," in which her mother refused to wear a bra. The caregiver employed in marketing said that her mother refused to take baths. "She wouldn't sit down in the bathtub and she wouldn't get in the shower. We just couldn't handle it." This

daughter was able to get her mother to comply with bathing by suggesting that her husband (the mother's son-in-law) assist with bathing as well. The prospect of embarrassment assured her compliance. One father refused to move to town to be closer to his caregiver. His daughter, a nurse, said: He said. "I'm not going anywhere. I'm gonna die right here on this couch.' He wants things the way they were ten years ago. Except he's not driving."

This resistance also involved emotional responses that the caregivers find stressful and difficult. Caregivers noted that care recipients often responded to the care with anger, and sometimes violence. The caregiver who worked in sales described the negative emotions as "He's rejecting me. He's rejecting me more and more."

Caregivers saw this refusal as a source of negative emotions and stress. Caregivers expressed regret and guilt especially when they lost their composure and showed their frustration to care for the recipient. The elementary principle caring for her mother stated: "Sometimes she'll say something to me and I'll say something. And I feel guilty about it." A homemaker caring for her mother described "Because you run out of patience. No matter how hard you try, you run out of patience at times." And the caregiver who worked in banking says. "You know some of the things that she pulls... you just wanna shake her. But yet you have to laugh about it. Or you go crazy."

Caregivers also described unreasonable demands for time and attention that were placed on them by care recipients, much as described by Kittay (1999). One caregiver said that her parents were constantly putting pressure on her to spend more time with them, even though she had already given up her home in another city and had moved into a home near them. A teacher talked about the pressure her mother put on her to quit her job and care for her full time. The pressure to put full attention on her mother included her mother's resentment of her watching TV or reading when she was at her mother's home.

She was demanding we be there at all times. She wanted me there at all times. She wanted me to quit my job. Quit teaching and take care of her. She didn't want to hear me when I said that I couldn't quit my job.

Parents also referred to their child's obligations to care for them because the parents provided care for the caregivers when they were children. In the case of one family, demands for care involved the expectation that a caregiver give up other family obligations and focus

entirely on her parents. The academic advisor caring for both parents said that:

At one point father told my husband that, uh, he had me long enough and that he was supposed to give me up and I was to move out there [California]. [He was saying that] you give up your life and move in with us and take care of us.

Much of the conflict in caregiving derives from conflicting expectations about control. Sometimes care recipients draw upon old hierarchies within the family to refuse care and maintain control. One father who was irritated at his middle aged daughter told her to "go to your room." A school counselor referred to behavior of a younger self when she stated,

I guess that's typical parent and child relationship. Uh, they're still masters of putting me on a guilt trip. And when they put me on the guilt trip is when I'd most like to run away from home and not come back.

As another school counselor stated.

Again I see in terms of the stress or the conflict as their being able to accept me as, uh, the one in caregiving. Uh, and me taking care of them now rather than them taking care of me. Uh, it's a control issue. I'm still their little girl. They're supposed to be in charge.

A nurse caring for her grandmother expressed frustration of her mother's continued need to be in control.

Well, she always had an opinion about what I should and when I should do it. Regardless of whether it met my needs of hers or the kids or. It was her way or no way. And she would always forget how to do things, but yet she always would tell you how to do them. And it'd be like cooking. She wouldn't know how to turn on the stove, but yet she would sure tell you how to cook.

A school counselor expressed frustration that her parents insisted on maintaining control in the relationship when she was trying to influence their care:

There are days, I feel like it's worse. When they don't listen to the advice I give 'em or the points that I try to make about something that I feel like needs to be done or taken care of in a certain way. And they're still, uh, they're still in control enough to be in control.

Caregivers do not always encounter resistance on the part of care recipients, and the resistance depends on the

stage of care. For example, the caregiver who worked in banking said:

She stopped driving probably six or seven years ago due to her passing out. And that was really easier than we thought it would be. I mean, we felt we, we'd have a real battle on our hands. But she was wise enough to see that she couldn't drive anymore.

#### *Paradox of dementia care*

This resistance and desire to maintain control on the part of care recipients raises a paradox about power. Even though one could say that women caregivers are powerful in this relationship, they feel the opposite. Many women describe feeling powerless and out of control of their own lives. The daughter who worked in marketing called caregiving a "total emersion project." A nurse caring for her mother said, "I don't think I can identify the feeling. Sometimes it's anger. Anger of having to do this all by myself, with a feeling that there's no relief and there's no one out there that understands." She added that family members have difficulty understanding her position. "They cannot understand the strain you are under 24 hours a day. That you have the responsibility of seeing to their every need." Simply put, she said: "I gave up my life." The depth of hopelessness that a caregiver can feel is illustrated in the following quote in which a caregiver was dealing with her father's increasing violence and need for institutionalization. She felt that she was failing him because she could no longer care for him at home and wanted to spare him the indignity of being in a nursing home without understanding why. She saw her father's death as the only solution to the dilemma.

You know. And, uh, and you wish that he would just die, and you know. I wish that daddy would just have a heart attack and die. ...it would be so much easier than him knowing something's wrong and not knowing what it is.

In this web of power women take on these responsibilities for a variety of reasons, including acceptance of knowledge about gender that says that they are the ones who can do it. The irony is that women in this study describe few if any sources of personal gain from this relationship. But they do this from a sense of obligation that they are the ones who should do this, because they are family members and they are women. This sense of obligation is accompanied by ambivalent feelings about caregiving as they deal with contradictory demands of dignity versus control, and anger and guilt versus acceptance.

## 5. Conclusion

The purpose of this research was to examine the way in which power and control were understood and used by caregivers to accomplish care. When looking at caregiving as occurring in the context of a relationship between two people rather than one person acting upon a powerless person with dementia, we found that caregiving can resemble a tug of war over control, especially in the early stages of the disease. Caregivers confront the task of caring for a family member with the expectation that the person is not competent and that they must substitute their judgment and care for that to of their family member. They use knowledge from medicine and social science as well as expectations about family and gender to shape the way they understand and give care. This knowledge includes the expectation that a role reversal occurs, in which they are now the parent and the care recipient is the child. While they adopt the concept of role reversal as a way of understanding care and as way of establishing control, they are also aware of the limits of that understanding. The parents they are caring for are not children, but adults who hold expectations that they will continue their lifelong patterns of autonomy and dignity rather than surrendering them to the disease. The fact that medical knowledge does not acknowledge the agency of care recipients in this process leaves a void in the support that is available to caregivers and can lead to patterns that exacerbate the problem. This void also contributes to the caregivers feelings of powerlessness and lack of control over the relationship because they must also battle with negative reactions from the care recipients.

The care recipient may understand she needs assistance, because at this stage of the disease, she is still aware of the changes in her memory and competency. As one caregiver stated her family member was "still in control enough to be in control." The task facing her is to maintain control over the care she receives in such a way as to support her identity as a competent adult and to meet her needs as she sees them. Persons with dementia may understand their need for help, but the decline in the cognitive abilities as well as the resulting dependency can lead to anger, frustration and exaggerated demands of the caregiver. What makes this more difficult for the caregiver is that the responses of the care recipient are often emotional, irrational and insistent upon being treated as a person in a position of authority as they have been most of their lives. While caregiver strategies using the concept of role reversal may be helpful for understanding the disease, it can also



exacerbate the care recipients' feelings of loss of dignity and autonomy.

The caregiver is trying to accomplish this task in the context of a culture that pursues the disciplining of the aging body with dementia through the dissemination of knowledge about the disease from professionals to family caregivers. Medical professionals influenced and controlled the caregiver through their control over medical diagnoses that not only justified their control but shaped the understanding of the relationship between care giver and care recipient. Physicians provided understandings of 'what's going on' when their family member exhibits bizarre and uncharacteristic behavior as well as a template for understanding the changing relationship to the care recipient in the form of the concept of role reversal. Physicians also collaborated with caregivers in practices of deception to control the care recipient's behavior, especially when the well-being seems at risk. This control occurs at the nexus between the formal medical practices of disciplining the body with dementia and the informal care provided by family members who are motivated by their own needs to maintain a positive identity as well as feelings of love and gratitude to family members who have cared for and nourished them earlier in life.

The disciplining of the body with dementia and the person who provides their care serves the needs of the larger community. Not only does this pattern minimize the disruption to the community from the behavior of people with severe cognitive impairment because it is isolated in the home, but the stressors experienced by women caregivers go unchallenged and unchanged. The feelings of powerlessness result from the inadequacies of the medical understandings and community supports that caregivers receive.

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