

Caring in Context: Structural factors, burden, and identity adoption for informal
Caregivers of patients with Alzheimer's dementia or Chronic Kidney Disease

An Honors Thesis for the Department of Sociology

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Abstract

Many older patients with chronic illnesses ranging from chronic kidney disease (CKD) to neurodegenerative disorders such as Alzheimer's dementia rely on family or friends to serve as informal caregivers for them. While there has been research done across multiple fields about individual aspects of caregiving, there is little communication across fields and no real attempt to look at the caregiving experience as a whole, and in particular what structural factors influence the wide range of caregiver experiences.

I conducted a series of 27 semi-structured qualitative interviews with caregivers of patients with either chronic kidney disease or Alzheimer's dementia exploring the patient-caregiver relationship, caregiver burden, and identity. I analyzed the interviews using grounded theory, developing a codebook to identify emergent themes.

I found that the experience of caregiving is contextual and dependent on factors such as disease type, strength and nature of the interpersonal relationship between patient and caregiver, socioeconomic factors, and temporal context related to uncertainty about the future. In particular, the type of disease and its symptoms and treatment were essential in shaping caregivers' responses to their situation, especially whether or not caregivers embraced a caregiver identity or not. Variations and combinations of these factors shape caregiver experiences, perceived burdens, and caregiver responses to these burdens.

The interactional nature of these contexts mean that theories and models developed by various disciplines may not be suitable to explain the experiences of

caregivers. Only research that takes a wide and interdisciplinary look at caregiving can illuminate the experience of informal caregivers, research which I hope this paper demonstrates would be immensely valuable.

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Introduction

Two caregiving experiences worlds apart

Tonight, Annette and her mother are having leftovers for dinner. Her mother, now entering her sixth year on hemodialysis to replace the function of her kidneys, which was removed in a surgery, made that request to Annette after she noticed that Annette looked particularly tired from work. Usually, Annette is in charge of cooking for herself and her mother, in addition to helping her mother with medications, doctors' appointments, housecleaning, and arranging for her transportation to the dialysis clinic. All this is on top of continuing to work full time remotely at home.

She has been in charge of these responsibilities ever since her mother got out of the hospital and started going to rehab and the dialysis clinic, and while she recognizes that these responsibilities take up a big part of her life, she thinks of the experience of caring for her mother as an overall positive experience. For Annette, caring for her mother was something that brought the two of them back together after drifting apart as adult children and their parents sometimes do, and Annette feels closer than ever to her mother. It has been good for Annette and her siblings as well, who help take care of their mother on weekends and call regularly to check how both of them are doing.

The picture is quite different for Cathy. She just got back from taking her mother with advanced Alzheimer's dementia to a family wedding, where she felt unappreciated and taken for granted by her siblings who she feels do not do their fair share of the responsibility of caring for their mother. Cathy, as the oldest

daughter and the one who was perceived as not having a family of her own to take care of, started caring for her mother five years ago. In that time, she has essentially had to stop working as a realtor, felt difficulty making time to spend with her own daughter even on her wedding day, and has slowly become drowned by the unceasing demands of caregiving on her every hour of every day. Life has been difficult for Cathy. She has tried to get some sort of help, and has recently entered her mother into a day program for individuals with Alzheimer's, but she feels as though she does not have enough time for herself and that she "can't be everything", being overwhelmed by her responsibilities.

Why is there such a stark contrast between Cathy and Annette? They are both what are considered informal caregivers, and yet their experiences, and more importantly their interpretation of the experiences, are radically different. The difference in diseases already provides one clue: how does disease type influence the type of experiences informal caregivers have? But even caregivers dealing with the same disease have different experiences. So this in turn leads to a broader question that must be answered: how do different contexts, including the context of disease type, affect and interact with the wide spectrum of caregiving experiences faced by informal caregivers?

Understanding more about how and why context matters for informal caregivers is critically important for the future of elder care in the United States. Currently, a large proportion of elderly persons who need long-term care, 1 in 3 by some calculations, is cared for by so-called informal caregivers (AARP Public Policy Institute, 2007). These are friends or family members who take the time

and effort to care for somebody they know, often without formal training or financial compensation as would be the case for a professional caregiver.

However, as the stories of Cathy and Annette illustrate, informal caregiving is not a monolithic experience for the caregivers involved, and current literature on caregiving is fragmented and compartmentalized across multiple disciplines from clinical medicine to psychology, to sociology and anthropology. An approach informed by the work done in all these disciplines is required to understand the broad range of caregiving experiences, which will become even more important as the number of individuals aged 65+, is expected to double in the United States by 2050, leading to a substantial increase of the number of informal caregivers barring demographic changes or massive changes in the healthcare system (AARP Public Policy Institute, 2007).

The disease context: Chronic Kidney Disease and Alzheimer's Dementia

In order to learn more about how context matters for informal caregivers, I decided to study caregivers of two different patient populations: patients undergoing dialysis treatment for Chronic Kidney Disease (CKD) and patients with Alzheimer's dementia or similar cognitive disorders. Chronic Kidney Disease is a disease which offers unique challenges to patients and caregivers alike. Patients with CKD have kidneys which are unable to function properly and are therefore unable to filter and process bodily waste. While the ultimate goal in most cases is to get a kidney transplant, the time to receive a transplant is often long. In the meantime, patients usually undergo dialysis, which replaces the function of their kidneys.

Dialysis can be done at home or in specialized dialysis clinics, but in both types of dialysis, the patient undergoes significant medical treatment on a regular basis, from every day in peritoneal dialysis to several times a week on hemodialysis. As a result, caregivers too become heavily involved in the patient's care, whether that means helping the patient with dialysis at home or driving them to the dialysis center. In addition, hemodialysis in particular is physically draining for patients, and they often end up needing other care to be given to them, from help shopping, to help cooking, and to help bathing in some cases. While memory issues can be co morbid with CKD, I am more interested in the physical nature of the illness, and so CKD patients with memory and personality disorders were excluded from this study.

Alzheimer's dementia on the other hand, is a progressive neurodegenerative disorder for which there is currently no treatment or cure. Over the course of the illness, the patient may experience changes in personality, memory loss, and loss of recognition of significant others in their life. Patients often become unable to take care of themselves, requiring the need of caregivers to go about daily activities as simple as getting dressed in the morning, and requiring the constant attention of caregivers as caregivers worry about them wandering off or getting lost if they are left unattended. Communication also becomes difficult as cognitive capacity of patients declines in parallel to losing a sense of their already established social connections. Caregivers for patients with Alzheimer's may not be able to help with direct medical procedures or

medications, but the time commitment is also significant, in addition to the unique challenges that come from the mental and cognitive changes of the patients.

What is known – State of the literature

The literature on caregiving, though varied across disciplines, does present significant insights. A variety of theoretical frameworks across social science disciplines are well suited to discuss caregiving. Whereas sociological concepts such as role theory, social exchange, and the sick role can provide insight into how patients and caregivers are expected to act, theories of dramaturgy and emotion work can offer explanations on how caregivers attempt to meet those expectations. Borrowed from the field of psychology, both the cognitive model of caregiving described by Kuipers et al and the modified caregiver stress-health model discussed by Monin et al offer a lens to understand caregiving that could possibly be applied to caregivers of patients with CKD or dementia.

The literature even helps describe the unique challenges facing caregivers of patients with CKD and dementia. In the CKD caregiver literature, researchers have emphasized the unique challenge for caregivers of patients on dialysis, including both hemodialysis and peritoneal dialysis. Researchers like Mollaoglu and Avsar dig deep into the heavy medical involvement demanded of CKD caregivers and the effects that has on their lives, whether from increased stress and physical symptoms to increased burden from worrying about insufficient medical knowledge. Amongst dementia caregivers, remarkable insight has been gleaned from researchers like Karner, Bliezner, and MacRae about the relationship and personal interaction challenges that caregivers face that play a

major role in caring for a patient with dementia. However, the literature does not sufficiently analyze or understand the importance that structural factors and context play in the caregiver experience, and while various disciplines touch on such factors here and there, by and large they are ignored, especially the context of disease type.

Sample and Methods

In order to better understand the experiences and contextual environments of these two caregiver groups, I decided to perform a qualitative interview study, with 27 semi-structured interviews conducted with caregivers of either of the two illnesses. Because of the nature and epidemiology of the illnesses being studied, the patients were older, aged 65+, though the ages of the caregivers were distributed over a wide range, with the only age cutoff criteria for caregivers being that they had to be over the age of 18.

Qualitative semi-structured in-depth interviews were chosen as a method in order to have a better understanding of not only the types of responsibilities and informal caregivers had, but also how that made them feel and how they managed them. A semi-structured interview guide was designed using insight gained from a review of the literature. The guide was reviewed and edited using input and suggestions from advising academics before being implemented.

Participant recruitment

The criteria for participation in this study were English speaking, age 18+, and caring for a friend or family member with one of the illnesses mentioned above. Part of the data was taken from a project conducted summer of 2015 as

part of an independent research project. For that study, I worked closely with dialysis centers and nephrologists in the Boston area to locate and interview known informal caregivers of patients being seen in those centers and by those physicians. A total of 28 caregivers were contacted by mail and by phone, in addition to time spent in waiting areas performing in-person recruitment. Of these, 10 caregivers agreed to be interviewed for the project. This series of 10 interviews were conducted in person between May 2015-August 2015, and the interviews were transcribed with the assistance of previously trained undergraduate student research assistants, serving as 10 out of the 27 total interviews conducted for this study. The associated patients for five of these caregivers had been interviewed earlier, and data from those interviews was used for analysis as well. These five patient interviews are not included in the total count of 27 caregiver interviews.

At the start of this project, initial caregiver recruitment was attempted through hospital-based physicians in the Greater-Boston area, including neurologists and geriatricians to locate caregivers of patients with dementia, and nephrologists to locate caregivers of patients on dialysis. I asked them if I could distribute informational flyers in waiting areas, or if they could recommend any informal caregivers that they knew through their practice. Initial response to this recruitment technique was low initially, and there were several cases where a response was not received. Next, caregiver recruitment was attempted through assisted living facilities and Alzheimer's day programs in the immediate vicinity. Two caregivers of care recipients with Alzheimer's were recruited through these

sources. Recruitment attempted via cold-contacting of Alzheimer's caregiver support groups were unsuccessful.

Between January 2016 and February 2016, a large number of elder care services were contacted with little to no success. Separately, after a lengthy verification process, the dialysis centers used for the summer 2015 project again began to refer caregivers of patients on dialysis, referring four additional caregivers in addition to the ones interviewed over the summer. In late February 2016, an in-person contact was able to introduce me to several contacts in other elder service programs and caregiver support groups who were able to refer me to several interested participants. Around this time, a modification was submitted to the IRB and approved to allow for phone interviews as a result of one of the original physician contacts explaining that the caregivers she knew were unable to be interviewed in person. As a result of this modification, 11 caregivers caring for patients with Alzheimer's dementia were recruited for the study through this pathway. In total, 17 caregivers of care recipients with either Alzheimer's or chronic kidney disease were interviewed during fall, winter, and spring, in addition to the 10 caregivers from the previous summer, for a total of 27 caregiver participants. Selected demographics for the entire caregiver sample can be found in the table below.

	Alzheimer's dementia n=13	Chronic Kidney Disease n=14
Partner/Spousal connection	3	8
In person interviews	6	13
Female sex	10	10
Race		
White	8	10
Black	3	2
Asian	2	0
Mixed	1	1
<p>Note: If caregiver did not have a partner/spousal connection, then caregiver had a child/grandchild connection. If an in-person interview was not conducted, a phone interview was conducted. If caregiver was not female sex, then caregiver was male.</p>		

The majority of the caregivers interviewed were female and white, though aside from underrepresentation of caregivers of Latino/a origin, the representation of persons of color is fairly close to the demographic breakdown of the city of Boston, at least among dialysis caregivers. Caregivers of patients with a neurodegenerative disorder such as Alzheimer's dementia were much less likely to be partners or spouses, and were often unable to meet in person, preferring interviews over the phone. It is possible that the discrepancy in the proportion of spouses providing care could be a result of sampling bias: the sources that participants were recruited from were sources which lend themselves to more active and involved caregivers, such as doctor's appointments or support groups. It is possible that there are more spouses and partners taking care of their care recipients who, due to their own age, might not be as involved in these systems, and so were not recruited.

Data Collection

Participants were interviewed either in person or over the phone using a semi-structured interview guide. Questions in the interview guide were focused on their caregiving responsibilities, social support networks, identity formation, and interactions with their care recipient. The interviews ranged in length from 45 minutes to 82 minutes, with the average length of an interview being 59.5 minutes. The participants were given an option of allowing or refusing for their interviews to be recorded for transcription purposes only, but all caregivers gave permission for recording. The interviews were recorded and then transcribed.

Data Analysis

Data coding was done using grounded theory to iteratively generate and identify themes from the interviews. A codebook of themes was developed after a preliminary read of the transcribed interviews. These themes were then supplemented from themes observed from the literature review of the caregiving literature. The themes were then used to code the transcribed interviews using NVivo 10 Software.

Outline of Chapters for the Thesis

In Chapter 1, I will review the current state of the caregiving literature as well as the theory behind it. I will explore broad sociological theory on interpersonal interactions and roles, social psychological models on suffering, anthropological concepts of liminality and uncertainty, and clinical studies on the burdens faced by informal caregivers. I will argue that the current literature does not do a good job of explaining the variation in caregiving experiences, with each

literature offering clues but not the whole picture of how different contexts result in vastly different caregiving experiences.

In Chapter 2, I examine the disease type context, and in particular how it affects the experiences of caregivers along with the context of interpersonal relationships. Here I will discuss the key differences between caring for a patient with CKD as opposed to a patient with Alzheimer's dementia, with special focus on the emotional burdens the diseases cause on caregivers. I find evidence of some social psychological models of changing interpersonal relationships in caregiving, but also find that they do not capture the interactional nature of disease type on caregiving experience.

In Chapter 3, I look at how the larger structural contexts affect perception of caregiver burden. I will discuss two main structural contexts in this chapter. First, socioeconomic context affects the caregiving experience in both patients on dialysis and patients with Alzheimer's. I will not only look at the financial aspects of work, compensation, and lost wages, but also social capital such as support networks and the role that significant others play in the lives of these informal caregivers. Next, I will examine how the idea of liminality comes into play to affect caregivers' perceptions of burden, and how certainty and uncertainty can play an important role in altering the caregiver experience. Together, I hope to explore the structural and socially constructed environment in which these caregivers operate, in order to understand how these broader concepts affect individual-level experiences.

In Chapter 4, I will take an in depth look at the social identity of informal caregivers, and how their work as informal caregivers affect their sense of self and their status. In particular, I will examine how some caregivers professionalize or moralize their caregiving status in order to build up their new social identity of being a caregiver. I will also touch on the idea of a master status of caregiving emerging for some caregivers, and how all of these shifts in identity, whether building a new one or rolling caregiving responsibilities into an existing identity, affect the continuum of caregiving experience and the challenges caregivers face on a day to day basis.

Finally, I will conclude with a summary of my findings, in particular how they relate to the existing caregiver literature in each field discussed in Chapter 1. I will discuss in depth about how context shapes the experience of caregivers, and close out with what that means for not only all of these research fields but also the caregivers themselves and others like them moving forward.

Chapter 1: Literature Review

In this chapter, I examine the disciplines and fields which together make up the bulk of the informal caregiving literature. I will start off in the field of sociology, discussing theories about roles, interpersonal interactions, and emotion work, before moving on to the field of psychology and social psychology, examining the role of suffering, past relationships, and empathy in caregiving. After a brief insight into the anthropological concept of liminality how it relates to uncertainty, I conclude by looking at clinical research which study informal caregivers, not only in general but also specifically for caregivers of CKD or Alzheimer's. By the end of this chapter, I demonstrate not only the strengths that individual disciplines bring to the table, but also areas where our understanding is lacking and a new synthetic approach is required.

Section 1: Sociology:

Role Theory: Acting the Part when "The World's a Stage"

In order to begin to understand the experience of caregiving, and especially the nature of the relationship between caregiver and care recipient, we must first start from social theory about the nature of interpersonal interactions. One important sociological framework for understanding individuals' behaviors is that of role theory. According to role theory, institutions, whether they be government, school, family, or more, are made up of role relationships, which have obligations and expectations (Goode, 1960). There are many ways of looking at roles within role theory, but one important lens to view roles through is through the symbolic interactionist school of thought. For symbolic interactionists thinking about role theory, roles are not simply a cookie-cutter list of expectations

assigned by society and institutions, but rather, roles themselves reflect the norms, attitudes, and negotiation of those role expectations and relationships as understood by the actors themselves. In other words, roles are constantly evolving and changing as actors find and renegotiate meaning within their roles. However, individuals can have difficulty in performing their role relationships. In some cases, people may be unable to perform the expectations of a single role, whether that is from role definitions being too vague in role ambiguity, or having too many expectations to meet them all, in role overload, also known as role strain (Biddle, 1986). In addition, there are cases when expectations of the roles associated with one status interfere or are mutually exclusive with expectations of another status, known as role conflict. They may require contradictory performances or obligations of time or resources such as energy. Goode (1960) discusses strategies that individuals can use to reduce role strain, from compartmentalizing role performances and responsibilities, to delegating some of those responsibilities to other people, to eliminating some role relationships all together. Goode (1960) does note that for ascribed statuses, that is statuses and roles that are assigned and not necessarily chosen such as familial relationships, there is a more limited ability to bargain and renegotiate role expectations because they have stronger social pressures to conform than achieved statuses. This could be potentially important in informal caregiving, as informal caregivers may find it difficult to disentangle or step back from the increased responsibilities of caregiving if they are connected to an ascribed status such as familial relationships.

Other authors provide theories on ways and strategies that individuals can manage their roles. One such author is the sociologist Erving Goffman, and his theory of dramaturgy. A symbolic interactionist, Goffman (1978) proposes that in a world governed by role relationships interactions between both familiars and strangers, there exist a set of rules and expectations based on one's role that must be followed for smooth interactions. He argues that these rules are important in facilitating interactions so that one can be prepared for an interaction with some sense of what to expect, to bring order and predictability to an otherwise uneasy interaction (Goffman, 1978).

The name of Goffman's theory, dramaturgy, suggests that social interaction can be viewed as actors on a stage. Goffman suggests the goal of the interaction to be to maintain a façade and to avoid disruptions that result from embarrassment, much as how an actor must avoid going off script for fear of breaking the immersion of the play. To avoid disrupting the mask, Goffman describes how not only do individuals have to maintain defensive practices for themselves, but must also know what questions not to ask or what topics not to prod another with; or otherwise put, to demonstrate tact. In this way, interactions can go smoothly and both parties can maintain an acceptable mask, supported by dozens of unspoken scripts and expectations that both parties know.

For informal caregivers, there is potential for both role strain and role conflict. Role strain can arise from not having the time, ability, or energy to perform the numerous responsibilities expected from the role of the informal caregiver. On the other hand, role conflict can arise from the addition of the

caregiving status and roles onto another existing familial status and roles: for instance, going from being a son or daughter to adding on the responsibilities of a caregiver for an infirm parent. There are different rules for playing a caregiver than there are for playing a daughter, different things that one can say or different ways one can act towards a care recipient as opposed to one's mother, and this can result in role conflict. For informal caregivers of patients with memory or personality loss, this issue perhaps made even more difficult, as patients with these disorders often lose their original sense of self and social connections or may have difficulty performing expected social functions. By not responding in a way that the caregiver can play off of, a care recipient with memory or personality loss can turn a dialogue into a monologue, and cause immense strain for the caregiver as all normal rules and expectations of interaction and communication break down.

Playing a Patient – the Sick Role and Parsons

This idea of rules and expectations is not unique to the role of the patient or the caregiver, but the role of care recipient is something we must specifically understand before attempting to understand the role of the caregiver. This is where the idea of the “sick role” comes in. First proposed by Talcott Parsons (1951), a notable functionalist sociologist, the “sick role” is the idea that when a person gets ill, they get a specific social role in addition to physical symptoms of being ill. This role allows for social benefits but at a cost. Parsons argued that that a sick person occupying the sick role is excused from having to perform day to day responsibilities they usually have, and is exempted from the responsibility of

being sick. That is to say, they may not be expected to work or do chores, and they are not blamed for being sick, or given the responsibility of getting better. However, Parsons argues that this is only the case for a socially defined and validated definition of sickness. This is important, because if a certain illness is not considered to qualify for a “sick role”, a patient trying to gain these exemptions will not be allowed them. In addition, being sick is defined as “undesirable” overall, and requires the individual to also take on the role of the patient to get better, which includes responsibilities of following the doctor’s instructions, taking the right medications, deference to clinical personnel and caregivers, and more (Parsons, 1951).

Over the years, many social science researchers have critiqued and added nuance to Parson’s sick role, pointing out in particular two major exceptions to the sick role. The first exception is psychosocial and psychiatric cases, where because of societal misunderstanding or stigma of mental illness, patients with mental illness are less likely to be allowed into the sick role to gain the benefits which lie within. Patients with mental illness are expected to keep up with their responsibilities in part because people see no physical lesions or impairments and don’t understand how they are limited from completing their role (Segall, 1976). In addition, society as a whole has not decided how much responsibility individuals have for resolving or coping with their own mental illness, in large part because it is invisible. The second exception to the sick role is for chronic illness. Because the illness is not temporary and there are no expectations that patients can “get better”, it becomes a process of adjusting to a permanent

condition instead of overcoming a temporary one. In addition, because many chronic patients can still walk and move about, they might be exempted less from responsibilities than another patient who was bedridden (Segall, 1976).

These two exceptions suggest that the sick role might not be appropriate for an analysis of CKD and dementia as chronic illnesses and in the case of dementia, having a psychiatric component to it. However, it goes back to Parson's clarification that admission to the sick role depends on social definition and validation of the sickness, which can be obtained through the process of medicalization. Medical sociologist Peter Conrad (1992) describes how according to some researchers, more and more aspects of life have been "made medical", from alcoholism to overeating, hyperactivity to aging. One of the side effects of this, Conrad suggests, is that medicine has become a dominant form of social control in our modern day and age, conferring immense legitimacy to issues which are deemed to be "medical". For instance, activists pushed for medical definitions of alcoholism and post-traumatic stress in order to confer legitimacy and resources to those issues. Conrad suggests that Alzheimer's disease as one disorder that has been conferred legitimacy through medicalization, turning what was considered senility, a normal part of aging, into a medical issue (Conrad, 1992). Does the medicalization of Alzheimer's dementia confer the sick role to patients in any way that may shape their caregivers' experiences and understanding of them, their illnesses, or caregiving at large? And do the intensive and regular medical treatments of CKD shape caregivers' understandings of the

“sick role” conferred to their care recipients on dialysis, even though it is a chronic, and not acute illness?

What is this feeling – Emotion Work and role interactions

Building off of Goffman’s work as well as the work of others, sociologist Arlie Hochschild (1979) built another framework of understanding role interaction not just as surface expression and acting, but something much deeper. In “Emotion Work, Feeling Rules, and Social Structure”, Hochschild suggests that individuals make an effort not only to display but even to feel emotions that they perceive to be “appropriate” to the situation. For instance, at a funeral, an ambivalent bystander may work to feel grief or sadness, whereas a bride at her wedding tries her best to be happy even though she might not be. Hochschild details how social factors play an important role in determining how we label, interpret, and manage emotions, resulting in a complex set of rules and expectations that not only dictate how we act, as Goffman writes, but how we feel (Hochschild, 1979).

To differentiate herself from Goffman, Hochschild describes emotion work as a method of deep acting, as opposed to what she perceives as Goffman’s surface acting in dramaturgy. Dramaturgical actors, Hochschild describes, do not look to change themselves within, only to manage how they are perceived on the outside. A dramaturgical actor at a funeral could shed crocodile tears even while feeling nothing on the inside, but an actor performing emotion work will try his best to conjure up a feeling of sadness for the occasion. This falls under evocation, or inducing feeling that we may not truly feel. Hochschild also details suppression,

or suppressing feelings that we do feel, such as suppressing feelings of doubt or sadness at a wedding celebration. In these ways, individuals work to not only control how they act, but also how they feel on the inside to promote those actions (Hochschild, 1979).

For informal caregivers, emotion work can come into play in a number of ways. Society can often view caregivers through a rose-colored lens, as people sacrificing time and effort to care for a close family member, working selflessly and generously as paragons of family values. While that may be a slight exaggeration, there is no question that there is a certain societal image of what a caregiver is, and there are times when caregivers feel that they are not living up to that image, whether that is because they feel impatient with their care recipient, or feel like they can't go on caring for them because it is too much work, or any of the myriad reasons that could be. Since caregivers aren't supposed to be impatient with their care recipient, a caregiver may find themselves working hard to suppress that emotion. When a care recipient wakes the caregiver up for the third time in a row in the middle of the night, a caregiver might find themselves working hard to evoke the same feeling of sympathy and caring that they felt the first time they woke up. When a neighbor remarks that they must love their spouse so much to be caring for them every day, a caregiver may genuinely want to feel that, and perform emotion work so that when they say "I do love them", it is the truth.

As with before, caregivers of care recipients with memory or personality loss may find the need to perform emotion work especially pressing. Where it can

be incredibly difficult caring for a cherished mother with an illness, it can be even more difficult when that parent has lost a great deal of her memories and slowly is becoming more and more of a stranger. When the familiar become estranged, it can become hard to maintain feelings that one might want to feel, or suppress negative emotions which may arise.

Relationships as Transactions – deposits, withdrawals, and investments

While dramaturgy looks at interpersonal interactions as a play, social exchange theory views it more as a business interaction consisting of relatively equivalent transactions. Researchers Dwyer et al (1994) sought to apply social exchange theory to dyads of mothers and their informal caregiver daughters. One aspect of social exchange theory which the researchers describe is that social exchange and interactions wants to be as equal as possible: it is uncomfortable to be the dependent party in a social exchange. This is why we bring a bottle of wine or a dessert when we are invited over to dinner. Dwyer et al argue that if we can reciprocate another's gift or service, then we are strengthening the bond between us. However, as the researchers point out, this is rarely the case in the caregiver – care recipient relationship, and especially for elder care, as almost always the care recipient will be in a position of dependency (Dwyer, Lee, & Jankowski, 1994). In cases of informal caregiving, this dependency is especially significant, since it reverses previous flows of dependency, whether that is an expected equal flow in a marriage or a flow to the current caregiver from their now ill parent. When the care recipient is able to reciprocate in small ways, it has been found that caregiver stress and burden decreases, whether that is from the actual actions performed by

the care recipient, or rather the social meaning of the gesture and the sense of reciprocity.

Call et al (1999) sought to analyze the burden of temporary caregivers for family members recovering from acute illness using the lens of social exchange theory. They expand upon the idea of reciprocity and desiring equal relationships, but point out that unlike many day to day instance of social exchange, informal caregiving and familial relationships operate more on generalized rules of reciprocity, where equivalency is not expected all of the time, but rather works to balance itself out over time. For instance, they suggest that in families with strong norms of obligation, children take care of older parents to reciprocate them taking care of them for such a long time while they were growing up (Call, Finch, Huck, & Kane, 1999). For the researchers, these generalized relationships are able to withstand long periods of time with one party providing extended periods of help, but reciprocity is still expected, as detailed in the research of Dwyer et al. Importantly, ideas of reciprocity can help caregivers in their work with family by reducing perceived burden. While non-family caregivers working out of altruism worked fewer hours per week than family caregivers working out of an ideal of reciprocity, the non-family caregivers perceived more burden in their work than the family caregivers. Thus, burden, the researchers suggest, occurs primarily when the effort put into caring exceeds the expected amount of effort needed for the job. That baseline expectation, however, can be high in families or relationships where there is an expectation of reciprocity and obligation, meaning

that caregivers can have high objective amounts of work they have to perform, but have low perceived burden from that work (Call et al., 1999).

Call et al's research is a fascinating perspective, but the demographics they studied were different in significant ways. Mainly, they were studying caregivers of older patients recovering from an acute hospitalization, not caring for long term chronic conditions. Since social exchanges should be relatively balanced over the long run, reciprocity can work fine when the amount of care needed is perceived to be intense but limited. What happens when that work is stretched over a long, or sometimes unknown period of time? With no definite end date and a low chance that the care recipient will be able to reciprocate in an equivalent manner back, the amount of work required to care for a relative becomes more than the amount of effort reciprocity would demand, possibly leading to increased burden. This idea of uncertainty will come up again in Section 3 of Chapter 1, when I will discuss uncertainty in more depth through the lens of liminality. All the same, Call as well as Dwyer rightfully point out the importance of considering the framework of social exchange in normal interactions onto an abnormal situation of informal caregiving.

One caregiver-specific look at this theoretical frame finds that reciprocation can indeed decrease caregiver burden. Richardson et al (2007), in a sociological paper studying caregiving of eight patients with chronic pain, find that while family members can provide support to patients, they also receive support as well. Patients with chronic pain cannot do everything because of their condition, but they still offer to help and do small chores around the house. While

the family recognize that in many cases, this is just a gesture, it still helps preserve a sense of normalcy and reciprocity in the household relationships. Emotionally as well, especially among spouses, patients provided support to their caregivers and cared for them when they were having difficulties as well (Richardson, Ong, & Sim, 2007). As Dwyer and other social exchange research discusses, this reciprocity is incredibly important for helping to alleviate caregiver burden and maintain a sense of relative equal social exchange.

Section 2: Social Psychology:

In this section, I take a look at contributions to the caregiving literature from psychologists and social psychologists. I examine how the state of the previous relationship between caregiver and care recipient can affect caregiving, in addition to the role suffering and empathy play in shaping the caregiver experience. These models and frameworks provide a valuable contribution to the growing literature. In particular, the cognitive model of caregiving in psychosis deserves a notable mention, as it will be analyzed in more detail in Chapter 2 of this paper.

Context – how the interpersonal past affects the present and the future

Where social exchange theory stands out is its consideration of the context within social interactions take place. While dramaturgical theory and emotion work are focused on one specific instance of interaction, social exchange recognizes that reciprocity does not have to be instant; in fact, the desire to reciprocate can originate from years ago. Other theories look even more into the context in which social interactions are taking place, analyzing how caregiver –

care recipient relationships in the past might affect their patient-caregiver relationship going forward.

In their cognitive psychology study, “Cognitive model of caregiving in psychosis”, Kuipers et al (2010) describe how caregiver appraisals of their patient’s illness may affect how they understand and treat their care recipient more so than the “objective” illness itself. Note that this is in direct contrast to what was described in social exchange theory, where the researchers found that elder’s perceptions of satisfaction are dependent on the actual impairments on the caregiver rather than the subjective impact on caregivers. This suggests that there could be a fundamental disconnect in how patients and caregivers understand the trials the other is facing, and that this could result in conflict later on. Kuipers et al describe how those caregiver appraisals are rooted in the past relationship with the patient. As a result, they develop models of patient-caregiver relationships dependent on the past nature of the relationship (Kuipers, Onwumere, & Bebbington, 2010). While this model is specifically for care recipients with mental illnesses such as schizophrenia, the model itself can be applicable for caregiving in general, and it can be especially pertinent for caring for a patient with memory or personality related disorders. In the first case, the caregiver and care recipient experienced a positive relationship in the past, and so the caregiver not only treats the care recipient as a person by respecting autonomy, but the illness is seen as being separate from the patient. In this example proposed by the authors, the caregiver is not overly invested in the patient but realizes that the care recipient needs help but is not responsible for his or her problems (Kuipers et al.,

2010). This echoes the sick role of Parsons, and suggests that in this model, the caregiver accepts the care recipient's placement into the sick role and affords them the associated benefits and exemptions from responsibilities.

The next example proposed by the authors is based off of an emotionally overinvolved relationship between the patient and caregiver in the past. The illness is viewed as something that has transformed the patient into something unrecognizable, and there is some degree of guilt with the caregiver. This results in the caregiver attempting to buffer the patient from everything and being consumed by the amount of effort they put into caring (Kuipers et al., 2010). The final example proposed by the authors is one based in a negative relationship in the past, where the care recipient is perceived to be at fault for their condition, suggesting that the caregiver does not afford the care recipient the benefits of the sick role. If the care recipient does believe themselves to fall into the category of the sick role, these different perceptions could lead to conflict between caregiver and patient. These caregivers are more prone to facing negative emotions such as anger, anxiety, or depression (Kuipers et al., 2010).

As mentioned above, this cognitive model of caregiving is based around the assumption of the care recipient having a mental illness, but it is not hard to imagine these examples working for caregivers of other illnesses as well. In particular, this model speaks with the idea of the sick role very well, in particular the critiques of the sick role for chronic and mental illness. This model shows cases where the disease is "ambiguous" in the sense that caregivers are not sure whether they should ascribe the sick role to their patient or not. For these cases

where patients may appear to violate or not qualify for the sick role, other factors such as past interpersonal relationships may influence caregivers' assessments of the patient's control over their actions and whether that constitutes a sick role. This may in turn lead to shaping the experience for the caregivers themselves, as one can imagine how a caregiving experience might differ if every difficulty and challenge facing a caregiver was ascribed to the care recipient rather than the illness.

The role of shared suffering through empathy

Another model worth discussing that relies on past relationships is a modified caregiver stress-health model proposed by psychologists Monin et al (2009). Unlike the traditional stress-health model, the authors note that because of spending so much time in proximity to and caring for their patients, caregivers experience a host of emotions as a response to the emotional suffering of the care recipient, causing many of the physiological and psychological distress that caregivers experience. They cite research linking patient distress to caregiver depression and other negative symptoms, and suggest that understanding caregiver responses to care recipient suffering is essential for understanding the caregiver experience (Monin & Schulz, 2009).

How does this relate to the effect of the past patient caregiver relationship on the present? Monin et al found that several factors moderated or exacerbated the effect of suffering on caregivers. Perhaps most pertinently, they found that the closer a caregiver was with their patient emotionally, the more they felt the patient's suffering. In some cases, the caregiver might not even need to witness

the patient's suffering: cognitive empathy can result in the caregiver imagining the suffering of the patient which can provide the same results. On the flip side, when caregivers were able to alleviate suffering, there were feelings of empowerment and other positive emotions which helped outweigh the effects of suffering on the caregiver (Monin & Schulz, 2009).

Of course, as Kuipers et al discussed, for something like suffering, the caregiver's appraisal might be more important than any "objective" measure of the patient's suffering. In addition, the authors did not go in depth about what they meant by suffering, whether that was physical suffering or emotional anguish. This raises an important question: caregivers can play an important helping role in physical illnesses and caring for physical symptoms, but may be comparatively helpless in neurodegenerative disorders where it can be difficult for caregiver interventions to improve the situation. How does this affect caregivers both socially and potentially physically, as well as their feelings of empowerment or suffering? While any physical effects of suffering on caregivers is outside the scope of this paper, its associated literature is important to understand the full scope of caregiving.

Section 3: Liminality

Borrowed from anthropology, liminality helps to better understand caregiver responses to uncertainty and ambiguity in their roles. This uncertainty is heavily rooted in the nature of the disease and both its presentation and progression. Everything about a disease, from what characteristics influence its diagnosis to treatment options to time until death, is rooted in what is known and

what is not known, and gray areas of uncertainty have a large role to play in the experience of caregivers.

Who knows what tomorrow brings – uncertainty in caregiving

An important distinction to make about informal caregiving is the uncertainty that is inherent in the role. Unlike professional caregivers such as nurses, informal caregivers often do not know what they are getting into beforehand, and do not know how long they will be in that state. This uncertainty comes forth through the concept of liminality, or the ambiguity and disorientation that comes from being in between two statuses (Hennings, Froggatt, & Payne, 2013). Hennings et al (2013) studied spousal caregivers of care recipients with advanced dementia in nursing homes. These spouses had stopped caring for their partners full time since the move to the nursing home but still visited and provided some care. This arrangement, however, was difficult for the caregivers as they struggled to define their role not only as caregivers, but also as spouses with one spouse describing her state as “quasi widowhood” (Hennings et al., 2013). Since their partners in the nursing homes were not quite dead, but also not fully alive and intact both mentally and socially, the caregivers felt their social identities and positions in society were unclear as well (Hennings et al., 2013). This liminality described of being between two statuses could also play a factor at the beginning of informal caregiving as family members attempt to reconcile no longer being only a spouse or son or daughter, and yet are not entirely caregivers either.

Another way uncertainty can manifest in informal caregiving is related to the nature of disease progression itself. Some sociologists have taken the term anomie, originally meaning a lack of moral direction and regulation that resulted in feeling adrift or alienated, and use it to convey a more general uncertainty instead. For instance, Olson (2011) describes how one of the main problems facing patients with a terminal diagnosis of cancer and their caregivers is the uncertainty of the future. Olsen provides quotes of caregivers who find themselves unable to make travel or even financial plans for the future because they don't know how much longer the care recipient has to live. Caregivers, she found, were left feeling confused and guilty about how they should plan for the future, or if they should be planning at all when their care recipient was still alive. This dilemma sounds like the result of a liminal state, as caregivers are caught between their previous life with the care recipient and life after they have passed. Olson uses the term "temporal anomie" to express the lack of temporal direction facing the caregivers: with the ability to plan for the future being so critical to many in modern society, having that taken away can result in a feeling adrift (Olson, 2011).

Olson describes three responses to temporal anomie she found in caregivers, mainly revolving around temporal orientation. The first was to take a present-oriented approach, appreciating the small positive things on a day to day basis, but being realistic about the prognosis and the future. On the other hand, some caregivers kept a future-oriented outlook, but instead became very optimistic about the prognosis of their care-recipient, hoping for a cure and doing

cognitive emotion work to convince themselves that the patient would survive. Finally, there were those who kept their future orientation but rather than being optimistic, instead they normalized the cancer, making statements reinforcing the idea that death is a normal part of life (Olson, 2011).

While “temporal anomie” in patients with chronic kidney disease or a neurodegenerative disorder may be more abstract or take longer to develop, the uncertainty is still there. Will my care recipient still be on dialysis in a year, or will they have gotten a transplant by then? How much longer until I can no longer take care of my mother and she needs to be put into a nursing home? How much longer will she stay alive? When we can no longer take time for granted, it’s no surprise that this can be disconcerting for people.

The term “emotional anomie” on the other hand, as used by Karp et al (2000) in “Mental Illness, caregiving, and emotion management”, refers to the period of time before diagnosis of a mental illness where future caregivers are unsure about the patient’s increasingly erratic actions. Karp et al offer up the idea that just as illness moves in stages and progresses, caregiving also goes through important stages in which the caregiver experience changes in role responsibilities between each phase. The phase that occurs after onset of symptoms but before a medical diagnosis is characterized by this “emotional anomie”. Without having a label or a diagnosis to describe the behavior of the patient, family and future caregivers are unsure what their role relationship is, or how to act or feel around the patient: is this something that is normal and we should treat him as usual, or does he need to be seen by a doctor? They are caught in between the normal

everyday status of being a family member or a new role of being a caregiver. In many cases, caregivers later reported that during this period they felt guilty about doubting whether or not the patient was ill or not. The diagnosis helps to provide direction and regulation again, as it puts a medical label on the patient's condition and behaviors, as Conrad discusses through the process of medicalization. By attaching a medical label to the patient's behavior, the family can transition into a role of caregiver, and out of the liminal in-between state they were in before the diagnosis, dispelling the "emotional anomie".

While again we would be remiss to ignore the difference in patient population, "emotional anomie" can also play an important role in period of time before diagnosis in other illnesses, especially in cases of memory loss disorders. Especially in the early stages of diseases such as Alzheimer's when the patient appears to be a little forgetful, uncertainty can play a large role in the lives of family during that time and perhaps initiate a liminal state. Even in physical illnesses, having a medical diagnosis to affirm that something is out of the ordinary can provide clarity and certainty in the form of clear role relationships and expectations in the sick role and the caregiver role.

Section 4: Beyond the theory – perspectives from medical researchers

In this section, I discuss the findings of research being done by medical and clinical researchers. This research is often done without the intention of proving a model or a theory, but rather to assess the degree of burden and stress experienced by informal caregivers. Much of the research done is quantitative and survey-based, but it is through the qualitative works where we get to see the

theories discussed above in action, though the researchers themselves often do not refer to them by name. One of the key findings of this body of work is the importance of the socioeconomic context on caregivers, with income, social support, and work flexibility all playing important roles in shaping the continuum of caregiving experiences. In addition, the importance of gender and the gendered nature of caregiving itself is discussed.

A clinical look at caregiver burden – socioeconomic factors matter

Clinical and medical researchers have had a particular interest in informal caregivers, since they play such an important role in providing care to their patients. The work done by clinical researchers here often does not refer to the theoretical frames or theories discussed in earlier sections by name, but does focus in on the same themes and important points as these theories do, providing a valuable look at these theories in action among real caregivers, even if the researchers themselves do not recognize they are doing so.

In addition, the focus in this field of research is on the what of caregiver burden, as opposed to the why or how, with much of the published research seeking to quantify or understand the degree to which caregivers experience burden, with a secondary focus in explaining it. One study in particular published in the American Journal of Hospice and Palliative Medicine conducted by Thai et al (2015) exemplifies many of the findings found in other similar papers. They studied forty-two caregivers of patients with a variety of late-life disabilities to determine changes to caregiver quality of life. They found that more than half of caregivers felt they had a decreased quality of life after caregiving than before,

but that caregivers had different reasons for reporting such a decrease. Some caregivers reported it was a result of increased stress and physical issues that came with caregiving, while others reported that the time and responsibilities of caregiving had not only a strong effect on their social life but also had a strong emotional impact on them (Thai, Barnhart, Cagle, & Smith, 2015). One caregiver stated, “My quality of life declined substantially because I loved my father so much and seeing him decline and the thought of losing him was extremely upsetting”, a statement which echoes the modified caregiver stress-health model of Monin et al about the shared suffering between patient and caregiver.

In addition to physical, social, and emotional burdens associated with caregiving, financial considerations are also important for informal caregivers. Researchers Medway et al (2015) studied 27 parents caring for children with chronic kidney disease (CKD) and the economic consequences of providing care. They found that being informal caregivers meant having to give up other economic opportunities especially in work, both in flexibility and ability to work. The economic burden was not only through the cost of lost employment, but also because of increased expenses required from medicine to travel related expenses. Especially because of the unpredictable nature of the health of the child, parents had to focus on basic needs and the present, often leaving future finances in an uncertain place (Medway et al., 2015). This response is similar to that of caregivers studied by Olsen studying temporal anomie, only in this case it is financial anomie.

Some researchers argue that the root of much of this caregiver burden comes from role conflict, in particular being unable to strike a work-life balance. Studying over 5,000 respondents from a longitudinal study of Wisconsinites, Nadine Marks (1998) found that there were psychological and other burdens faced by the caregivers, but that these burdens were often minimized when controlling for work-family conflict. Marks found that family and caregiving stress often spilled over into work, and vice versa, as these working informal caregivers had to juggle two different role sets and responsibilities. When work-family conflict was controlled for analysis, she found that negative effects of caregiving were diminished, and that positive effects of caregiving came to the fore, including personal growth, more purpose in life, and more positive relations with others (Marks, 1998). This suggests that caregiving itself may not be inherently negative, but rather caregiving has added obligations on top of existing role responsibilities in other positions such as work, which may be what brings about negative effects for caregiver. This socioeconomic context of work and caring serves as an important frame for understanding caregiving. This context not only includes social position in society or financial resources, but also the idea of work flexibility as the work-family conflict alludes to. It is not just the income a job brings in, but also the type of job and flexibility of the work that affects the socioeconomic context that may shape a caregiver's experience.

In fact, Thai et al (2015) also found positive benefits of caregiving. While there were caregivers as described earlier who faced physical and emotional stress from caregiving, other caregivers either reported no change in quality of life, or in

fact an improvement in quality of life. A common theme reported among caregivers who had an improved quality of life was that they found the experience to be rewarding, with one caregiver saying “When I give my mom a bath or rub her back I just am joyful to do it and it’s as blessing to me that I can do that for her.” However, it should be noted that among caregivers who reported an improvement in quality of life, many of them had help either from institutionalized care or adequate financial resources allowing them to use strategies discussed by Goode (1960) such as delegation to decrease the strain of their role relationship. Those unable to enact these strategies to reduce role strain, on the other hand, were those who have financial difficulty or a lack of external support, resulting in them facing a decline in quality of life. Also of note were the caregivers who reported no change in their quality of life from caregiving. In this subgroup of caregivers, filial duty came up when interviewed, a form of reciprocity as discussed by Call et al (1999). Much as how Call et al suggest that caregivers may not feel burdened because they feel the care is expected in return for years of care given to them earlier, the caregivers who cited filial duty as a reason for unchanged quality of life said, “I think it’s my responsibility to care for them. You only have one mom and dad in your whole lifetime. So I want to do the best of my ability” (Thai et al., 2015).

The gendered nature of caregiving

Women serve as a majority of informal caregivers, which makes it so much more important to understand gender differences in caregiving. Kramer (1995) finds that female caregivers feel a greater caregiver burden, and posits

potential theories why it is, from increased secondary burden and responsibilities in both work and family, again reiterating the potential for role conflict and the importance of the socioeconomic context, to women providing more intensive kinds of care such as hands on activities and personal care than men (Kramer & Kipnis, 1995). On the other hand, Hagedoorn (2000), studying spousal caregivers, posits that female caregivers are more strongly influenced by the condition of their partner than men are, relating this back to socio-psychological theories of suffering and empathy as discussed by Monin et al (Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000).

Overall in the literature though, it is accepted that women caregivers are subjected to greater caregiver burden, which makes findings such as that of Miller (1990) stand out, who found that while women experienced greater health strain, they did not experience statistically more emotional strain than male caregivers (Miller, 1990). In general, researchers explain findings such as these by suggesting that rather than female caregivers themselves being more susceptible to burden, they have additional responsibilities from other roles that result in the caregiving role being more difficult for them overall resulting from the role conflict they face.

Section 5: Disease specific caregiver research

While the previous section dealt with caregivers in general, the diseases being studied in this paper, CKD and Alzheimer's, have their own distinct issues which affect the experience of caregivers. For caregivers of patients with CKD on

dialysis, this challenge comes in the form of the burden of having to learn more about the process of dialysis and in some cases, how to do it. For Alzheimer's caregivers, the degenerative nature of the disease adds burdens of emotion management and uncertainty to the equation, in addition to the unclear sick role assignment for a primarily mental disorder.

Knowledge, information, and training of CKD caregivers.

Like with other diseases, caregivers of patients with CKD face intense burden. Belasco et al (2002) conducted a survey of 100 caregivers of hemodialysis patients and found significant subjective burden and poor quality of life outcomes, especially in female spouses of care recipients, as discussed in Section 4 (Belasco & Sesso, 2002). One dialysis-specific cause of burden is explored further by Mollaoglu et al (2013), who explored the educational needs of caregivers of patients undergoing hemodialysis. They found that for many of the caregivers they studied, important information about managing CKD was lacking, especially on the subject of nutrition, dialysis, and care of the insertion points of dialysis. When training sessions were held to help caregivers understand how to better take care of their patients and to raise awareness, Mollaoglu et al found that caregiver burden dropped (Mollaoglu, Kayataş, & Yürügen, 2013). This illustrates one of the unique challenges of caring for a patient undergoing dialysis, which is being well versed in the day to day medical treatment of the care recipient in a way that other caregivers don't have to. The challenges caregivers of patients on peritoneal dialysis are hardly easier. In a study conducted by Avsar

et al (2013), researchers found that caregivers of recipients on peritoneal dialysis had higher rates of anxiety, depression, and poor sleep quality than caregivers whose recipients had recently undergone renal transplantation (Avsar et al., 2013). All in all, caring for a patient with chronic kidney disease on dialysis proves to be a challenge in large part due to its demands on the caregiver not only in terms of time and patience, but also in terms of knowledge and technical expertise in medical equipment.

One last interesting note is that patients and caregivers appear to have different priorities when it comes to dialysis. In a study conducted by Manns et al (2014) looking at research priorities and questions amongst patients, informal caregivers, and medical staff, patients often wanted to learn more about day to day issues on dialysis, including physical symptoms such as itching while on dialysis, and how to improve quality of life on dialysis. While there was some overlap, caregivers were primarily concerned with ways to make dialysis easier and more convenient, as well as ways to get off of dialysis (Manns et al., 2014). In some ways this is unsurprising, as the patients are undergoing the treatment in ways that the caregivers are not, but it also points to a difference in priorities that could result in tension down the line.

The sick role, personality changes, and liminality – unique challenges of psychiatric and neurodegenerative disorders

While physical illnesses have been studied by researchers examining caregiver burden, it is in psychological illnesses that a hefty amount of significant research has been done, especially using the lens of emotion work and other

theories of patient-caregiver relationships. One key difference between physical illnesses and mental illnesses are their effect on the patient's memory and personality. In a study comparing family burden on caregivers of chronic physical illnesses as opposed to caregivers of schizophrenic patients, Magliano et al (2005) discovered that family and caregivers of schizophrenic patients reported higher levels of perceived burden than their counterparts taking care of chronic physical illness. Among the reasoning they list is stigma and lack of information in the public sphere, but also a tendency of caregivers to overestimate the amount of autonomy and control over their symptoms patients have, in other words not giving the patients the benefits of the sick role as described by Parsons because they believe they don't qualify for it. Whereas caregivers of patients with physical illnesses are by and large aware that their care recipients are not in control of their cancer or their failing kidneys, for example, there is still a tendency to believe that mental health patients have control over their disorders to some degree: as inappropriate as it is to tell a cancer patient undergoing chemotherapy to "walk it off", it is by and large not considered as inappropriate to tell someone with depression that they need to "focus on the positive". The idea that the patient has more control than he has results in what Magliano et al describe as "feelings of frustration as well as critical attitudes toward the patient", resulting in higher caregiver burden and more negative feelings (Magliano et al., 2005). This suggests that the idea of Alzheimer's as a mental disease still flavors caregivers' perceptions of patient responsibilities, resulting in a denial of the sick role for them. Even with the increasing medicalization of Alzheimer's as described by

Conrad in Section 1, from senility as a normal part of aging to a diagnosis of Alzheimer's, it appears that that legitimization has not resulted in patients being afforded the benefits of the sick role.

Two aspects unique to memory and personality disorders worth mentioning are the loss of self from the patient, and challenges in communication between patient and caregiver. The loss of self from memory and personality loss in neurodegenerative disorders is particularly harmful to two-way communication and dyadic relationships. In the sociological journal, *Symbolic Interaction*, Karner and Bobbitt-Zeher (2005) describe the transformations caregivers undergo as their patients with neurodegenerative disorders gradually become silenced by the disorder and become unable to respond in a meaningful way as they eventually are unable to recognize their own family. As a result, caregivers became frustrated they could no longer communicate or rely on norms of reciprocity that they had come to expect from their past experience, and became disoriented by their own memories of their past relationship with the care recipient and the current altered present. One caregiver stated, speaking about his mother, "it was like this is someone I don't even know anymore ... she's just different [...] but the difficult part for me is because I have always been obedient and I have been and she is still my mom" (Karner & Bobbitt-Zeher, 2005). Eventually, this unease about the liminality of being in between these two relationships, one alive in the past and one non-existent in the future, results in family caregivers redefining themselves and acknowledging the end of the past relationship, ending their liminal state. Some spouses reported almost mourning the loss of their husband even though he

was physically alive, while others complete an identity shift from being a spouse or a child of the patient into being the patient's caregiver. Caregivers here reported their lives being so radically changed and flipped upside down that caregivers of physical illnesses did not report because they still had the patient's personality and their relationship to them intact (Karner & Bobbitt-Zeher, 2005).

Researchers Blieszner and Shifflett (1990) also looked at the effect that personality loss had on the patient-caregiver relationship. Looking at changes in intimacy between caregivers and the Alzheimer's patients they were taking care of, they found similar results to Karner and Bobbitt-Zeher. Specifically, there was evidence of the "emotional anomie" described Karp et al: in the early phases of having symptoms but no diagnosis, caregivers were frustrated and confused about patients' behavior, but proceeded to feel relief, even though there was sadness with it as well, upon the diagnosis of Alzheimer's, for reasons explained by Parsons earlier. Expanding on Karner and Bobbitt-Zeher's description of gradually terminating the relationship, this study found the same frustration at the loss of a normal reciprocal relationship, but also mentioned that in many cases, the patient lost the ability to communicate before the caregiver could get closure with them (Blieszner & Shifflett, 1990). In a sense, this makes neurodegenerative disorders like Alzheimer's particularly insidious to caregivers: for physical illnesses, at least there is a chance to say final words and make peace as the patient dies, but for some, that chance never comes when the patient has a neurodegenerative disorder. If this is the case as opposed to the cases Karner et al described of caregivers moving on with their lives, then it could be possible that

the caregivers become stuck in a liminal stage between statuses, having never gained the closure necessary to move on.

As the relationship deteriorates, caregivers find themselves in a bizarre realm when the normal rules of communication are thrown out the window, but more than that, normal rules of feeling are gone as well resulting in an increased need to perform emotion work. This is the subject that Hazel MacRae (1998) seeks to address when she applies the lens of emotion work to caregivers of persons with Alzheimer's disease. MacRae finds strong evidence that because late stage Alzheimer's patients can no longer determine what feelings are supposed to be owed or given in the context of their relationships, the people at the receiving end, in this case their caregivers; try to continue feeling appropriate emotions even when those emotions are not reciprocated (Mac Rae, 1998). Like the man mentioned in the Karner piece, past relationships and feeling rules still play an important part in the lives of caregivers, so that even if the patient acts in a way contrary to the expectations of the previous relationship, the caregivers have to control their own emotions and not respond in kind, because of their dedication to the past rules of their relationship. Caregivers reported feeling frustrated and impatient with their spouses or parents, and then immediately feeling guilty about having those feelings, exemplifying what Hochschild would describe as "suppression" of emotions. Over time, some caregivers came up with the strategy of disassociating the patient from their behaviors, with one caregiver saying "I don't think I really got too angry because I always tried to keep in the back of my mind that these things mum was doing she was not responsible for", taking the

first step to realizing that the disease had changed their relationship permanently (Mac Rae, 1998). It is important to note that this is an example of emotion work, rather than dramaturgy, as caregivers rationalize in ways to make it easier for them to feel what they are expected to. They are actively trying to manage their emotions and feelings, and not just how they show it. One concern that MacRae puts forth is whether this disassociation and emotion work puts caregivers in a position where they “care for” but no longer “care about”, a very real possibility as Blieszner and Shifflett described as family caregivers became just caregivers and lose their family role relation.

This diminishing and degradation of the patient-caregiver relationship is an especially important issue for caregivers because having a strong patient-caregiver relationship plays such a strong role in reducing caregiver burden. Lawrence et al (1998) studied 118 caregivers of disabled older people, looking at the relationship between interpersonal closeness and caregiver burden. They found that relationship quality was a key factor in mediating caregiver burden in areas such as depression. In particular having a strong and close relationship was correlated with major decreases in feelings of role captivity, that is, caregivers feeling they were stuck in that role with no way out of it (Lawrence, Tennstedt, & Assmann, 1998). This can translate into a caregiver perception that it is their choice to care for the patient, and feelings of more freedom and control. When neurodegenerative disorders severely hamper the opportunity to have a strong and meaningful relationship, caregivers lose out on this potentially powerful mediating force for the burden they face.

Section 6: Building off the literature

There are some commonalities or overarching themes present in all of the work done through the disciplines. It is apparent that regardless of the illness, there is stress and burden associated with the act of providing care to another. There are discussions about what the root causes are behind this caregiver burden, but researchers generally agree that being a caregiver can have negative consequences, whether physical, emotional, or other. At the same time, it is generally accepted that not all caregiver experiences are made equally. Some researchers have found that caregivers can be relatively unaffected, or even experience positive outcomes or emotions from caregiving, depending on certain factors such as motivation, strength of relationship, and external factors whether they be socioeconomic, liminal, or interpersonal in nature. These factors studied by researchers such as Lawrence and Thai offer some possible avenues for exploring how different individuals experience caregiving differently, perhaps across different illness types as well.

However, despite all the research already done on the subject of caregivers, there are still questions unanswered. First and foremost, the literature as it stands often treats caregiving as something that occurs in isolation, just between a caregiver and their care recipient. It for the most part ignores, or does not sufficiently consider, the broader context in which caregiving is taking place. Some of the individual disciplines have brushed upon some of these contexts, whether it is the temporal context with liminality and uncertainty, the socioeconomic context, or the context of disease type and symptomology, but

these contributions are being ignored across disciplines when they have a lot to offer each other. For instance, one of the contexts discussed by socio-psychological researchers and medical researchers of Alzheimer's is the context of interpersonal relationships. These researchers have examined in depth the role past relationships and plays in the caregiver experience and how it affects caregiver behavior and use of emotion work. However, research on caregivers of CKD patients has largely ignored the interpersonal relationship context. While this can partially be explained by the fact that these topics of changing relationships and communication are more apparent and on the surface when the care recipient is experiencing memory and personality loss, the context of the past relationship between caregiver and care recipient is also important in CKD caring situations and should not be minimized. Just because the relationship is not as drastically changed does not mean that the relationship between patient and caregiver does not change, and that change does not affect the caregiver's experience of caregiving, understanding that change is critical for understanding the overarching caregiver experience. Cases like this occur throughout the literature for each of the structural contexts described: disease type, interpersonal relationship, temporal, and socioeconomic, where these contexts are not fully appreciated by the researchers themselves.

In addition, while the dementia literature does look closely at the challenges dementia caregivers face with regards to changing relationships, neither the dementia literature nor the CKD literature looks particularly closely at the ways in which caregivers manage the transition from their life before

caregiving to during their caregiving stage, navigating through the influences of greater structural factors. The exception to this is a few longitudinal studies of mental illness caregivers that followed caregivers throughout the course of the illness from initial onset of symptoms to years after diagnosis. However, besides for the fact that this was for schizophrenia generally in younger patients, these studies focused more on how caregiving had changed their perception and their life, and less about the processes by which caregivers attempt to manage that change. I am particularly interested in these processes: the paths by which caregivers use their own agency to respond to new responsibilities and duties in the context of larger structural contexts often placed beyond their control.

Finally, while lack of discussion of structural contexts across disciplines is true for all of the various factors described, particularly egregious is the lack of research on the effects of the context of disease type on the caregiver experience. I found no literature performing a comparative analysis between the caregiving experiences of caregivers of physical illnesses such as CKD and neurodegenerative illnesses such as dementia specifically. As discussed earlier, while they are both chronic illnesses, patients face different problems that caregivers are expected to manage, as well as very distinct treatment regimens both in terms of medical intensity and caregiver involvement. While both groups have informal caregivers, these caregivers might have very different experiences as a result of the nature of the illness of the care recipient they are caring for. It is impossible to fully understand the experiences of these caregivers without understanding the context of disease type that they are working within.

Understanding what aspects of the patient experience with illness, including symptoms and treatment, affect the caregiver experience could prove useful in order to better understand the nuances across the experiences of informal caregivers but also to understand the unique areas of support that different caregivers might need depending on the illness that they are caring for.

Section 7: How the literature informs the project

For this research project, caregivers of patients with chronic kidney disease and caregivers of patients with memory-loss related disorders were chosen because of the contrast of disease experience the two groups of illnesses provide. Both of them are chronic disorders, so unlike being diagnosed with advanced cancer, the prognosis for chronic kidney disorder or Alzheimer's dementia can be several years, though it can be difficult to be precise. At the same time, both of these disorders are considered incurable illnesses, in the sense that with the exception of getting a transplant in the case of chronic kidney disease, there is no way for patients to fully go back to the life they had. Therefore, caregiving in these situations is not a short term act of generosity with a limited time frame, but rather a large commitment that can potentially take up years of the caregiver's life. The similarities in length of time that care is expected to be needed offer the opportunity to compare these illnesses experiences in a way that would be more difficult for short-term illnesses such as recovery from serious traumatic injury or palliative caring for late stage cancer diagnoses.

On the one hand, important differences between the two illnesses make them valuable to examine broader themes in the caregiving role. Chronic Kidney

Disease is an extremely medically intensive illness, with even conservative management requiring changes to diet and habits. More often than not though, it requires invasive treatment on a regular basis in the form of dialysis. While types of dialysis vary in terms of how many times a week it must be performed and how long each dialysis session takes, it is still at least several times a week of intensive and invasive medical procedures, combined with changes in medication, diet, and activities of daily life. This makes the disease medically intensive for not only the patients, but also for their caregivers, who often must be responsible for transportation to treatment, organizing and sorting medication, ensuring compliance with diet, and sometimes even directly assisting with the dialysis procedure at home after medical training from nurses and dialysis technicians.

On the other hand, while dementia such as Alzheimer's often has other physical comorbidities, one of the main ways it manifests is through memory and other cognitive decline, severely inhibiting the patient's ability to perform everyday activities. This cognitive decline also affects their ability to hold social interaction and it can affect their relationships with friends and family through changes in personality and loss of memory. In addition, unlike in CKD, there is no clear treatment regimen, though there are medications that can help address symptoms and attempt to slow the disease's progression. In this sense, caregivers for patients may be less medically involved in their patients' care than caregivers of patients with CKD. However, as patients with dementia gradually become more forgetful or mentally incapable of performing activities or recognizing actions that are dangerous or off limits, caregivers of these patients often have to

pay constant attention to their care recipients, and often have to manage every aspect of the care recipients' life in a way that caregivers of CKD patients don't have to.

In the following chapters, I look to take the various structural factors hinted to by the various disciplines discussed in this chapter to integrate and apply them to studying the experience of caregivers of dialysis or Alzheimer's patients. By the end of the next three chapters, I hope to have shown the effect that structural context can have on the caregiver experience, with a particular focus on the context of disease type and its effect on not only perception of caregiver burden but also caregivers' responses to it, as I seek to find a fuller and more complete understanding of informal caregiving.

Chapter 2: The Relationship Context

Rachel helps to coordinate care and care for both her parents, who have been in and out of the emergency room for the past few months for falls and illnesses. Both of them have moderate to severe Alzheimer's, which has proven to be difficult for Rachel. Not just because of the caregiving responsibilities she now has, but because she feels that too much has changed with her parents. They used to listen to what she had to say about her day, and could discuss the latest happenings in the news or their community, but after Alzheimer's set in, she lost that ability to communicate and connect with them, which has had a profound emotional impact on her.

In this chapter, I will be discussing the importance of the context of interpersonal relationships in how it affects caregivers' experiences and how they perceive burden. I find that the current relationship between caregiver and care recipient is really the factor that matters most in influencing the caregiver experience, and while the previous relationship between caregiver and care recipient does play an important role in determining the current relationship, it is the nature of the disease that plays an important role in modifying the past relationship, such that the same relationship context may have two radically different meanings if taken in different disease contexts.

Section 1: The importance of the interpersonal relationship in informal caregiving

The relationship between care-recipient and caregiver is one of the key differences between informal caregivers and professional caregivers, and is

therefore essential if we are to have a full understanding of the experience of informal caregiving. As one informal caregiver who was a former nurse explained,

“When you're at work it's not personal, it's you're doing your job and you're doing everything you need to do for that human being but it's not personal. It's personal when it's your mother, or a family member, so your feelings get involved: when I'm working I turn it off after the 8 hours, but you can't turn off those emotions and worries about a family member, because they're with you 24/7.”

From the very beginning, the caregiver-care recipient relationship plays a large part in providing caregivers with motivation or rationale for caregiving, and can be the main reason that informal caregivers do what they do at all. Informal caregivers cited norms of obligation, responsibility, and reciprocity as strong motivating factors for their caregiving. As one dialysis caregiver stated, “You know, she took care of me all her life. You know, she took care of my kids. [...] I just think of it that I'm her daughter and she needs to be taken care of.” This finding was expected from Call et al's (1999) findings that a desire for equivalency might drive caregiving as a way to balance out the ledger. Interestingly though, this sense of duty and obligation was present even in cases where the relationship between caregiver and care recipient was poor prior to initiation of care. While the above quotation from the dialysis caregiver came from a daughter who had a good relationship in the past with her mother, another caregiver, a wife caring for her husband with dementia had a similar motivation to caregiving even with a different previous relationship. She admitted to having a “not great” relationship with him prior to the disease, but stated that even so, “I do what I do because I feel responsible to do it. [...] somebody needs to and he's my

husband.” This suggests that the quality of the past relationship does not matter as much as the social expectations of the relationship. In other words, in terms of the concept of reciprocation, it may not necessarily be equivalency for past assistance provided in the relationship that drives an obligation to care, but rather societal expectations of the responsibilities of the position itself regardless of whether the caregiver received assistance in the past or not. This finding is in line with Call et al’s (1999) findings, which make no mention of quality of the relationship, only obligations arising from those relationships. Despite this, the nature of the past interpersonal relationship makes its influence known in other aspects of caregiving besides for motivations for caregiving.

Section 2: Disease’s effect on relationship context

The relationship between caregiver and care recipient, and in particular the change of that relationship over time, plays an important role in adding to or mitigating caregiver burden. The change in relationship, though is in large part a result of the nature of the disease of the patient, which also plays an important role in modifying the ways relationships can either alleviate or exacerbate the burden of caregivers. I find that some of the theories discussed in the literature review in Chapter 1 of the importance of the interpersonal relationship context only stand up to scrutiny in certain disease types, and is therefore very dependent on the disease context.

Relationships in Alzheimer’s

One of the main ways Alzheimer’s can cause stress on the interpersonal relationships of patients and caregivers, and therefore add to stress, is through the

mental decline of their care recipients. This challenge can manifest itself in many different ways. First of all, the loss of ability to hold conversation or otherwise do things that they could once do proved to be troubling to several of the caregivers interviewed. One caregiver of a patient with stated, “I can’t share anything with her. If anything would happen where you want to call your mom or your dad and be like, ‘You can’t believe this blah blah blah.’ So that’s completely gone and I can’t do that anymore because she wouldn’t comprehend that anymore.” Another caregiver, Rachel as mentioned in the beginning of this chapter, who cares for both of her parents with Alzheimer’s dementia, found a challenge not only in a lack of communication but also in a loss of day to day social activities. She said,

“Um, I’m hardly ever eating with them anymore because they pretty much have to eat at the facility, [...] We’re doing fewer things that could be counted as fun. We don’t go out as much. Theoretically, they could do it, but I find it to be so difficult because I have to bring two walkers. I don’t have a disabled sticker yet. [...] As the illness progresses more and more, it seems like as they [...] can do less and less.

This slow degradation of previous relationships and ties as a result of the context of the disease results in enough stress that in some caregivers distancing themselves emotionally from their care recipients as a coping mechanism. In some cases, this distancing occurred through embracing a new role, or even identity, as “caregiver” to replace the old role, a theme that will be explored more in Chapter 4 along with other facets of caregiver identity formation. For the time being, it is useful to note that informal caregivers can still see themselves as children or spouses with altered responsibilities and behavioral expectations rather than full caregivers, but that they can simply have a more detached

approach to caring for their care recipient. This takes the form, in cases of patients with Alzheimer's, of caregivers expressing that while emotionally they still recognized that they were taking care of the care recipients and still loved them, there were times when they perceived that "it's not them", especially when they were being frustrated by the care recipients' behavior. Says one daughter caring for a mother with Alzheimer's,

"You know, it feels like she's not really my mom, I mean, she's there, she looks like my mom, but I would say, you know, it's like the death of my mom in little daily increments, [...] I can't really talk to her about anything going on in my life. She doesn't understand. [...] it just feels like the person she was is mostly not there."

Beyond just simple distancing of the caregiver from the care recipient, there were situations where roles in the relationship completely reversed or were completely redefined. For a few caregivers, a change in role was seen as a neutral, or even positive thing to happen. One caregiver caring for her husband in an assisted living environment shared,

"It's almost a mother-son relationship [...] I'm very tender with him, very affectionate. And I love him more now than I've ever loved him. I don't know whether it's sorrow, sadness for him, pity. I don't know, and I'm not going to worry about what it is, I just know I love him more now than I ever have."

For the majority of caregivers experiencing a change in the role relationship though, the experience was difficult. A husband caring for his wife with Alzheimer's said,

"I call it "death by a thousand knives", that's what it is, right in front of you you'll just see somebody declining [...] we had a good, stable marriage, we had a

good relationship, so that's the hard part. I talk to her now like I'm talking to a 5-year-old, but she's not my partner, that's the big difference."

The difficulty was magnified in cases of role reversal with children caring for their parents. For these caregivers, the new arrangement felt strange at best, and played an important role in adding stress to their lives. One caregiver likened her new relationship with her mother as one where she was the parent and her mother was a child, saying "the roles have so reversed that, like I said, she calls me her 'mom.' [...] she was my caretaker and now I'm her caretaker. [...] When she finally went to bed, I was exhausted it was like putting my toddler to bed. I was tired – like emotionally tired." For this caregiver, role reversal also came with role strain. Since she already had a toddler, suddenly, being a mom had double the responsibility; taking care of a toddler and taking care of her care recipient, proving to be too much. In addition, this role reversal for many caregivers signified the end of their previous relationship with their parent; a sad occasion. One caregiver said of her role reversal with her father, "well it's very sad, because I've lost a lot of who my father was," while another said "I'm definitely have changed -they totally treat me like I am their parent now, we've really done that role reversal. [...] I'd rather it wasn't like that."

Another relationship issue that Alzheimer's in particular brings up is a change in communication between caregiver and care recipient. The question of how to communicate and interact with a care recipient that may not understand you is an issue that faced many caregivers interviewed. Because of the nature of Alzheimer's dementia, cognitive communication ability declines over time,

resulting in distress from caregivers as their relationships deteriorate. This also has the result of caregivers having to find new ways and strategies to communicate with their care recipient. However, there is no uniform response to this cognitive decline, as different caregivers have come up with different solutions to the problem. For instance, while some caregivers believe that it is inappropriate to belittle their care recipients because of their disorder, others strongly believe in simplifying some explanations when the details are not important, in order to help comprehension or avoid agitation. While on the one hand, one caregiver said, “I try to maintain a level of, you know, adulthood, you know so I do get aggravated when other people um, talk like baby talk type because she's not a baby, you know”, another caregiver stated,

“So it has changed the things that I can share to her, and I do try to keep things very simple and not complicated, because she can't really, I can't really explain, the explanation is not something she's going to process cognitively, so trying to simplify things so she can understand them better.”

The concept of lying was also important to the caregivers interviewed. Some caregivers were adamant that they were always honest towards their care recipients, with one explaining, “I've never believed in lying, so I'm not going to start with her now, mm-mmm. I always tell the truth with everyone, not just with her, I don't like to lie so I don't bother.” Even so, that doesn't include omission, as the same caregiver also said, “I just think she can't always handle all the details if she's in a bad space”. Many of the other caregivers, however, especially those expressing high levels of burden, expressed that they sometimes tell white lies or half-truths to their care recipients. Interestingly enough, a term seems to have

been spread through caregiver support groups to cover these, calling them “fiblets”. Says one caregiver who uses this term,

“Sometimes it's easier to lie than to explain, and it's true! It's much easier to lie to her and say "Margaret's at the desk" than to say "there's nobody at the desk but you know there's somebody at the desk from this hour to this hour, and then the security guard comes on at 10 pm and everything's going to be okay", no, that's much more complicated and that doesn't alleviate her anxiety. [...] it's more comforting for her, she'll ask me about people, and there's another thing I learned from these counselling sessions my husband and I were in, she'll ask about people that are dead, and rather than say they're dead, I'll say "they live away", or "I haven't seen them in a long time.”

As explained in the quote, one of the main reasons for engaging in fiblets and white lies is an effort to protect the patient emotionally, and this brings us into another aspect of communication between caregivers and care recipients, which is the difference between emotional and cognitive communication. Says one caregiver on the distinction,

“She doesn't understand, you know, like what I'm trying to convey to her. She understands I'm upset, she thinks I'm upset with her or something, you know, when it's true that I'm upset, she's getting that, but she doesn't understand and even if- even if I did happen to be upset with her she wouldn't really understand why or what to do about it or anything, so she still reads me emotionally, but she doesn't read me intellectually anymore.”

This awareness of emotional communication is, in a sense, one aspect of performing emotion work on the part of the caregivers, but in another way, it goes back to the idea of role reversal. The idea that the tone in addition to the content

of the message is important is something parents know, but in this situation, instead of applying it to a younger child, it has to be applied to an older care recipient. Caregivers were acutely aware of the effect their words, tone, and actions could have on their care recipients, and as such were careful to control what they showed in the presence of the care recipients. Says one spousal caregiver,

“He knows me so well, he knows if I’m upset or disturbed or things, so I have to remember not to be that way in front of him. If I have something that’s bothering me, it’s better to not be near him. Not that that happens very often, but um, because I can see a worried look on his face, we’re like that together, we know each other so well, he can tell when I’m upset, so I have to be careful not to be upset in front of him.”

This effort to avoid patient distress could play a major role in caregivers’ attempts to avoid shared empathetic suffering with the patient. In particular, the suffering in the case of Alzheimer’s dementia comes from watching an unstoppable cognitive decline and a feeling that the person is slowly being lost forever. Says one caregiver, “It breaks my heart to see her, but I know that this kind of, um, fragile state that she’s in right now is-is not her 'cause she always was like strong, independent, but more so because she had to be, but I think she always wanted to be something else and now she’s very clingy and stuff.” While attempts are made by caregivers not to increase the patient’s distress beyond what it already is, there is a great deal of caregiver-perceived suffering on the part of the patients, which affects caregivers regardless of how attentive they are to the patient’s emotional responsiveness.

Relationships in Dialysis

Due to the differences in disease symptomology and progression, caring for dialysis patients presents a distinct set of challenges than caring for Alzheimer's patients. Several similar tools used by the caregivers come into play, but they are used in different ways.

Caregivers of dialysis patients I interviewed deal with patients both emotionally and cognitively aware, and unlike in Alzheimer's, where the emphasis on emotional communication comes in large part from a degradation of cognitive communication, emotional communication in dialysis becomes emphasized as a response to the care recipients' struggle with themes about their mortality, struggles with their treatment, and the end of life. One caregiver of her mother in law on dialysis says,

"She gets down and depressed about it, and she'll look in the mirror and say I wonder who that old lady in the mirror is looking at me [...] She misses her husband and she divorced when her youngest son was 14. [...] she says, I don't miss him, I wouldn't get married again, but I miss the human touch. So I'm always rubbing her back, or scratching her head, she likes that. [...] Because she gets down very easily, so I try to keep her more lighthearted."

While these communication strategies appear primarily for the care recipient's benefit, they also play an important role in helping to manage caregiver burden, both directly and indirectly. Directly, it helps caregivers avoid having to repeatedly discuss issues which may bother the caregiver as much as the care recipient, such as deaths of close relatives. Indirectly, drawing on the findings of Monin et al (2009), these communication strategies help reduce the

potential suffering of care recipients, and as such, reduce the empathetic suffering of the caregivers themselves. By attempting to minimize any distress or suffering of the care recipient by different communication strategies, they are also helping to minimize their own distress of having to watch the further decline of the person they are caring for.

Another way that caregivers of dialysis patients had a different experience was through their patient's retained mental capacity, unlike the situation in Alzheimer's. This is especially true through disagreements over care. As one caregiver describes with her mother on dialysis,

"She gets into a little attitude mood, like anybody else. 'You're not doing this right, you know, you wanna do it your way, you don't wanna do it my way.' I'm like okay, because for me, your way is hard, and I do it an easier way, you know! [...] I was like okay, I'll do exactly what you want it, and I'll be like ma, I could have been done, you know? 'No you couldn't have, no you couldn't have!' Okay, I'll do it your way, so I'll be like, let's go on and just do it and get it done."

It is possible that this controlling attitude the care being provided is a result of a personality trait, but it could also be an effort by the patient to retain some control over their lives even as the necessity of being on dialysis takes some of that control away. Several patients on dialysis interviewed strove to be independent in the face of their dialysis care, whether that meant being able to help around the house or being able to do what they wanted. At times, this clashed with what their caregivers were trying to accomplish, resulting in feelings of frustration or exasperation from the caregiver. However, more often than not, the caregiver was able to let the care recipient have it their way for non-essential

aspects of care, meaning the overall burden added from patients' desire for independence was relatively low.

Here is one of the main differences in the context of disease type. While the relationships between Alzheimer's caregivers and patients is in many cases one-way, caregivers of patients on dialysis are still able to negotiate and communicate by getting both verbal communication and nonverbal cues from their care recipients. The lack of two-way communication for Alzheimer's caregivers, in addition to the strong negative impact loss of communication has on interpersonal relationships, means that the burdens that caregivers of Alzheimer's patients face are likely more difficult, and more difficult to address on an interpersonal level alone than the burdens for caregivers of dialysis patients.

Section 3: Interactions between disease identity and relationship strengthening

In the literature in Chapter 1, I discussed the cognitive model of caregiving by Kuipers et al (2010), which proposed that stronger interpersonal relationships prior to onset of disease would lead to more positive caregiving experiences for caregivers. Based on my findings, I argue that amongst caregivers of patients with Alzheimer's or on dialysis, their model only reflects the experiences of dialysis caregivers, which is surprising given that their model was based on mental illnesses such as schizophrenia. The root of this is again, in the differences in disease, where caregivers of dialysis patients have more options and strategies to focus on their relationships as a way to decrease their burden.

Caregivers of family members with chronic kidney disease can, under certain circumstances, grow closer to with their care recipients through two main mechanisms. First of all, these caregivers get to spend more time with their care recipients, but importantly, they get to spend more time together in their familial roles as opposed to a patient-caregiver relationship. This was true both for caregivers who had strong prior relationships, and those whose prior relationships were sometimes strained or distant. For instance, one dialysis caregiver taking care of her mom on dialysis mentioned that while she was close to her mom growing up, she and her siblings had drifted apart from their mom over time until their mom needed care again. Through the course of care, the siblings became closer to their mom, but also closer to each other, describing the process as “waking up”, showing that a distant prior relationship is not necessarily a barrier to having a strong current relationship and a generally positive caregiving experience. On the other side, another dialysis caregiver who already had a strong relationship with her wife said,

“Well it's just that we spend more time talking to each other, and you know, um, there wouldn't have been time, or we wouldn't even think about it probably as much as we do now. Now I know, you know, we talk about everything on the news, politics, feelings about things, emails that she gets. Conversations with her friends. So, it's a lot more, time spent, and a higher level of detail or intense amount of contact.”

Contrast this with many of the caregivers of family with Alzheimer's, who were unable to communicate with their care recipients or spend social time with them, and felt that they were losing their relationship instead. This was especially

hard for those who previously had strong relationships with their care recipients, as they felt that they had lost more in terms of their relationship. Rather than serving as a basis for better caregiver experiences, strong prior relationships in the case of many Alzheimer's caregivers actually had seemingly negative effect on their experience, as they struggled to come to terms with what they had lost.

There were one or two caregivers of family with Alzheimer's who felt closer to the people they were caring for, and the common thread between those caregivers was a feeling of being able to spend non-caregiving time together, much like caregivers of dialysis patients. In one of the cases, a daughter caring for her father with moderate Alzheimer's was able to spend time with him through activities and trips around town, mental exercises, and everyday conversation, and in doing so, felt that she had gotten closer with her father by getting to know him "on a different level". In another case, a daughter who had been caring for her mother before helping her move into a long term facility explained how ever since her caregiving responsibilities had been transferred over to the nurses taking care of her mother, she was able to spend more time with her mother just as a daughter, where she started to have a much better experience with her mother in a role that was enjoyable, rather than a role that she felt was necessary. She explained,

"Every day I still feed her, even though the staff would do that, I feel that it's something I want to do, we talk about the past, we talk about the future, we watch the news, so at this point it's more of a visit than actual caregiving now that she's in the facility, um, so um, I just spend time with her, just chatting like you would do if she was in her house at her table, so that kind of quality time I spend with her now, so it's not about the physical doing the task anymore, you know. [...] instead of a true caregiver, I'm just a loved one who is visiting and being with her,

not because I absolutely have to make sure things are done but because I want to be, because I want to be with her.”

As these examples show, not all time is equal. Quality time spent together, even if it is just talking, helps to strengthen relationships, while time spent caregiving may not have the same effect. One aspect that strengthened relationships between caregivers and care recipients of dialysis patients not present in the Alzheimer’s caregivers interviewed was closeness as a result of openness and the sharing of emotions and vulnerabilities prompted by an end of life diagnosis and death being at the forefront of the mind. For many care recipients diagnosed with chronic kidney disease, and more importantly kidney failure requiring dialysis, this diagnosis of an end of life condition resulted in a more expressive and emotional personality. Caregivers of these individuals reported more openness in the relationship and feeling closer as a result of shared fears, vulnerabilities, and worries. One caregiver caring for her husband on dialysis noted that her husband was more open to expressing unhappiness or sorrow, something which she felt helped strengthen the bond they had together. Another caregiver of a husband on dialysis said,

“[Caregiving has] made it stronger. It's added facets to it. It's stronger, it's deeper, I think sometimes it can be on edge, it can be scary. We've both admitted that we're both, we're both afraid of dying. I'm afraid of living without him. But we also know I could get hit by a bus tomorrow, which I told him, you know, I'm going to do all this work and then check out before you, how good is that!”

As the quote illustrates, sharing goes both ways. It is not only that the care recipient shares their concerns and fears, but also that the caregiver responds with

emotional support and opening up their own worries. This two-way communication, something lacking in the caregiver-care recipient relationship in Alzheimer's disease, can offer a chance for both patient and caregiver to express themselves and support one another in a way that reinforces previous role expectations. For my respondents, this had the effect of strengthening the bond in the process, resulting in a more positive experience overall. In instances when the two-way communication is interrupted, caregivers can experience stress and frustration, similarly to what caregivers of Alzheimer's' patients experience. As a caregiver caring for his husband said,

“Whenever we have a really tense time, it usually ends up that we are both scared to death about what is going to happen. Uh, and can't talk about it. It all boils down to there's not going to be a happy ending, and he's going to get sick, or get more sick and die, and he's going to have this cascade of events that is irreversible and, you know.”

However, when they are able to communicate together, the caregiver acknowledges that

“The whole experience has been stressful at times and um, has put a strain on the relationship, but at least we're able to talk about it and process it and, you know.”

Unfortunately for caregivers of patients with advanced Alzheimer's, two-way communication is not something that can be regained in their relationship to their care recipient, due to the nature of the illness itself. One special case of communication from the care recipient to the caregiver I want to mention is that of appreciation. It goes back to the concept of social exchange theory as discussed by Dwyer (1994), and in particular how even when put in a position of

dependency, care recipients want to reciprocate in some way, no matter how small, to try to even the imbalance in the social exchange. This is also the case in Parson's sick role, as the patient is supposed to be appreciative of clinicians or caregivers' efforts. Just as Dwyer et al (1994) found in their study, the caregivers interviewed in this study who reported feeling appreciated by their care recipients found some burden alleviated through that, possibly because it was relieving to them that their patients were acting within the patient role. This concept of appreciation played out differently in caregivers of chronic kidney disease and Alzheimer's, but it was present in both populations. For care recipients on dialysis, they were more cognitively aware of exactly how much effort caregivers were putting into taking care of them, and appropriately acknowledged that effort. In the case of the patient on dialysis being cared for by his husband, he was very aware of the effort his husband was making in caring for him, and described one of the reasons he wanted to get a kidney transplant as "I knew I had to get [my husband] away from dialysis". In another instance, a caregiver caring for her mom describes,

"If I'm tired, she says oh, I want to eat salad today. So salad is easy to prepare, you know. [...] after I do my job, my work, I go 'mom, I'm so tired, my neck hurts', she says, 'we can eat salad today'. Or cooking leftovers. And she can tell. I say, oh I'm tired too. And she says oh we don't have to cook, just eat whatever leftovers. Now she recognizes more."

In this case, the caregiver's mother, aware of the burden that cooking and caring for her placed on her daughter, purposefully adjusted the amount of care, in this case in the form of cooking, she required in order to be appreciative of her

daughter's time and effort. In cases of Alzheimer's, this appreciation from patients was more nuanced, but still present in a number of patient-caregiver relationships. Again, there was no clear correlation on what quality of past relationship resulted in appreciation or not. Appreciation came from patients with Alzheimer's who were close to their caregivers before illness, but also from patients who were cold or ambivalent to their caregivers before their illness. One wife caring for her husband with Alzheimer's reported that he was more appreciative now, with Alzheimer's, than he ever was when they were married together without Alzheimer's. Alzheimer's caregivers reported being thanked for small things, that they did for their care recipient, a token gesture, but one that nevertheless had a profound impact on the caregiver. One caregiver taking care of her mom explained,

“She’ll say ‘Well thank you for giving me a shower,’ ‘Thank you for the nice food,’ you know what more could you want right? She’s so happy with little things. You know, I bought her a bathrobe – you would have thought I bought her a million-dollar scratch ticket or something; ‘This is so beautiful you bought this for me.’ So she still does appreciate, but it’s such a small little-nothing. A little...you know? It changes your perspective for sure.”

Despite feeling overwhelmed overall by her experience caring for her mom, for this caregiver, the thanks she received on a regular basis, no matter how small, helped her feel rewarded and appreciated, even if it was only for a little bit. In more advanced cases of Alzheimer's dementia, there were still some cases of appreciation, even with nonverbal cues such as giving a smile or another indication. However, in advanced cases of Alzheimer's dementia, appreciation

from the patient had a comparatively lesser effect given the increased burden faced by the caregiver.

The roots of appreciation in patients with Alzheimer's deserves examination, as it illuminates an interesting divide in the perceptions of caregivers and care recipients. In one example, a daughter caring for her father emphasized in many points throughout the interview that she saw caring for her father as an act of reciprocation, something that she ought to do because he took care of her when she was growing up. However, she says about her father being appreciative of her effort, "He doesn't see it that I'm paying him back. [laughs]". While the caregiver feels her role is expected and ordinary, the patient feels that she is stepping above and beyond her expectations. These two perspectives on the same role then, result in appreciation being expressed even as the illness diminishes cognitive and social skills.

Section 4: Summary

There are many ways that caregivers adapt and cope with the experience of caregiving on their own, but it is also important to remember that caregiving does not happen in a vacuum. The relationship between caregiver and care recipient is an interpersonal factor which serves as a context within which caregivers' experiences occur. However, I found that contrary to Kuipers (2010) cognitive model, the past relationship does not matter as much as the current relationship context for Alzheimer's, and that the current relationship context, which does play an important role, is greatly dependent on the nature of the patient's disease. Kuipers' (2010) model does approximate the experiences of

caregivers of dialysis patients, as strong past relationships lead to strong present relationships, but in cases of Alzheimer's, strong past relationships have no visible impact on caregiver burden and experience down the road, and often resulted in more distress for caregivers as they feel they are losing even more as the disease progresses. Being able to compare these two general types of illness side by side illuminates just how much potential support is lost for the caregiver when the patient they care for gradually stops responding to them in Alzheimer's.

In Chapter 3, I will again tackle the context of disease, this time on how it relates to both the temporal and socioeconomic contexts of the caregiver's situation to change their ability to respond to increased responsibilities and demands.

Chapter 3: Money can't buy happiness, but it certainly helps.

In this chapter, I look beyond the patient and the caregiver at the socioeconomic context in which the caregiver exists. Variations within this context, especially with regards to disposable income, work flexibility, and social supports, greatly affect the responses caregivers can pursue to find help with their caregiving. I will also discuss the responses of caregivers without as many socioeconomic resources, and how the temporal context of disease and mortality serves to affect frustrations patients have over their experience. I find that the socioeconomic context in which caregivers operate plays a much larger role in their experience than the current literature supports, which has implications further down the road in Chapter 4.

Section 1: Socioeconomic effects on a caregiver's ability to care

A theme that came up time and time again when interviewing informal caregivers was that caring for their care recipient was a 24/7 job. This was especially true for caregivers of patients with Alzheimer's dementia, as caregivers worried about them wandering off or putting themselves in danger. Even if not every hour of the day involved caregiving, the rest of the hours in the day were filled with worrying and being ready to provide care should the need arise. As one caregiver of a mother with Alzheimer's said,

“Now (pauses) yeah that is totally time consuming, especially this past year because she's gotten more – she's been living with me. It'll be two years since July. So, I can't leave her for five minutes unattended so it's like having a toddler. It's really (pauses) a lot. It's a lot harder than I thought it would be. I got to be honest with you.”

While caregivers of both care recipients on dialysis or with Alzheimer's faced the ever-present role of caregiving in their life, I find that it affected caregivers of patients with Alzheimer's dementia more. While caregivers of patients with Alzheimer's felt they could not leave their care recipients alone for even short amounts of time and therefore found themselves unable to really work another job, caregivers of dialysis patients were often able to still work while they were caring for their care recipients, albeit perhaps cutting back on their time or working remotely. In both cases though, caregivers felt themselves losing free time for themselves or to spend socializing with others, often resulting in a feeling of a deteriorating social life. A daughter-in-law caring for her mother-in-law on dialysis, provides a good example of this for dialysis caregivers, explaining

“My social life has gone down, unless it includes her, just because I'm afraid to leave her at home alone. I used to go to my girlfriend's house every Friday night, had take-out and watched movies. And one night I was there, and I came home early, didn't know why, went in the back door, which we never do, and she had fallen, she missed the bottom step, so she was leaning against the door, so we couldn't have gotten in if we tried, and it was just, it was so scary, so ever since then I'm like, kinda wary [...] I would feel horrible if she hurt somebody, or if she got hurt herself, and something happens”

It is important to note though, that even though the daughter-in-law was afraid to leave her at home alone, this fear was not so strong that she felt she had to stop working to watch over her: she was still able to work with her mother-in-law at home but felt that she had to curtail her social life, which she perhaps perceived to be less critical, to better ensure the safety of her mother-in-law.

This example raises an important point within the broader socioeconomic context: job flexibility is particularly important for caregivers. Not only does it give caregivers income to spend on themselves or their care recipient, but it also offers a break from the monotony of only caregiving by giving them something to do that connects with their old life. For instance, one former real-estate agent and current daughter caring for her mother with Alzheimer's described the toll caregiving had on her entire life and in particular her work life, saying

“My whole career is gone and you know, just I have a few residual clients that, you know, kind of trailed through, I mean, I think I did two deals this year [laughs] you know, so financially it's kind of that whole aspect is gone, um, my social life is gone, [...] a lot of personal stuff I kind of put off and, but the biggest one I think is the job, which I think is just I just don't have time you know, and you lose friends and you lose your business stuff and- (trails off)”

On the other hand, in two cases, one caring for Alzheimer's and one caring for chronic kidney disease, caregivers were able to keep working because they had the flexibility to work remotely from home. As one dialysis caregiver who works at home recalls,

And I'm lucky, I have my boss, he understands it. So he let me take short-term disability, two weeks, no 6 weeks, to take care of my mom, rehab. After that I went home, talking with him, I told him, I have my choice, either I continue work at home, twice a week I go to office, and the rest I'll be home, if you need anything, just text me or call me or email me, I will do it right away, or I quit my job. He said let me think about it, and he give me the answer for me. One week after it, he called me up, and said, let us try one month, see if it works. If not, you can decide. So far, after one month, I do good, so I still continue. I mean, lucky part for me, I have a boss, he really understands it.”

Other caregivers who were working were either in jobs that had flexible hours or were able to talk to their bosses and employers in order to work out more flexible hours that would allow them to work and provide care. This was the case for three Alzheimer's caregivers, two of whom were doing shift-based hourly work that gave them more control about how much to work, while the third had a supportive boss and a flexible salaried position. While these caregivers expressed more challenges balancing caregiving and work than those who were working at home, having a flexible work schedule was something they were very grateful for. This is evidenced by one caregiver caring for a mother with Alzheimer's, who didn't have the luxury of complete workplace flexibility. She said,

“If you’ve got to spend three hours picking your mother up, taking her to the doctors, eating lunch and then going back, you know, you’ve lost work time and then so if you’re lucky your boss says, ‘Why don’t you take the rest of the day?’ If you’re not lucky, you have to go back to work or you have to stay really late to get the work done. And that completely screws up your family life or your social life.”

Moving beyond economic resources and into social network resources, social support could come in the form of direct caregiving support, most often from siblings or adult children. Several caregivers interviewed described how they set up caregiving patterns and schedules with their siblings in order to help spread some of the load. Some siblings helped to provide care on weekends, while others helped provide care overnight so that a working caregiver could get enough sleep to wake up early for work in the morning. Even these small efforts from members of the caregivers' social networks taking some of the responsibility off the primary caregiver were appreciated by the primary caregivers. One caregiver

taking care of her husband described how in recent months, her children started to help out to allow her to take a break once in a while. She said,

“Participant: In more recent times, we worked out a system, um, whereby I would go away for two nights every three or four months and, um, one of them would come stay.

Interviewer: Right. And is that helpful – are those breaks helpful for you?

Participant: Oh, they’re invaluable.”

Even when breaks came only occasionally with long periods of time between them, they were still valued immensely because they broke up the non-stop 24/7 need to provide care. In some cases, additional caregiving support came from paying for professional agencies and paid care workers who would perform much of the day to day care-work. For the caregivers using these services, this was a great help, though it did require significant financial resources and disposable income. For caregivers who utilized these services, they saw their responsibility was more along the lines of a facilitator or coordinator trying to put all these services together for their care recipient, a challenge which was at times difficult for them, but which they acknowledged could have been much more difficult had they had to provide the care themselves. One younger caregiver, who was balancing school, work, and caring for her grandmother, described the turning point that pushed her to get additional help for her grandmother on dialysis. She says,

“I had one day I was working when I got an emergency call saying something happened to my grandmother, and at that point, I had to rush to tell my boss that I had an emergency and she gave me a dirty look, she told me that "oh, you can't

really always help your grandmother, you always have to be at work." [...] so that was my experience for me to be told that you're doing too much for your grandmother, you can't always be there for her. That's when I started to call and look up online."

Here we see an intersection of workplace flexibility and additional resources, in the sense that it was lack of flexibility that prompted the need to find additional help. This realization that she wouldn't be able to continue juggle everything she was doing that prompted her to take action and seek the help of a social worker helping with her grandmother's case. The case was echoed in several Alzheimer's caregivers, including Rachel, from the beginning of Chapter 2, who has delegated most of the day to day caregiving for her parents to paid care workers. In her case, like in many others', this additional help was not necessarily easy to get, coordinate, or to pay for. Many of the caregivers receiving additional care, whether through long-term facilities or through home care work services recognized that they had the financial privilege to hire these workers to help them on a regular basis. For other caregivers interviewed, however, this was not always an option, leaving them to shoulder the majority of the burden of providing care.

Section 2: Individual stop-gap measures for structural problems

These caregivers who do not have the job flexibility or means to hire assistance, and who do not have the help of their social networks are often left to bear the overwhelming brunt of providing care. For many of these caregivers, "self-care" has become the word of the day as a main focus to try to find relief from nonstop caregiving. This is especially true for caregivers who have been

providing care for months or even years, In the beginning, many caregivers feel they are expected to be sacrificing and to be fully devoted to the person they are caring for, but over time this rosy view of caregiving is replaced by one where the wellbeing of the caregiver is just as important as the wellbeing of the care recipient. One caregiver providing home based dialysis to his husband said about this idea of self-care,

“In my perception, caregivers are supposed to be supportive and providing care and love [...] and I don't think that's the reality after all of these years; I don't think it's very helpful to just put on this face of "I'll do anything for you" and "whatever my needs are don't really matter". [...] I think at the beginning with me taking care of Matthew and the beginning of his illness, people said "you have to take care of yourself because if you don't take care of yourself you won't be able to take care of him.” And I intellectually agreed with that, and I think it's partially who I am and I think I was raised to be very independent and not ask for help, and I think I survived with that attitude, I don't know if I survived gracefully or elegantly, I dunno, it's certainly a conflict for me, feeling like I'm a caregiver and I should do everything because if I was in Matthew's shoes I would want him to do everything for me, but I know that it's really taxing to our relationship not to let other people in or let them help, or let them help me, because I think it's important to have time for yourself and get rejuvenated, things like that.”

This change in view point is an individual adaptation by the caregiver to a structural issue: the issue of insufficient socioeconomic resources to help adequately care for the patient. It is almost a reflexive response, experienced by many caregivers interviewed who had moderate to heavy levels of perceived burden, but many of the caregivers were unable to capitalize on this desire to care for themselves because of a lack of structural resources Without additional financial or social resources, caregivers face burnout and increasing frustration

towards both their care and their patients. These are the situations where caregivers express a desire to self-care, in an attempt to decrease the amount of responsibilities they feel responsible for so that they can continue managing the care on their own. However, self-care only truly works when there is a support system in place to assist the caregiver. For instance, the caregiver who described her adult children taking care of her husband once every few weeks was also subscribing to the idea of self-care, but she was able to do so successfully because she had the necessary support from her family. Without the support of her children or else a paid care worker, there is no way she would be able to go away for a weekend once in a while.

In the absence of additional resources, this desire of caregivers to self-care and take time for themselves came at an emotional cost. For several caregivers, this adoption of a new idea of self-care went against what they thought a caregiver should be, and as a result made them feel extremely guilty, as though they were somehow abandoning the patient they were caring for. However, for the caregivers who espouse the ideals of self-care and feel that it is a part of being a caregiver, they find ways to rationalize away the initial guilt that they feel. Says one caregiver of her mother on Alzheimer's,

“So as a caretaker, we devote a lot of time right? And energy and you know, I give up a lot of social things – I don't go to...and then I feel guilty if in my mind I'm like, ‘Oh I don't want to do this anymore or it's hard.’ So I think we beat ourselves up and I don't think we should - is what I'm trying to say. I don't know how to express that, but I think we're too hard on ourselves.”

This idea of caregiver being too hard on themselves is echoed by several other caregivers. Other caregivers interviewed found other ways to rationalize cases where they were not devoting 100% of their time to their care recipient. For instance, one caregiver for her father, who is also a mother to her own kids, explained her reasoning to take time for herself and her kids as the following:

“The way I rationalize it is my allegiance is to my children. Because I’m their only mother. Dad has four kids. And the other three need to step up. And I let the siblings know, okay my kids are gonna be home for a week. Time to step it up. It never happens. But at least I’ve reached out to them, so they’re working back to me to say hey, what’s going on, I’ll say hey, you guys didn’t step up when I told you I needed help.”

In this case, while taking care of her dad is important to her, she values her role as a mother to her kids just as much, or perhaps more, and so she does not feel guilty when she has to step away from her dad to spend time with her kids. Another caregiver explained how absurd the idea of complete devotion is, claiming, “in a sense there’s never ‘enough’. You could be totally sucked in and there would never be enough”. For her, she does not feel guilty because to her, greater societal expectations are simply not feasible, and she as an active caregiver has a better idea of what it takes and what limits need to be placed. One final way of rationalizing it was to think of self-care as a way to quality care for the patient. Caregivers with this point of view discussed how taking on too much responsibility would degrade the quality of their care either because of being unable to provide appropriate care, or because they would start to make mistakes and over time. Says one Alzheimer’s caregiver,

“Well, you should not feel guilty (laughs), you know, because people will say, well, “maybe your mother should live with you”, and that makes sense to a certain extent, but when I think about bringing her into my house and leaving her here all day long, versus where she is all day long, she's safer where she is. You know, for now, you know. I think being comfortable with the decisions that you're making, I don't know if one day I can move her here or one day she might need to enter a facility, I don't know, but I'll have to make the decisions that's the best for her and for me.”

It is important to note, however, that these caregivers would absolutely like to provide the highest level of care that they can to their care recipient, but they just can't on their own. Rationalization does not stem from a desire to excuse less work, but rather it stems from an unsatisfied need for help, whether that is financial or social. It comes as an individual level response to a broader socioeconomic context which requires a socioeconomic response. Some of the caregivers who do use self-care as a rationalization do realize this. One caregiver of an Alzheimer's patient is heavily involved at the state level trying to get compensation or else other financial support for unpaid informal caregivers, seeing that as a way to help others like herself manage their care. The caregiver of his husband on home dialysis, which this section opened with, also expressed the desire for more structural supports, which for him would have taken the form of respite care; having a nurse come once a week to give him some time off.

And so, I find the recognition that self-care is important to be a necessary but inadequate response to the strain of overwhelming responsibilities that many caregivers find themselves in. Needing but not having the resources to serve in multiple roles in the way that they want to, caregivers struggle with their burden

and call for a self-care mentality, while the real solution, more socioeconomic support, lies outside their research.

Section 3: The effect of uncertainty and time on caregiver's abilities

Feeling of guilt from unsupported self-care were not the only feelings that caregivers struggled with feeling. Feelings of frustration were also rampant among the caregivers interviewed, though the cause of that frustration varied not only between type of illness being cared for, but also between individual situations. For extreme cases of frustration and difficulty, the temporal context of the disease came into play, offering caregivers of different diseases different strategies to resolve their frustrations.

For caregivers of patients on dialysis, frustration sometimes came over expectations of what a patient should do or not. Revolving around the idea of the sick role, in some cases caregivers became frustrated when they thought their care recipients should be contributing more to housework or chores, their pre-diagnosis responsibilities, as they appeared to be healthy and energetic enough to do so. On the flip side, patients who insisted they did not need help in certain aspects of their lives when their caregivers thought otherwise proved to be frustrating for the caregivers. For caregivers of patients with Alzheimer's, much of the frustration came from the cognitive decline of their care recipients as a result of the illness. Forgetfulness, short term memory loss, and behavioral changes were challenging for caregivers to deal with, but futility and a sense of not being able to do anything was especially challenging. Says one caregiver of an Alzheimer's patient,

“Kind of impotent, like I'm not able to, you know, lead them to this obvious logical conclusion because they can't think logically anymore, and so you're, you know- if only they would just listen to me then, you know, their lives would be better. It's really frustrating that I can see so clearly that if they would just, you know take in this information then, you know, things would be better for them, and I think I'm right about that it- they- it would be better for them. But they can't, they're not able to, so it's just- you feel really like you don't have any power, you know, like when they were younger you could've said those things and they'd sort of go "oh right, yeah ok." and um, but uh now they just, you know, you can't help them and they can't help themselves. They're just like- you can only affect things kind of around the edges. You can't make these really big changes by just showing someone the error of their thinking, they're just- they're not able to see it or if they happen to see it for a brief moment they won't remember that, and then you have to start all over again and they may or may not come to the same conclusion the second time.”

These feelings of frustration could sometimes be felt towards the care recipient which provided an interesting situation for caregivers. Caregivers were divided on whether or not it was okay to feel frustration towards the care recipient, but all caregivers interviewed emphasized that even if one felt that way, it was inappropriate to act on or display those frustrations. Some caregivers strongly felt that these feelings were misplaced, using concepts such as the patient role to absolve the care recipient for any blame of the frustration. One such Alzheimer's caregiver said,

“If you're starting to feel angry because the person's asked you something seventeen times, you need to check yourself, say, you know what, this person has memory loss. This is what the definition is. [...] But if the caregiver ever finds

himself trying to take it out on someone then you're definitely not in the right field and you should not be anywhere near someone who's innocent with this disease."

Others viewed such frustration towards the patient with Alzheimer's as natural and an unavoidable part of caregiving process in general, without necessarily placing blame on the care recipient. This was distinct from the very vocal and blunt frustration that many caregivers expressed towards unsupportive social networks. Caregivers of both Alzheimer's and dialysis patients expressed desires that their siblings do more, but that frustration was distinct from the frustration felt over the actions of the patient. That said, the frustration towards the patient is taking place in the socioeconomic context: caregivers of Alzheimer's patients who had day to day care work delegated to paid careworkers reported less frustration towards their care recipients, presumably because they did not have to deal with the frustrating aspects of the disease as frequently.

Surprisingly, none of these caregivers interviewed described performing deep emotion work on their frustration towards their patient in the way researchers such as Hochschild or MacRae describe it. Rather, for caregivers who felt frustration and believed it was natural to feel, caregivers were focused more on not displaying their frustration in front of their care recipient rather than trying to change or diminish their frustration on the inside, an example of dramaturgy or surface acting as described by Goffman. Such techniques include masking their frustrations in front of the patient, and a whole host of avoidance techniques from walking out to take some deep breaths or go for a walk, to taking more time for themselves through spirituality or hobbies such as reading. For some caregivers

whose care recipients had moved to long-term facilities, shortening the length of their visit was an option if they felt they could not stay with their care recipient for a longer period of time without showing their frustration. In all situations, caregivers made sure not to show their frustration to those they were caring for, largely because, as described in Chapter 2, they felt that their care recipients could still read emotion even if they could not understand what they said on a cognitive level.

For some caregivers though, the stress, frustrations, and burden of caregiving was too much, necessitating a shift in their entire attitude and mindset towards caregiving facilitated by the end of life nature of the illnesses involved. For these caregivers, their experience of caregiving became viewed through the lens of a necessary, but ultimately temporary, interruption to their lives. This idea that caring was only temporary gave these caregivers strength in the face of incredible burden to continue caring. One Alzheimer's caregiver in particular, caring for her mother with great difficulty, described at length how she perceived her caring.

“And I’m just very matter-of-fact about it now, which is probably not good but like I tell myself, ‘it’s temporary.’ My mother is 87, how long is she...I would say she’s five or six years in this diagnosis. Usually they say it’s seven years? [...] the doctor a few months ago says ‘Oh she’s put weight on’ and I said ‘yeah, I should probably put her on...’ and she says, ‘Let her eat whatever she wants; she wants to eat cake for breakfast who cares?’ She said, ‘From what I can guess, six months, nine months? She won’t be eating anymore.’ So whatever indicator the doctor saw, you know, I don’t think she’s going to be around for another

year...So it's temporary. She's my priority. My husband...you know, it's temporary. We just have to suck it up. That's how I feel."

No matter the burden she was currently facing, she was reassured that she would not have to continue doing this for much longer. Earlier in the interview she mentioned how caring for her mother was starting to strain her relationship with her husband. In this quotation, her response to that deteriorating relationship is to "suck it up" and deal with it for a short amount of time. And yet this adoption of a short-term temporal orientation was not without incident. She described feeling guilty about thinking about her mother with Alzheimer's in this way, saying

"I feel guilty. I feel guilty that I wish I was someplace else instead of taking care of her. It's hard. But like I said, it's only going to be for another – I don't see her surviving another year. [...] I hate [caregiving] to be honest. I don't like it. But, you know, you're forced into these things sometimes in your life. But, she's number one priority, I guess right now. And everything else takes a backseat. I know it's temporary so I'm willing to sacrifice.

Without this hope that the process of caregiving would be temporary, she might not be willing to sacrifice so much for her mother, but because in her mind, caregiving will only go on for another year, she is willing to be "forced into" caregiving until then. This was not limited solely to Alzheimer's caregivers. For one dialysis caregiver, faced with the prospect of years or more of his patient on dialysis with no clear date of death in sight, said,

"I think I've certainly had conflicts and I feel like I burned out and had a lot of compassion fatigue um, especially around being the caregiver for dialysis,

because you know there was one point where there was no end in sight, that it was going to be a lifetime thing, so I dunno. I felt conflicted with that.”

Just as the idea that Alzheimer’s would be over soon, in this case, the caregiver’s burnout and fatigue was resolved when his care recipient got put on the list for a transplant, and eventually got a transplant. During the time of getting on the transplant, part of that burden was relieved through the knowledge that whatever burden remained, whether that was physical, emotional, or economic, it would only be for a short period of time, much like in the Alzheimer’s case. This relates back to the idea of liminality discussed in the literature review: for these caregivers, caregiving is an in-between state bridging the relationship they had with the care recipient before diagnosis, and the period of time after the patient’s final treatment or death. This liminal state is highlighted by its disorientation and uncertainty not only in expectations but also in duration. When the duration of this liminal state is unknown, it adds more uncertainty and burden onto the caregivers. However, by either knowing the end point, or believing that the end point will come soon, caregivers are able to have at least one point of certainty in an otherwise uncertain liminal state, giving them the strength to power on.

Focusing on the temporary nature of caregiving was not the only temporal orientation shift noticed among the caregivers. For both caregivers of Alzheimer’s dementia and chronic kidney disease who had comparatively lower burdens than their peers, many caregivers reported living day by day and enjoying every moment with their patient, not worrying about the future. One dialysis caregiver described her feeling as such:

“I know when she does pass it's gonna be awful, so that's why I enjoy the time that we have, because no matter what I feel like I've gotten the best, I've gotten to spend the time with her. When she asks "what do you want" I say "I don't want anything, I've gotten what I wanted, just live another day". Things are things, they just collect dust.”

It is interesting to note that this temporal orientation has the same roots as the first shift discussed: they both are rooted in the fact that there is not much time left to spend with the patient. Whereas the first shift in temporal thinking saw the remaining days as a finite number of difficulty to soldier through, this second shift in thinking in a sense tries to prolong and savor every last moment of those finite remaining days. Again, this seems to be connected to the level of caregiving burden the caregiver is facing and the socioeconomic resources they have to bring to bear on the situation: the first temporal shift was exhibited by caregivers providing substantial amounts of hands-on care with their patient and who expressed high levels of burden without much support, whereas the second temporal shift came up with caregivers who were not as much close to their breaking point, either because their patient needed less care overall, or because they had help from either paid care workers or members of their social networks.

This is not to say that the caregivers were divided into these two camps of thought, in fact most of the caregivers did not express any change in the way they thought about the time left with their care recipient. There was one caregiver who articulated looking ahead and making plans for after the care recipient's death, saying

“When Joan does pass away, we have 2 years to sell the house and then it pays back what she used and then the rest is split between the 9 kids. And that's a huge priority. I want to be ready for it. It's going to be traumatic enough when it happens that I don't want to have to deal with clutter and figure out where we're going to move and what we're going to do, so that's very present in our mind right now.”

That's not to say this caregiver was apathetic to the time she spent with her care recipient, she in fact enjoyed it and appreciated it day by day. However, that didn't change the fact that she knew it couldn't go on forever, and so she had to start making plans for the future. Reflecting on Olson's research on methods to cope with “temporal anomie” as discussed in the literature review, there were not that many cases of a future-oriented, optimistic outlook overall, and no examples of that mindset among Alzheimer's caregivers. On the chronic kidney disease side, there was one caregiver who was overwhelmingly positive and insisted that her care recipient would get a donor transplant, and that everything would be fine. An analogous mindset such as this was totally lacking amongst caregivers of patients with Alzheimer's. One likely cause for this is the nature of the illness and sense of control over its prognosis, again showing the importance of the disease context on the caregiver experience. Whereas chronic kidney disease can be “cured” through a kidney transplant, and late stage cancer as Olson (2011) describes could possibly still be affected by a novel drug, there is no cure or treatment for Alzheimer's, a fact which caregivers were very well aware of and mentioned in the interviews. Perhaps because the incurable nature and inevitable decline in Alzheimer's patients is such a major part of the diagnosis and understanding of the illness, there is no way to be optimistic of the prognosis of the patient.

Section 4: Summary

The challenges and responsibilities put on informal caregivers are intense and burdensome, and caregivers must face up against societal expectations and also their own doubts and worries within. Having socioeconomic support, whether that is from flexible jobs, higher levels of disposable income, or more supportive social networks, all form a socioeconomic context in which a variety of caregiving experiences can exist. For those without, a patchwork solution of self-care holds them together while a lasting solution is not available. The context of disease is less apparent in its interaction on the socioeconomic context, where having more resources is better for all types of caregivers, but it does have an effect on the temporal context that also affects caregivers' ways of thinking and experiences.

In Chapter 4, I now turn to how caregivers' identities develop in response to their responsibilities of caregiving.

Chapter 4: Building a Caregiver Identity

In this chapter, I discuss how the various contexts discussed: disease, interpersonal, socioeconomic, and temporal, intersect to shape caregivers' caregiving identity formation. In particular, I set the adoption of a caregiver identity within the context of social identity theory.

Section 1: Identifying as a Caregiver

The idea of building a caregiver identity has its roots in finding some way to classify and describe what informal caregivers are doing. For some, this meant that the responsibilities of caregiving were rolled into an existing identity. Others rejected the identity of caregiver, though in these cases the informal caregiver had either only been taking care of their care recipient for a short time or else was having an emotional struggle with defining what it was that they were doing. For most though, this meant ascribing to or building an entirely new caregiving identity.

According to social identity theory, groups which people belong to can be significant sources of pride and self-esteem (Ellemers, Spears, & Doosje, 2002). For informal caregivers who are otherwise unpaid and uncompensated, this pride and self-esteem can be extremely important to how they manage to continuing doing the work they do. This can be observed in looking at which caregivers were more likely to adopt an identity and association with being a caregiver. For some Alzheimer's caregivers, a new caregiver identity was essential as a defense or coping mechanism, as they found that their previous status as a spouse or child had been lost completely over the course of the disease progression. As they lose

their status as spouse or child, something has to fill that void, and that something is often a new status of caregiver. This change was considered to be necessary, if not desired, by the caregivers interviewed because otherwise there would be nothing else to put in its place. Says one caregiver of a husband with Alzheimer's,

***Interviewer:** Do you see yourself as a caregiver?*

***Participant:** Absolutely.*

***Interviewer:** What does being a caregiver mean to you?*

***Participant:** It means I don't have a relationship with my husband as a spouse. I don't receive, I give. I take care of.*

Another case was a daughter taking care of her mother with Alzheimer's, who said,

"I have to continue to tell myself that this isn't – my mother-daughter relationship is long gone. Now it's caretaker and it's a disease that's taken her mind – her. Yeah, it's hard."

In both these cases, taking on the status of a caregiver was a way to justify or find the strength to continue caregiving upon the loss of any other expectations or obligations to do so from other statuses and norms. The adoption of the caregiver status operates almost in the reverse of the traditional idea of role theory. While in role theory, one's status produces a role, or a series of expectations, to go along with it, in these cases, having a new set of expectations for caring helps develop a new status these caregivers faced upon the loss of their status as spouse or child. This can be illustrated in Figure 1 below.

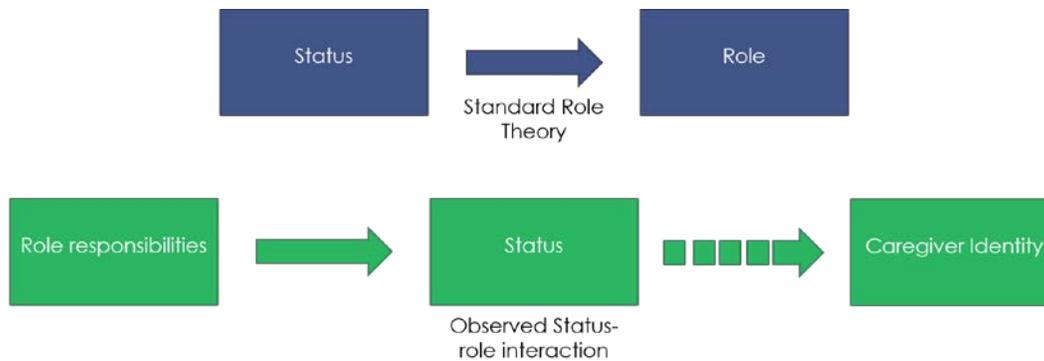


Figure 1: Illustration of observed interaction between status and role, and interaction predicted by existing role theory. Existing role theory posits that roles, and the responsibilities and expectations they entail, develop out of having a status. For instance, being a teacher leads to enacting the role which includes designing assignments, grading, fostering a learning environment, etc. What I observed in several caregivers was that having the responsibilities of being a caregiver: handling medications, going to appointments, providing care at home, resulted in the development of a caregiver status, an acceptance that caregiving was part of what they did. In some, but not all cases, as indicated by the dashed arrow, this caregiver status developed into caregivers embracing and adopting an identity as a caregiver, which will be discussed later in this chapter.

On the other hand, some caregivers took on the identity of a caregiver not because they lost all other identities to connect them to their care recipients, but because the commitment required and all-consuming nature of their caregiving responsibilities made caregiving, in their minds at least, a part of who they were whether they wanted to identify that way or not. From a role theory perspective, caregiving could be described as a part of their life that has become a master status; something of exceptional importance to the caregiver's life such that it becomes a predominant feature of their personality and identity. These caregivers expressed that it was the "only thing I have in my life", especially caregivers who had been forced out of the workforce or forced to cut back on leisure or social activities. As they stop being 'employees' or 'friends' because of the responsibilities they have, sooner or later caregiving comes to dominate who they

are, to the point where they identify with being a caregiver, even if they don't want to. The responses from this category of caregivers was characterized by a reluctant acceptance of the term, saying "I guess that's what I am, even though it doesn't sound very glamorous", or "I never really have [thought of myself as a caregiver] but earlier this year, I did this survey with [the care recipient] and I was like, 'yeah, I guess'".

This reluctant acceptance of the caregiver status was also present in caregivers of patients on dialysis, though not to the same extent. For the dialysis caregivers who felt this way, it was not about the overwhelming nature of caregivers, but rather just the responsibilities that had defined the status for them. One son caring for his elderly father on dialysis said when asked if he thought of himself as a caregiver,

"in the strictest sense of the word probably not, because I don't have to give him a lot of care. But I am, just take the translation of caregiver loosely, I guess I am, but I don't need to do near as much as some other people might need to do as far as providing care to an elderly relative, or relative regardless of age. But everything that needs to be done I do, so I guess you can say that I am."

This sort of acceptance though, does not seem indicative of a master status, but rather an acceptance of one status of many. This feeling towards caregiving is common among caregivers of dialysis patients, many of whom felt lighter burdens than their Alzheimer's counterparts. In cases of lighter caregiver burden, such as the provided quotation, caregivers often found ways to incorporate their caregiving responsibilities into other relationship identities, something that will be discussed later in this chapter.

Caregivers who were providing large amounts of indirect care, such as coordinating additional services, making phone calls to set up appointments, and negotiating insurance, found themselves in an interesting spot with relation to caregiver status. Their mental image of being a caregiver was taking care of the day to day physical responsibilities of providing care, but they also felt that the amount of time and work they put into coordinating the care of their care recipients must count for something. For these caregivers, they adopted an expanded definition of caregiving that went beyond their perceived boundaries of the term, to include the work they spent so much time doing. Says one caregiver caring for her mother with Alzheimer's,

“Caregiver for me means making sure that my mother gets the care that she needs, whether that's what I need to provide for her or what her doctor needs to provide for her or what her insurance needs to provide for her, she gets the care that she needs.”

While she acknowledged the work that the nurses and PCAs she was working with was definitely caregiving, for this caregiver, what she did behind the scenes was also a part of coordinating care, and so made her a caregiver just as much as anyone else providing physical care. In these cases, though, caregivers were less likely to consider caregiving to be a master status or an identity they held, but again, like the dialysis caregivers mentioned on the previous page, as one part of an overall non-caregiving identity.

That's not to say that all dialysis caregivers felt that way though. For the purposes of taking on caregiving status or identifying as a caregiver, amount of

burden experienced seems to be the important factor, largely independent of disease context. For instance, informal caregivers of patients on dialysis who identified as caregivers cited for the most part that they were caregivers because of what and how much they did. These caregivers, often with moderate to heavy care responsibilities on a daily basis, firmly saw themselves as caregiver because they helped to clean their care recipients, helped them with medications, or helped with the actual procedure of dialysis. There was not as much doubt among caregivers of dialysis patients than there was in some Alzheimer's caregivers, perhaps because the caregiving responsibilities in dialysis were more physical and medically defined than the responsibilities of caring for patients with Alzheimer's. For them, the responsibilities they had lined up with their those of the caregiver role they envisioned, making adopting a caregiving status easier.

On the whole, caregivers of patients on dialysis did not see themselves in a distinct caregiver identity. Some of these caregivers had logic contrasting that of the Alzheimer's caregivers coordinating care: while the Alzheimer's caregivers saw the heavy amount of indirect care as being a caregiver nonetheless, many dialysis caregivers who did not provide hands-on care maintained that they did not identify as caregivers because of not having that responsibility. When asked if she thinks of herself as a caregiver, one caregiver caring for her husband on dialysis said she did not because she did not see what she did, primarily providing emotional support and "being there", as something that needed a separate caregiver identity.

Even though for the most part, burden was the key factor at play, the context of disease did have some role in determining whether people embraced a caregiver identity or not. In this case, it was only dialysis caregivers who rejected adoption of a distinctive caregiving identity, and instead integrate the responsibilities of caregiving into another preexisting status, for instance that of a spouse. Some of these caregivers had comparatively fewer caregiving responsibilities, but there were caregivers, especially among home dialysis patients, who had this mindset even as they were performing numerous and intensive caregiving tasks. One husband providing home dialysis care to his wife, when asked whether he viewed a caregiver role and husband role as separate, responded “No, they’re one role”. A wife providing help with her husband’s home dialysis went even further, responding when asked when she realized her husband might need help

“I realized he needed help the day I married him [...] I think all spouses, mothers, are caregivers, so it's just part of the role. I don't specifically consider myself a caregiver first.”

This mentality could be a result of many of the structural factors described in Chapters 2 and 3. It could be very strongly tied to disease context, as this mentality was much more prevalent with caregivers of dialysis patients than in caregivers of patients with Alzheimer’s. This could be related to the context of interpersonal relationships, as discussed in Chapter 2, as dialysis caregivers may find it easier to retain that preexisting social relationship to their care recipient than Alzheimer’s caregivers often lose.

In addition to the structural contexts discussed, this mentality could be related to the idea of the sick role. Much as the sick role best describes acute physical illnesses, there may be a caregiver role that exists in the collective knowledge of people that is keyed specifically to short term physical illnesses. For instance, responsibilities of dialysis patients such as assisting with transportation to appointments, helping with medications, or otherwise assisting with medical care, are closer to caring behaviors present for common, everyday illnesses such as a stomach bug or respiratory infection. I do not say this to belittle the responsibilities faced by caregivers of dialysis patients, but rather to observe that much like how the sick role is often not afforded to patients with mental illness, the leap from providing care to a sick child staying home from school or a spouse too ill to go to work, to providing care for a dialysis patient, is a smaller leap than going from taking care of those illnesses to taking care of a relative with a neurodegenerative disorder such as Alzheimer's dementia. In the first case, the biomedical, physical illness model still applies: something is wrong with the person's body that medications or treatment can help to alleviate or treat. Despite the caveats regarding chronic illnesses, the rules and expectations of Parson's sick role as discussed in the literature review still generally apply for these cases, and most importantly, previously existing social and emotional connections between caregivers and care recipients are still present.

Contrast this to caregivers of Alzheimer's patients, for whom there is no clear biomedical treatment for the disease, which erodes and erases previous connections and ties, and which requires changes in how the caregiver perceives

the person they are caring for to a degree unimaginable for someone whose previous experience of caregiving might have involved taking care of a child with pneumonia. The disease and interpersonal contexts for Alzheimer's patients is so different that it is no wonder that their experiences are so different from that of dialysis caregivers. The differences in disease progression and caregiving responsibilities results in the mindset shift available to dialysis caregivers, that is caregivers rolling their caregiver responsibilities into the responsibilities and expectations of their previous role, is not readily available to caregivers of patients with Alzheimer's dementia. There were some caregivers of Alzheimer's patients who explained their motivation for caring as being a part of that familial tie, saying they provide care because "she's my mom" or explaining that they were reciprocating for past care the care recipient provided for them. However, even in these situations, the informal caregivers still described a separate caregiving identity from their identity as a child or spouse, never fully able to integrate their responsibilities as a caregiver into their previous relationship role they had with the care recipient. The distinction between the two different ways of approaching the status of being a caregiver is shown visually below in Figure 2.

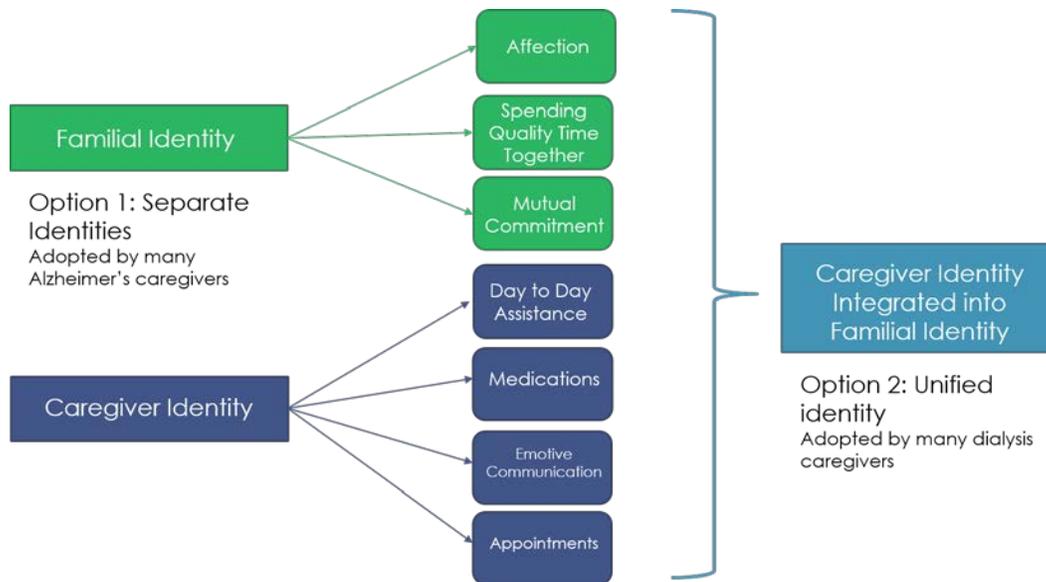


Figure 2: Caregiving as a separate or integrated identity. In the middle are a selected sample of responsibilities and expectations that a caregiver caring for a family member might have to contend with. The situation on the left occurs as caregivers make a distinct separation in the responsibilities and develop a separate identity around caring for their care recipients. This was often due to difficulties, primarily in Alzheimer's with interpersonal interactions and emotional challenges of caregiving for Alzheimer's patients. The situation on the right occurs when caregivers view the responsibilities of caregiving as a subset of another identity, such as a familial identity of being a child or a spouse. This situation occurs more with caregivers of dialysis patients, for the reasons discussed earlier in this section.

Section 2: In groups and out groups - Professionalization

One of the main concepts of social identity theory is that the self-esteem and social identity gained from being part of a group is in large part due to comparing members of the in-group to members of out-groups (Ellemers et al., 2002). If the identity of caregiving is important to those who adopted the identity, I would expect to see examples of such comparison when discussing non-formal caregivers. In fact, I found this to be the case, not only in comparing themselves to non-caregivers, but more surprisingly, comparing themselves to professional caregivers.

For many caregivers who expressed affinity towards a distinct caregiver identity, there was an immense sense of almost professionalism among the caregivers. Despite the fact that these informal caregivers for the most part had received no formal training and were acting in a nonprofessional capacity, many of them felt not only pride in the quality of their work, but some degree of pride in being a caregiver and all that entailed. This included having a set of beliefs akin to a code of ethics or professional guidelines that they followed as though it were for an actual job. These included an emphasis by most of the caregivers and especially almost all of the Alzheimer's caregivers, that patience was the number one trait necessary for a caregiver. In addition, many caregivers had strong opinions about expectations and standards for informal caregivers. Said one caregiver caring for her mother with Alzheimer's,

“A good caregiver should not exploit the person. [...] We shouldn't exploit the-the person even-even though it's- it could be funny to you, it's not funny to them, and you know, I really get upset and I think I take it personally when I see people, um, with elderly people which if they don't understand and they don't know it's not- it's not a fault, it's just the way it is and don't make fun of them and don't do things like that.”

As this quote shows, even though the role of a caregiver is not professional role, a sense of professionalism and expectations of ethics were expressed by multiple caregivers. It is interesting to note that this caregiver was having a hard time in other aspects of caring for her mother, including trouble managing the role reversal and the declining relationship with her, but even so, felt strongly about upholding standards of care such as this one. It is unclear

whether this means that she held to these standards in spite of her difficulties in her caregiver role, or because of her difficulties in the caregiver role. She also expressed strong feelings about caregiver motivation, a topic echoed by other caregivers interviewed. She said,

“[Caregivers] should not feel obligated and they should not feel like it's, um, like they're only doing it for some ulterior motive, ok? [...] you can take the position of like a... a nursing home, people in a nursing home are probably overwhelmed with what they have to do, but you know, just going in and giving somebody a glass of water that's their job, but to the person receiving the glass of water it's probably the highlight of the day, ok? So if you're doing something nice so, well, that's my job I have to, you know so, I mean take an extra five minutes and spend, you know, "how you doing?" and you know stuff like that so I mean I don't think they should feel obliged to do something, it should just come naturally.”

This idea that informal caregivers should not feel obliged to do what they do, but that they should want to do it and it should “come naturally”, is a strong example of deep emotion work being performed. Being an informal caregiver, at its heart, does not require the caregiver to want to do it, but for this caregiver and others like her, much of the self-esteem they got from their work came from the idea that they were doing it of their own accord. Since the perceived voluntary nature of caregiving was such an important part of the pride of being an informal caregiver, some, though not all, of the caregivers interviewed came to feel that it came naturally which in turn helped to moralize the work they did as better than if someone felt an obligation to care.

This raises another theme that occurred in the caregiver interviews, comparing the work they did with that of other care workers including personal

care attendants and staff at nursing homes. One way this comparison played out was through exasperation over the fact informal caregivers were not being paid for the work they were doing. One caregiver for her mother on dialysis put it most strongly, saying

“They wanted me to take a course, pay them \$800 to take care of my mother. Okay, what kind of sense is that? I’m paying you \$800 to take care of my mother? Yeah, that’s what they wanted me to do, to take the class at Blue Cross Blue Shield, and I was like, for what? [...] it’s like a job to me, waking up and going to a job, being a PCA (Personal Care Assistant) worker for her, but only thing is I’m not on a PCA clock. (laughs) Or getting PCA money.”

Another caregiver, no longer able to work since starting to care for her father with Alzheimer’s, said

I mean I’m living off my retirement so my concern is well, what am I gonna live on when I actually do get old? So that’s a huge, um, a huge burden for me, is not knowing financially what’s gonna happen to me. Because it’s five years now that I haven’t had an income. That’s a long time. That’s a lot of money that I haven’t made in my age. [...] What is the state doing about helping those of us who have chosen not to put our parents in a nursing home, thus saving the state thousands of dollars. Yet they can’t have it both ways. So, I need to have some kind of compensation. So that I can keep doing that for Dad.

Both of these statements show how informal caregivers are comparing their work to paid caregivers and perceive their work to be on par, or at least equally as valuable as the work of professional care workers such as personal care assistants. While they may have other motivation or reasons for caring, the fact remains that caregiving can be financially strenuous, as discussed in Chapter 3 about socioeconomic resources. For these people, who have taken up the identity

of caregiver, to not be appropriately recognized at least financially for the work they do feels like a slap in the face for what is as they perceive it, at the very least equal work.

As a result, many of the informal caregivers interviewed began to see the care they provided as better than the care of paid caregivers, moralizing their work. In some cases, especially with Alzheimer's caregivers, this is because caregivers think that the familiar setting of the home can help with some of the symptoms of the disease and with the disease progression as a whole. Even for those caregivers who did not vocalize that concern though, there was a feeling that the work informal caregivers did, not just the environment, was better for the care recipient than what they would get in nursing homes. This was true for informal caregivers of both illnesses. Says one Alzheimer's caregiver,

"I know for a fact that I'm taking better care of him than he could get in any assisted living or nursing home. I know that because his every need is met by me. I, um, he's, he's never had a fall with me. And I'm very proud of that. Falls take place, in nursing homes often. And often that's the beginning of the decline for someone. [...] I compare him to many people who were diagnosed about the same time that I know that Dad was, and, and they are so far advanced compared to Dad."

Compare that sentiment to this one expressed by a caregiver of a dialysis patient:

"She's not getting all the bed sores like people getting in the nursing homes and don't be changed. Her skin is really clearer and no bed sores, no nothing, none of that stuff you see in the nursing homes. That's the rewarding part for me. Ever since I've been taking care of her."

The satisfaction these caregivers get is similar to professional satisfaction, perhaps even more significant since they are comparing themselves to these professional care workers. In the absence of being paid as professional care workers, comparing their work to that of professional care workers helps with the group self-esteem, giving informal caregivers some source of pride even as they don't receive financial compensation.

Another way the informal caregivers perceive the superior care they provide goes back to the motivation part. As discussed in Chapter 2, the relationship between caregiver and care recipient, the interpersonal context, is one of the key differences between informal caregivers and professional caregivers. For some of the informal caregivers interviewed, that difference made them better caregivers than professional ones could be. Explained one caregiver caring for her mother on dialysis,

“Some [professional] caregivers they're good. But it's not the relatives. I mean they do the part, they have you dressed up, or eating. But they're not the ones that you really, really go deep for, find out what is this medication for, and how much you're really sick. I don't know, for me it's different”

This relationship, the fact that caregiver and care recipient are relatives, makes informal caregivers more effective, in her opinion, because they are driven to learn and do more for their care recipients. Caregivers for Alzheimer's patients on the other hand might have a different perspective, and a few of them mentioned how their relationship with the care recipient made caring more

emotionally challenging, which again goes back to the concept discussed in Chapter 2 about the deterioration of the relationship in Alzheimer's dementia.

Informal caregiving then, despite not being a formal profession, has become the master status and main identity for many of the caregivers and despite the challenges, they find some satisfaction from it through the satisfaction of being a part of meaningful group with a positive self-image. This sense of professional pride and confidence in their own abilities, especially when compared to out-groups such as professional caregivers, also plays a key role in motivation for continuing to provide care for their care recipients. In addition to comparing the care they provided with the care they either envision or had heard about in nursing homes, informal caregivers were driven to continue caring because they knew and saw patients who did not have people to care for them. By embracing certain values and qualities of caregiving and comparing their work to that done by outgroups, caregivers get a sense of belonging by being a part of this identity of informal caregivers, something that gives a sense of pride and self-esteem to help cope with the challenges of caregiving. Even for caregivers who were facing substantial challenges and difficulties in their work, having this identity they could embrace and having examples from the out-group they could compare themselves to solidified their belief that they had to continue caregiving for the good of the patient.

Section 3: Feeling good and Being good – morality and identity.

Having a sense of professionalism and comparing their work to the work of professional caregivers was not the only way those who identified with being

caregivers built self-esteem. Part of building self-esteem is not only helping caregivers feel good, but helping caregivers feel that they are good. Much of this again came from comparisons to out-groups, but in this case, the out-group were non-caregivers.

The idea of feeling good, or being rewarded for what they do, was rooted heavily in disease context for caregivers, in particular what the expected progression and outcome of the disease was. For caregivers of dialysis patients, this often came in the form of helping their patient live up to the ideals of being a good biomedical patient as defined by the patient role. In helping their patient be a good patient, they felt like they were good caregivers. For example, a wife helping with in-home dialysis for her husband described a trip to the hospital, saying

“His last bout in the hospital was with peritonitis (infection of the peritoneum), and I was very upset, because I thought, he didn't have a fever, how would I have picked this up. He was not eating, he was lethargic, but you know, we thought it was the cold or the flu. And when we got to the hospital, they're like, you should be used to this by now. Why would I be used to him having peritonitis? And they said, because he's been on peritonitis for a while, 2 years, I said this is the first time he's had it. And they're like, really? They were all kind of surprised, so that made me feel good.”

Having avoided a common pitfall of dialysis by providing good dialysis at home vindicated this caregiver's actions, and made her feel like she was doing something right in her care to her husband. Other caregivers reported feeling rewarded by seeing their care recipient getting more energy, walking, and going out more as a result of good dialysis treatment. Such a direct and clinical benefit

for a patient from a caregiver's work was less apparent in the case of Alzheimer's patients, but Alzheimer's caregivers too felt rewarded by seeing the results in their patients through deviations from the expected progression of the disease. In particular, they felt rewarded through emotional communication with their care recipient, since cognitive communication was in most cases lacking as described in Chapter 2. For these caregivers, just knowing that because of their care, their care recipients were "safe and peaceful" and happy, and therefore in a better spot than many Alzheimer's patients, was enough to make them feel rewarded for their work. One caregiver caring for her husband with Alzheimer's described,

"At night, after supper, he sits in this big fancy chair, and we watch television together. He doesn't really get much out of it, but he's there, and my reward is that he'll smile at me. He doesn't talk, but he'll, I know he's alright because he'll smile at me."

These are small points of light in an otherwise unrewarding field of carework, but they are enough for caregivers to feel good about the work they do in a way that helps them continue to do so. This is not to whitewash the experience of other caregivers who were open and honest about the complete lack of rewarding experiences they felt taking care of their care recipient. For these caregivers, all Alzheimer's caregivers, providing care was more than just work, it was a burden. These were the caregivers who felt the greatest need for breaks or help from additional sources to provide respite for them, and compared to the other caregivers, these caregivers felt more drained, both physically and emotionally, from providing care. There are a few possible explanations as to why an informal caregiver might feel no reward whatsoever from caring, all related to

the structural contexts discussed in previous chapters. The first might be an advanced stage of illness, the disease progression, which deteriorated the patient's ability to communicate or respond past the point of having meaningful relationships, which goes back to the interpersonal context. In addition, these caregivers were often not only lacking in support, but they saw support as being available but being just out of reach. These were cases, for example, where siblings were close by and would be available to help, but refused. Unfortunately, because of the small sample of caregivers who felt this way, it is difficult to explain the role of such factors to any reasonable degree.

There is a difference though, between being rewarded and finding meaning through the work. In my mind, feelings of reward and of being rewarded for one's work operate the same continuum as burden: on a scale that has burden on one side and reward on the other. With enough reward, burden can become manageable or even completely overshadowed by positive feelings such as being rewarded. Meaning, on the other hand, does not operate quantitatively on the same scale, it does not serve to counteract burden on a one for one basis. Rather, being able to find meaning, no matter how seemingly small or insignificant, out of their work allows caregivers to continue in spite of high burden and low reward. For many, this took the form of trying to build a moral identity, similar to those caregivers who were trying to build a pseudo-professional identity around caregiving. Instead of comparing themselves to professional caregivers, some of the caregivers in this category found meaning by trying to build a moral identity in comparison to non-caregivers.

For some, meaning was found from being at peace within themselves. These caregivers were looking ahead at the future, at a time after their care recipients had passed, and imagining what they would regret doing or not doing during this point in their lives. The answer, for most, was that they would feel guilty or ashamed if they did not try their best and put in the work now to take care of their care recipient: by working and providing care now, they felt that they wouldn't feel like they owed anything at the end of life and beyond, thereby building for themselves a 'good life'. Explained one Alzheimer's caregiver, responding to a comment by the interviewer that caregiving seemed like a thankless job,

"In a way it is, but in itself it's peaceful. When she passes away I can have a clear conscience knowing that I've done everything I could to make her life better. So I don't feel bad."

It is important to note the nuance here as well, caregivers specify that it's everything that they "could" do, allowing for philosophies of self-care to also exist for caregivers at the same time. This is especially important for caregivers of Alzheimer's patients, for whom the inevitable progression of the disease can be frustrating. In these cases, "all I can do" requires definition, as there is no clear metrics as there are in dialysis caregiving. For the most part, it was the emotional carework being provided that caregivers felt was meaningful. Says one Alzheimer's caregiver,

"I know at some point there will be an end point, and that will be very sad, but I think that I'm preparing myself on this journey with her that I know at some point this will come to an end as will all of our lives and at that endpoint, I'll know in

my heart that I've done all that I can do, I've let her know how much she's loved, how much, you know, I don't resent the fact I have to care for her, that I know we've done the very best we can to make her life happy and comfortable through all those years when she was not at her best. And at the end I'll have no regret in terms of "I could have done more, I should've done more, or I should've done things differently", and I will have no guilt in that area either because I'll know I did the very best I could through all of this to make her comfortable, to enjoy whatever life she's able to grasp on to. I don't know if that answers the question but that's just how I feel."

Making the care recipients feel loved, happy, and comfortable were themes that came up repeatedly as ways to work now to avoid guilt later. The idea that the work had to be done now, before the care recipient passed away, was something that both caregivers of Alzheimer's and dialysis patients felt strongly about. One dialysis caregiver in particular had strong feelings about why it was important to her to care for her mother now, saying

"I see a lot of people who don't even give a hootenanny about their parents and it's like, leave 'em in a nursing home and don't bring them nothing and don't do nothing for them and just talk about them. I ain't the one. So I tell them you know, you only got one, that's all I can say, and when they're gone you can't say "oh, sorry mommy I didn't do this, I didn't do that", tell them while they're here, don't tell them when they're gone or talking to God about it."

By caring for her mom now, as opposed to later when good intentions could no longer turn into meaningful actions, this caregiver, and others like her, found some measure of peace within themselves and from that, a measure of motivation to continue providing care before it was too late. This was also in a comparative context to other non-caregivers, who some caregivers morally

devalued as they were perceived as not taking on the same level of responsibilities that they were. This again supports the in-group, out-group theory outlined by social identity theory, the idea that self-esteem from a group identity comes from comparing ones' group to another group. By devaluing another group, one's own group becomes raised in status.

Other caregivers found the experience of caring meaningful because they felt it taught them valuable life lessons. For them, the experience of caregiving gave them a real life example of what things were important in life. Some caregivers felt that the experience had emphasized the importance of family in their lives, something that they may have lost for a while before starting to provide care. This was more so the case for children taking care of their parents than it was for spouses, possibly because adult children were more likely to move out and have less contact with their parents as they grew up. As one caregiver of both her parents with Alzheimer's explained,

"Yes, and I think that might be that I know they were such good parents to me that it's- it does feel like I can kind of give back a bit, and that's meaningful to know that um, that really up until now I wasn't ever able to give back to them, I mean other than being friends with them or, you know, I was able to in the sense that we had a harmonious family and I liked them and I always had my kids hang around them a lot. You know, it wasn't like I didn't appreciate them or anything, but um this is a bit of a chance to, to really, really give back to them."

This goes back to the idea of reciprocity in relationships as these caregivers tried to do their best to make amends and balance accounts before it was too late. In the process of doing so though, it became more than just

reciprocity, they rekindled familial ties and found intangible rewards in the process of caring.

For other caregivers, the important life lessons they felt they learned were more general, more about what it meant to live a good life and what qualities a life like that took. One daughter caring for a mother with Alzheimer's said, *"I think it took a long time to come around to this, but I mean it's taught me a lot about sacrifice and love and how you really have to, you know just kinda put that stuff aside and think that, you know, I mean, especially in today's world I just think that there's so many outside influences on any one action, so when these tragedies happen with these shootings and stuff like that and everybody says, you know, hug your kids and do all that, but how many people actually do it?"*

Important to note is that the process of finding meaning is not an easy one. For this caregiver, whose experience was very difficult for her with little social support, she only found meaning gradually and over time. This may help explain in part why this search for meaning was more present in caregivers of patients with Alzheimer's dementia. Again, it goes back to the contexts discussed. When the contexts are favorable, whether that be disease, interpersonal, socioeconomic, or temporal, there are more opportunities or possibilities for caregivers to relieve burden or feel rewarded by what they do. The pathways by which they felt rewarded, however, were often not available to caregivers of patients with contexts aligned against them, such as in Alzheimer's because of the nature of the disease as a primarily cognitive, and incurable disease that affects memory, personality, and relationships, or those who a severe deficit of social and economic support. In the absence of simpler and more direct ways to alleviate burden and feel rewarded, finding meaning from caregiving seems to be one of

the only paths left available for Alzheimer's caregivers; a difficult path that often only comes with time, which dialysis caregivers and caregivers with more favorable contexts have less need of because they have alternatives available for feeling rewarded for their work.

Section 4: Summary

Informal caregiving is a stressful, and often thankless job as described by the informal caregivers interviewed, but in the face of the challenge, caregivers have found ways to adapt, in many cases taking on a new status as caregiver and the internalizations that go with it. By adopting a new identity as a caregiver and becoming a part of that group, informal caregivers could find some reward and self-esteem in the work they did, even as the burden continued to weigh on them. Whether this took the shape of professionalization and comparison to paid caregivers or moralization and comparison to non-caregivers, informal caregivers could find something in what they did that made the work they did easier to bear.

The broad continuum of caregiver experiences are shaped by the structural forces discussed in Chapters 2, 3, and 4. From disease context as described in Chapter 2 which affects all other contexts, to the importance of the context of interpersonal relationships, from the all-important question of socioeconomic resources discussed in Chapter 3 to how perceptions of time and end point affect caregiver frustration, all these factors profoundly impact how caregivers both perceive burden and respond to it, from coping mechanisms to identity adoption as discussed in Chapter 4. Informal caregiving is not monolithic: it is dependent on all of these structural contexts and more. In order to better understand the

diverse range of caregiving experiences, a broader examination, cognizant of structural factors, is needed.

Chapter 5: Conclusion

For this project, I sought to bring together what I perceive to be a fragmented and scattered literature on informal caregiving, with many good tool sets and theories scattered across disciplines but not communicating to each other. I perceived a gap in the literature in a lack of consideration of the range of broader structural factors that add nuance and variation to the caregiver experience, resulting not in a monolithic experience, but rather a broad continuum. I sought to do this by examining how these structural factors influenced and interacted with caregivers' perceptions of burden and their responses within the boundaries of those structural contexts.

In Chapter 2, I examined the importance of the context of disease, and how that specifically affected the context of interpersonal relations. With regards to Kuipers (2010) et al's cognitive model of psychosis, I have raised some concerns that while it holds up for caregivers of dialysis patients, stronger pre-illness relationships did not appear to shape my respondents' relationships or caregiver experiences in caregivers of Alzheimer's dementia. I do think Kuipers et al have identified one strong factor, but I do believe more work needs to be done so that it takes into account variations of disease context. Overall in the chapter, I demonstrate the importance of taking note of the type of disease and its symptomology, progression, and diagnosis, which prove to have heavy overlap with other structural contexts discussed.

In Chapter 3, I examined the significance of the caregiver's socioeconomic context on not only caregivers' perceptions of burden, but also

their abilities to respond to it. To Medway's (2015) research on economic challenges faced by caregivers of chronic kidney disease, I contribute a qualitative perspective that examines the pathways through which variation in socioeconomic resources can interact with burden. To Mark's (1998) finding that controlling work-life balance decreases caregiver burden, I offer some specific factors which may help the work-life balance, including job flexibility and disposable income, which helps obtain a better understanding of exactly how work-life balance affects caregiver burden. To the concept of liminality as discussed by Hennings (2013), I find strong supporting evidence that the uncertainty of being stuck between two long-term statuses has a serious effect on caregiver burden. However, I also contribute to the application of liminality by showing how having a fixed actual or imagined end point to caring can help relieve caregiver burden. This finding runs contrary to findings by Olson (2011), whose studies of cancer caregivers finds that having an end point can force caregivers to adjust to a new temporal mindset to help alleviate the burden of having limited time left. Instead, I found that disease context again matters, as for some caregivers of Alzheimer's patients, having a fixed end point was often the only thing keeping them going. This helps contribute to the work of both Hennings and Olson by suggesting an examination of disease context variation, and how that might affect their work.

In Chapter 4, I find significant evidence supporting social identity theory, finding that informal caregivers who identify with being caregivers compare themselves to out-groups, whether they be professional caregivers or non-caregivers, to build self-esteem and find worth in their work. I also find an

unusual inversion of role theory. Where the traditional view of role theory says that having a status will cause one to act out responsibilities based on the role expectations from that status, what I found in some of the caregivers, especially those for whom their previous status as spouse or child was eroded by Alzheimer's dementia, a new status of caregiver was embraced based on the responsibilities already being performed by the individual: a reverse of the standard progression from status to responsibilities.

Overall, I believe that this thesis demonstrates the importance for individuals from all fields described in the literature review in Chapter 1 to be aware of two things. Firstly, what the other disciplines have to contribute to the caregiving literature, whether that is theoretical models or a perspective from on the ground. Secondly, to be aware of and seek to integrate these structural factors and contexts wherever possible, as without an understanding of them, the broad continuum of caregiving experiences is lost. In particular, this thesis contributes two main points to the caregiving literature. First, the importance of accounting for and studying the context of disease in understanding the experiences of caregivers. As the previous chapters have shown, although there are a wide range of structural factors at play, many of them interact with and are modified by the context of disease, making a thorough understanding of disease symptomology, progression, and treatment options essential even for non-biomedical researchers studying caregivers. Secondly, the identification of situations where role theory is reversed, that is to say roles lead to statuses, for certain caregivers would prove to be an addition to the literature on role theory. In particular, whether role

expectations and responsibilities lead to status or vice versa appears to again be rooted in the context of disease. Caregivers of Alzheimer's patients, who often had a gradual start to caregiving and no clearly defined moment where they "became" caregivers, developed a status of caregiver over time, often from their role responsibilities. Caregivers of patients on dialysis on the other hand, often started with a clear diagnosis and a defined starting moment of caregiving, and so developed their responsibilities around the status of being a caregiver. Better understanding what factors and situations beyond the disease context impact this reversal in role theory would be valuable future research to conduct.

There were a few limitations with this study. It was also difficult to be able to schedule times to meet with caregivers of dementia patients in person, necessitating conducting interviews by phone. While this was often the only solution and there were good conversations that came out of them, there is something to be said about phone interviews being more impersonal than meeting in-person. Especially about a topic that is inherently personal and intimate, in-person interviews would have been preferred, though perhaps not feasible given the all-encompassing nature of dementia caregiving. In addition, because this was a onetime study, no longitudinal data could be collected, either caregiving over time or seeing changes from before start of care to after care has been performed for a while. This makes it difficult to perform direct observation on changes to relationships or other factors such as that that might have an important temporal component. That being said, what we did capture in our snapshot interview was patient perceptions of such changes, which is valuable in its own right.

Future research should focus on expanding understanding of other contexts that were not able to be covered in this study. For instance, research shows that caregiving depends greatly on the cultural background of caregiver and patient. An important future study to do might be to see how racial and ethnic contexts affect the caregiving experience, with more specific questions about race and a more diverse study sample. Another study could be done on the context of caregiver sex or gender. While research shows that women make up a majority of informal caregivers (Family Caregiver Alliance, 2009), understanding the unique challenges that men face is important not only to help current men who serve as informal caregivers, but also help understand women caregivers through a better understanding of the context within they work.

Beyond theoretical work, I think this thesis shows the importance of offering structural support to informal caregivers. The informal caregivers I interviewed do the best they can in accordance to their individual abilities and resources, but they are facing factors and contexts which are much greater than them. And while there is a growing literature on aging and caregiving, that has not translated particularly well into the policy realm. In particular, I think that this thesis shows the importance of having policy regarding socioeconomic support to informal caregivers, whether that is in the form of direct financial compensation to caregivers, or provision of respite care. Socioeconomic support is not enough though, as that is just one of many structural factors caregivers faced. Physicians and other clinical health workers working with the patient can play an important role in providing initial informational support to new caregivers, and should work

to link new caregivers to resources such as caregiving support groups so that new caregivers can have an easier time making the transition. In addition to providing clinical support, provision of psychological support, whether in the form of one on one counselling or group sessions through support groups, could be valuable to assist caregivers, particularly those of Alzheimer's patients, with the emotional challenges of caregiving. This would obviously have to be accompanied with provision of some sort of respite care so that the caregivers could attend such sessions without worry about their care recipient, again highlighting the importance of providing socioeconomic support for caregivers. Such support programs would greatly help many of the informal caregivers interviewed for this study and others like them, and would be a major step forward in supporting these caregivers who are so important to elder care in this country.

Informal caregiving is a difficult job. So many factors compound each other, and so many of them are multidimensional. Additional responsibilities cannot only be considered as the time it takes to do them, but also the physical intensity, mental agility, and emotional cost it takes to perform them as well. In addition to all of that, the context in which those responsibilities are being performed must be taken to account, whether that is disease context, interpersonal context, temporal context, or socioeconomic context. Relationships are not a simple matter of adding up positives and subtracting negatives, but rather are complex webs that intertwine caregiver and patient. In the face of a challenge of that scale, the day to day ways that informal caregivers find to adapt and survive in that environment so important to recognize and share, but even so, they are

dealing with forces outside their control. As the need for informal caregiving is not going away soon, sooner or later, we as a society will have to find ways to support the individuals providing a great deal of support to their friends and families at their own personal expense.

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Appendix 1: Interview Guide

INTERVIEW SCRIPT

Participant ID#: _____

Interviewer: _____

Date: ____ / ____ / ____

Start time: _____

Stop time: _____

Interviewer Script:

Thank you for participating in my study. I appreciate you taking the time out of your day to talk to me and we want your voice to be heard.

This interview asks you to think about your experience in caring for a friend or family member with a **CHRONIC KIDNEY DISEASE / DEMENTIA**. I'm interested in learning about how the experience affects you, including your relationships and your overall quality of life. The results will be used to help us understand how illness and caregiving affects caregivers, not just patients so we may understand and help caregivers in the future.

I would like to assure you that your responses are confidential. Information that identifies you will not be linked to this recording and will not be shared with anyone. Again, I won't be collecting any information about your friend or family member; I'm just interested in your experience caring for them.

Thank you for agreeing to participate.

Section 1: Structural factors of caregiving and care work

1. What is your relationship to the person you are currently caring for?
2. How long have you been caring for your RELATIVE?
3. Would you please describe for me what your relationship with your RELATIVE was like WHEN YOU WERE GROWING UP / SINCE YOU'VE BEEN TOGETHER?
 - a. PROMPT (For child): What was it like growing up with them?
 - b. PROMPT (For partner/spouse): How and when did you meet?
4. What was your relationship like in the year leading up to you starting to take care of RELATIVE?
 - a. What were you doing then?
 - b. What was your RELATIVE doing?
 - c. What did a typical week or day look like for you?
 - d. How often did you talk or see or care for your relative that year?
 - e. Were you working?
5. So at some point your relative started to need frequent care. Can you tell me a bit about that?
 - a. How did you come to start caring for your RELATIVE?
 - b. What responsibilities did you have to take on that you didn't have before?
 - c. Did you have to let any others go?
 - d. How did you end up being the one to take care of your RELATIVE?
 - i. How did you feel about the decision-making process? Were you heavily involved in the process?
 - e. When you started taking care of your RELATIVE, was there anything that surprised you?
6. Could you describe what you do on a typical day in terms of caring for your RELATIVE?
 - a. How many hours would you estimate goes into caring for your RELATIVE
 - b. What do you find most rewarding about caring for your RELATIVE? Can you tell me about any examples?

- c. What do you find to be the most challenging part about caring for your RELATIVE? (Physically, mentally, emotionally)
 - i. IF participant denies: Is there anything at all, even if it's brief, that you find to be challenging in any capacity, whether that is physically, mentally, or emotionally?
 - ii. How do you feel at the time of the challenge? How have you tried to overcome it?
7. In what ways has caring for your RELATIVE affected your life?
- a. Are you working another job outside of caring for your RELATIVE?
 - b. What is your relationship like now with your RELATIVE How about the rest of your family and friends?
 - i. Has it changed from what it used to be like or not? In what ways?
 - ii. Do your other family and friends help in any way with caregiving for your RELATIVE? Would you like them to help more or less in the caregiving process? Do they help to provide emotional or financial support, or provide other forms of assistance?
 - c. Where does caregiving rank among your current priorities in your life right now? How has this changed from before you started caring for your RELATIVE?
 - d. OTHER PROMPTS: (Free time, financial stability, stress/fulfillment)
8. Do you think that caring for your RELATIVE affects your other roles and responsibilities? Such as parent, friend, or employee? Tell me more.
- a. How does it affect these other responsibilities? Does it make it easier or harder? Can you give me an example of cases where caregiving has affected other responsibilities?

Section 2: Building a moral identity and doing good

- 1. Do you see yourself as a caregiver? How so?
 - a. If yes, could you describe to me how your role of caregiver fits into the rest of your life?
 - i. How do you make it work for you?
 - ii. Would you say caregiver is one of the main ways you think of yourself? Why or why not?
- 2. Do you know any other people in a similar situation as yours, taking care of family or friends?
 - a. Is there anybody whom you admire for their caregiving?
 - b. Is there anybody who caregives in a way that you would avoid or do differently? Why?

3. What does it mean to be a good caregiver? (Attitudes, actions, behavior?)
 - a. Is that different or similar to what other people think? How so?
 - b. Are there things good caregivers should avoid doing or acting?
 - c. Do you think that a good caregiver is a good person?
 - d. Is there any emotions or feelings that you think a good caregiver should feel?
 - i. Is there anything a caregiver should try not to feel?
 - ii. Have you ever felt any of these things? When? How did you deal with it?
4. Have you ever felt “good” about caring for your RELATIVE? When? Why?
 - a. Have you ever felt “bad” about it, confused, or uncertain?
5. Why do you provide care for your RELATIVE?
 - a. What drives you to wake up in the morning and keep taking care of your RELATIVE?
 - b. What about the caring you provide do you find meaningful?
 - c. PROBES:
 - i. *(Covered earlier, ask only if necessary)* Were there preexisting responsibilities or expectations that you would provide care for your RELATIVE? If so, what roles had that expectation?
 - ii. Do you feel that you are rewarded by caregiving? Either financially, emotionally, or socially?
6. I’d like to learn more about how caring for your RELATIVE affected your previous relationship with them.
 - a. What was it like going from just being a RELATIONSHIP to being a RELATIONSHIP and also caring for your RELATIVE?
 - b. Has caring for them created any new aspects in your relationship? How?
 - c. Does being a RELATIONSHIP make it easier or harder to care for your RELATIVE? How?
7. What has been the most rewarding thing about caring for your RELATIVE?
 - a. What do you feel you have gained from caring for your RELATIVE? Are there any moments that stand out to you?
8. Can you describe to me what the response has been from people you meet when they learn that you care for your RELATIVE?
 - a. Do you feel valued for your work? Why? Why not? Can you give me an example? By who?
9. What has the response been from friends and relatives as you became more and more involved with caregiving?
10. Is there anything that would make caregiving a better experience for you? (That could mean easier, more rewarding, more enjoyable) A worse experience?

Section 3: Dramaturgical theory and emotion work in the Pt. Caregiver Relationship.

1. I'd like to learn more about your current relationship with your patient.
 - a. What are your day to day interactions like now?
 - i. Are they any different than before? How so?
 - b. Do you feel more or less emotionally close to them since you began caring for them consistently? Why or why not?
 - i. What factors make you close/distant from them now?
 - c. Do you miss the previous relationship you had with them? How?
 - d. Do you think this is similar or different to how other caregivers feel?

2. I'd like to know more about how you communicate with your RELATIVE.
 - a. Has anything changed in the way you talk to and otherwise communicate with them since before the illness?
 - b. Do you feel that your RELATIVE has become more or less responsive, such as in terms of communication or emotional responsiveness? In what ways?
 - i. PROMPTS: (Emotional Responsiveness) For example, do you feel that if you try to comfort them, they feel comforted? Do you feel that they compensate or try to accommodate for your emotions when they interact with you? How does that impact you and make you feel?
 - ii. PROMPTS: (Communication Responsiveness) Do they have any difficulty understanding or communicating with you? Do they ever say inappropriate things at inappropriate times? How do you react? How does it impact you and make you feel?
 - c. Do you know anyone else who is or has taken care of a family member? How do you think your situation is similar or different from their experience?
 - i. Do you think it's different taking care of somebody with a primarily PHYSICAL/MENTAL illness than what you are currently taking care of?
 - d. Can you describe any situations where you feel you can't be totally open or honest with your relative such as white lies or holding something back to protect them?
 - i. PROMPT: Some caregivers mention that they feel that they have to stay positive and try to keep their relative upbeat.

Do you feel this statement applies to you and your RELATIVE? Do any particular moments come to mind?

- ii. What about other caregivers you know? Do they experience this?
3. I'm interested in how you've been since you started caregiving. How has your general mental and emotional wellness been during since you began caring for your RELATIVE?
 - a. Everyone experiences caregiving differently. I've talked to some people who find that it's really tough and that it's challenging enough to affect their own wellbeing. Others I talk to may find it difficult or not and push through okay. Where on that spectrum has your caregiving experience been?
 - b. Sometimes, family caregivers can struggle with feelings that they think they shouldn't feel. Other times, they can struggle to feel an emotion that they wish they could feel in a certain situation. Has either of these ever happened to you? Can you give me some examples?
4. How do you handle times when your RELATIVE is being difficult or challenging?
 - a. How does that make you feel?
5. If you could go back in time and give yourself advice before you started caring for your RELATIVE, what would you tell yourself about the experience?
 - a. What advice would you give them?

Thank you so much for taking some time out of your day to speak with me, I really appreciate it. Is there any additional information you'd like to share that you feel would help me better understand your caregiving experience?