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April 13, 2021

End-of-Life Perspectives Among Couples Aging Together in Assisted Living:  
A Narrative Approach

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An abstract of  
a thesis submitted to the Faculty of Emory College of Arts and Sciences  
of Emory University in partial fulfillment  
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Bachelor of Science with Honors

Department of Anthropology

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## Abstract

### End-of-Life Perspectives Among Couples Aging Together in Assisted Living: A Narrative Approach

By Isabella Z. Cantor

As the population ages and caregiving trends change, assisted living (AL) is increasingly becoming a place where people spend the final years of their lives. While the majority of AL residents are widowed women due to gender gaps in life expectancy, couples may represent an increasing proportion of residents as the life expectancy gap narrows. Considering these dynamics, couplehood in AL represents an important avenue of research and has received increased attention in recent years. This ethnographic thesis examines the end-of-life perspectives of two Jewish couples aging together in an AL community in suburban Atlanta. The research addresses the following factors: Individual-level factors (e.g., life history and Jewish ancestry), marital-level factors (e.g., marital history and caregiving roles), AL community-level factors (e.g., its social and religious culture), and societal-level factors (e.g., a global pandemic, societal attitudes regarding death and dying). A variety of qualitative methods were used to examine these factors, including analysis of previously conducted, in-person, in-depth interviews, COVID-safe field visits to important places in the couples' lives, and Zoom interviews with a key informant. Findings show that AL can be a highly beneficial and supportive environment for couples and that less impaired spouses need occasional breaks from caregiving responsibilities. Couples' life experiences and end-of-life perspectives surrounding mourning and burial were highly variable, but there were similarities in their attitudes toward death as well as their ideal deaths and attitudes toward cognitive decline. Implications for research and family decisions are discussed.

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## Acknowledgements

This thesis would not have been possible without the help, support, and encouragement from a number of people. First, I would like to thank my amazing thesis team: my advisors, Dr. Molly Perkins and Dr. Melvin Konner, and my committee member, Dr. Alexis Bender. I mean it when I say team—I got so lucky to have had the three of you with me every step of the way. I cannot tell you how much I have appreciated your commitment to my success. Somehow you trusted that I'd be able to do this, even when I wasn't so sure. Thank you for sharing your wisdom and experience with me, for teaching me invaluable life and research lessons, and for laughing with me (and probably worrying for me) when I submitted writing to you at 11:59 PM. Your mentorship and guidance have meant the world to me, and I just cannot thank you enough.

Dr. Debra Vidali and Heather Carpenter: Thank you for making this project manageable for the past year and a half. Your dedication to our community of scholars and enthusiasm for our work have been tremendous sources of motivation for me as I completed this project.

Sabrina: As my roommate, you've had to deal with me at my best and also at my most obnoxious! Thank you for being my friend and supporter even when I was stressed and anxious about deadlines, worried about something or other, or just generally grouchy. Thank you, also, for letting me take over our entire dining room table with two computers, a million notebooks and journal articles, books, etc. You are a true friend, and I appreciate you so much!

Julie, Margot, and Anna: You inspire me every day. I am so grateful to have been able to go on this crazy thesis journey with you all. From Zoom thesis sessions to working together at the library, you have held me accountable and motivated me more than I can express. I am so thankful that we have been able to celebrate our little milestones and accomplishments together throughout this past year. Thank you for having faith in me and reminding me that we are all in this together. I am so grateful for your friendship and am seriously impressed by the work you all have done.

To my family, friends, and CMBC community: Thank you for standing by me during this process. Thank you for all of your support and for being willing to listen to my ideas and share your perspectives.

Lastly, thank you to my research participants at Haber Gardens, especially to Max. I have so enjoyed getting to know you these past several months. Our Zoom conversations have given me so much insight into your community and your life, and I am so grateful that you were willing to share your stories with me.

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## Chapter 1: Introduction

As the culture of aging and caregiving changes in the world, assisted living (AL) has increasingly become a place where people spend the final years of their lives (e.g., Ball et al. 2004; Vandenberg et al. 2018). Thus, in recent decades, the experiences of aging and end-of-life transitions among older adults in assisted living have received increased attention. Life in assisted living represents a fascinating and necessary realm in which to study the ways people negotiate life transitions at their “last stop,” finding meaning and reflecting as they approach the ends of their lives (Ball et al. 2014).

The social sciences, including sociology and anthropology, offer distinct and useful lenses through which to study the nuances of end-of-life perspectives. Death and dying, while certainly medical and physiological processes, are also profoundly social phenomena shaped by lifetime experiences, relationships with others, and positioning vis-à-vis one’s surroundings (e.g., Nuland 1994; Marshall 1975; Ball et al. 2014). At their core, the social sciences seek to answer the questions of how we live our lives, how we find meaning in our surroundings and actions, and broadly, what makes us human. Sometimes, however, the intricacies of a single human life may become lost in this search. We explore cultural and social practices and are enlightened by the discovery of generalizable patterns, but we run the risk of overlooking the nuances of the individuals and their thoughts, experiences, and life narratives. Sherwin Nuland, one of the world’s most prominent scholars on death and dying, began his seminal work on the subject with the assertion that “Every life is different from any that has gone before it, and so is every death. The uniqueness of each of us extends even to the way we die” (1994, 1). Anthropologists Michael Jackson and Albert Piette pioneered an approach to anthropology known as existential

anthropology, in which increased attention is given to the unique story of the individual. They wrote:

By shifting our focus from macrocosm to microcosm, or from focal to fringe, we do not mean to deny that impersonal powers, presences, or processes, at once transcendent and concealed, govern our lives; rather we wish to restore to the anthropological worldview a sense of the small and tangible things that make life viable and negotiable despite the forces that elude our comprehension and control (Jackson and Piette 2015, 5).

By investigating individual narratives and perspectives toward end-of-life experiences, we can be reminded of the individuality and unpredictability of human existence within the complex search for meaning.

The objective of this project is to understand how two Jewish couples residing in a non-profit, Jewish-affiliated assisted living community in metropolitan Atlanta contemplate their end-of-life experiences both prior to and in the context of the COVID-19 pandemic. To accomplish this, I will address how the following factors shape these perspectives:

- a. Individual-level factors (e.g., life history and Jewish ancestry, religious and cultural beliefs, and illness, such as Alzheimer's disease)
- b. Marital-level factors (e.g., marital history, quality of the marital relationship, caregiving roles)
- c. AL community-level factors (e.g., the AL community and its social and religious culture)
- d. Societal-level factors (e.g., a global pandemic, societal attitudes regarding death and dying)

Through this thesis, I hope to do justice to the individuality of my research participants in portraying the experiences that have shaped their worldviews, investigating their searches for meaning in their long lives, and exploring their personal negotiations with death and loss.

## **I. Why Couples?**

As the baby boomer generation ages, individuals over 85, the “oldest old,” will soon comprise the highest proportion of older adults in the US, nearly tripling in number from 2020 to 2060 (Houser, Fox-Grage, and Ujvari 2018; Mather and Kilduff 2020). Life expectancies are increasing around the world, but in almost every country, women continue to have a longer life expectancy at any given age (Population Reference Bureau 2001). In 2017, the average 65-year-old American female could expect to live an additional 20.6 years, while her average male counterpart could only expect an additional 18.1 years. In that same year, the life expectancy gap between the average 75-year-old American female and her 75-year-old American male counterpart was 1.7 years (Kochanek et al. 2019).

Sex ratios are also a useful tool for understanding the gender gap in life expectancy, as these ratios indicate the number of males per 100 females in a given age group (Mather and Kilduff 2020). At birth, for example, the sex ratio slightly favors males, but the projected 2020 sex ratio for adults 85 years and older is 54. In other words, for every 100 females 85 and over, there will only be 54 males (Vespa, Medina, and Armstrong 2020).

In recent decades, the gender gap in life expectancy has been shrinking (Mather and Kilduff 2020). Preston and Wang (2006) offer the potential explanation of changes in smoking patterns between men and women with the finding that the peak of smoking prevalence among women took place in the age cohort born between 1940 and 1944. These trends are consistent with increased female mortality, suggesting that an increase in smoking prevalence among females coupled with a decrease in smoking prevalence among males has led to a narrowing of the gender gap for life expectancy.

This gender gap is largely understood to be the result of gender differences in both behavior and biology, but research has not yet been able to fully explain its intricacies. It is known, however, that gender differences in smoking and tobacco-use habits play a substantial role in the gap—smoking increases risk of lung cancers, heart disease, chronic obstructive pulmonary disease (COPD), and ischemic stroke (Fielding 1985; Preston and Wang 2006).

These changing demographics indicate that more couples, both married and unmarried, will be aging together in the decades to come (Mather and Kilduff 2020). These trends have significant implications for almost all realms of the process of aging, including living arrangements, relationships with family and friends, relationships with significant others, caregiving, and end-of-life perspectives.

## **II. Personal Interest**

Old age, death, and dying were rarely guarded subjects during my upbringing. My parents and grandparents were significantly older than average when I was born, so I have been surrounded by aging and caregiving ever since I have been mature enough to think about these topics. I have also been surrounded by dementia. My paternal grandfather, Sidney Cantor (z"l),<sup>1</sup> died of Alzheimer's disease many years before I was born, and I grew up hearing stories about the devoted care that my grandmother, Bertha Cantor (z"l), provided for him toward the end of his life. My maternal grandmother, Hazel Karp, was diagnosed with Alzheimer's when I was just seven years old. Her husband, my grandfather Herbert Karp (z"l), a celebrated neurologist who cared for patients with Alzheimer's and other dementias throughout his extensive career, was diagnosed with frontotemporal dementia not many years later.

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<sup>1</sup> z"l stands for the Hebrew phrase *zikhrono (zikhrona) livrakha*, which means "May his/her memory be for a blessing."

My relationship with my maternal grandparents, whom I call Bubbe and Papa, has been tremendously important to me throughout my life. I spent most Friday nights with them for Shabbat dinners as a child and teenager, attended Atlanta Symphony Orchestra concerts and Fox Theater ballet performances with them, went to synagogue with them on Saturdays and on holidays, and generally spent a lot of time with them at their home in Northwest Atlanta.

As my grandparents aged and became more cognitively impaired, I witnessed my mother's incredible feats of emotional strength, foresight, and levelheadedness as she endured the severe stress and anxiety that accompanied the decline of her parents. I watched as she transitioned from her role as daughter to her role as caregiver, and I was inspired by her fierce dedication to helping my grandparents age with dignity, despite the numerous and painful challenges in her way.

I remember the various transitions in my grandparents' lives that accompanied their decline: the loss of drivers' licenses, introductions of home healthcare aids, move to assisted living, and eventually the move to a nursing home. I recall the progression of their diseases—in my grandmother, it began with forgetting ingredients to familiar recipes. With my grandfather, it began as frustration and anger at my grandmother's forgetfulness. As the years went on, my grandmother's mild forgetfulness and my grandfather's frustration were supplanted by increasingly complicated care needs, loss of mobility, loss of speech, and eventually my grandfather's death.

Throughout these transitions, their marriage was a constant in their lives as it had been since 1948. It comforted me that despite the turmoil in their physical health, cognitive awareness, and home environment, they still had one another. When my grandfather died at 94, my grandmother already had fairly advanced Alzheimer's. She was almost completely reliant on her

aides for assistance, and while she was still able to talk, I recall that her sentences were mostly illogical non-sequiturs, and she had not been fully present for years. No one knew quite how to handle the subject of my grandfather's death with her the day he died. She was cognitively aware enough that withholding the news would have been extremely cruel and paternalistic, but her short-term memory was also so nonexistent that we figured she would not fully absorb the reality of her husband's death. When we finally told her, she broke down in uncontrollable and heartbreaking sobs. Just a few minutes later, she had already forgotten.

Witnessing these complicated trajectories of caregiving and dying with my grandparents, I became interested in the study of aging, I suppose, by convenience and circumstance—it was a substantial portion of my world, and I wanted to learn more about the experiences of older adults and families like my own.

### **III. Positionality**

For most of the history of anthropological work, anthropologists largely used their methodologies to learn about 'the Other,' or cultures and civilizations far different from their own. Barbara Myerhoff, a young, Jewish anthropologist at the University of Southern California, pioneered the practice of studying one's own culture when she conducted fieldwork among the elders of the Israel Levin Senior Center in Venice, California in the 1970s. Although she was not a member of their particular Jewish community of elders and was thus still an outsider, Myerhoff's Jewish identity afforded her a more intimate, nearly in-group membership into the world of her participants. Although she differed from her research participants in many ways, including age, level of education, place of birth, and Jewish background, her Jewishness undoubtedly allowed for greater mutual understanding between her and the elders.

Additionally, she recognized that as a young Jewish woman, she would one day become an old Jewish woman. Comparing her work with the Jewish elders to her previous fieldwork with the Huichol Indians, Myerhoff wrote that “Identifying with the ‘Other’...is an act of imagination, a means for discovering what one is not and will never be. Identifying with what one is now and will be someday is quite a different process” (Myerhoff 1978, 18).

Myerhoff’s ethnography on those Jewish elders, *Number Our Days*, was tremendously influential to me throughout the course of my project. In many ways, I see my project as a small-scale continuation of her work, so it is fitting that a major aspect of my positionality—a young, Jewish woman researching older Jews—is so similar to hers. If I am fortunate enough to live into old age, I too will become an old Jewish woman one day, and I might be in a very similar position as that of the people in my study.

My experiences with my grandparents also provided for aspects of my positionality as I undertook this project. From witnessing their life transitions into and out of different social contexts, into assisted living, and into a skilled nursing facility, I did not approach this project as a blank slate. Rather, I approached this as someone who had experienced these types of environments and formed memories and perceptions as my grandparents navigated these transitions that were thoroughly challenging for them.

To account for any incoming biases and experiences, I made sure to be reflexive throughout this research process by keeping a journal, discussing my thoughts with friends and with my advisors, and questioning any assumptions I had. Of course, I cannot completely eliminate my identity and prior experiences from my project, but I believe they allow me to bring unique and useful insight into this work.

## Chapter 2: A Review of the Literature

Before beginning the discussion of my own research, it is necessary to provide an overview of the existing literature relating to the intersecting factors of my research. I have utilized research and perspectives from a wide variety of academic specialties, including anthropology, sociology, gerontology, psychology, Jewish studies, and philosophy. My research is situated at the cross-roads of these academic disciplines. As such, I will review literature on assistance needs and classifying disability; long-term care models; relationships in assisted living; couple relationships in late-life; and Jewish perceptions and rituals surrounding death and dying.

### I. Evaluating Assistance Needs

A wide range of options exist for individuals seeking increased care as they age, anywhere on the spectrum from increased help with tasks around the home to nursing care. The indices of activities of daily living (ADLs) and instrumental activities of daily living (IADLs) are useful assessment tools to determine an individual's place on the spectrum.

In the 1950s, Dr. Sidney Katz and colleagues produced the *Index of Independence in Activities of Daily Living*, an unprecedented assessment tool that evaluated and classified levels of physical function in patients with disabling hip fractures. The patients were measured in their abilities to accomplish independently the following six functions: bathing, dressing, toileting, transferring, continence, and feeding. The researchers identified patterns in function loss, as certain functions frequently deteriorated before others. They recommended that their index be used to assess changes over time in patients' degrees of independence (The Staff of The Benjamin Rose Hospital 1958).



Katz and his colleagues published a subsequent article a few years later that would inextricably link the study of aging with the ADLs for decades to come.<sup>2</sup> The researchers found that these measures were widely applicable for the classification of independence and dependence in older adults (Katz 1963). Today, Dr. Katz' ADLs are central to the study of geriatrics and gerontology all over the world (Noelker and Browdie 2014). The six categories are now: ambulating, feeding, dressing, personal hygiene, continence, and toileting. These basic ADLs provide an objective and effective system for evaluating assistance needs of older adults.

Since the inception of the Katz and colleagues' ADLs, another index has been created called the instrumental activities of daily living (IADLs). Often used in conjunction with the basic ADLs, the IADLs assess independence with six functions that require higher-level thinking skills than the basic ADLs: transportation and shopping (for groceries), finance management, shopping (for clothing and other items) and meal preparation, house cleaning and home maintenance, communication management (with telephone and mail), and medication management (Cahn-Weiner, Boyle, and Malloy 2002). With these assessment tools, healthcare providers are equipped to evaluate the independence levels of older adults. Understanding where on the spectrum of independence an individual lies is essential for decisions regarding aging in place, in-home healthcare aids, and moves out of the home.

## **II. Understanding Assisted Living**

Assisted living (AL) falls under the umbrella of residential care facilities (RCFs) along with personal care homes, and AL is one of the fastest growing sectors of senior housing in the United

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<sup>2</sup> Slightly problematically, however, Katz and colleagues also suggested in this article that their index be used by anthropologists to evaluate "primitive societies," arguing that the levels of independence measured by their index were parallel to societal evolution from primitive to advanced (Katz 1963).

States (Metlife Mature Market Institute 2011). AL communities seek to provide a safe, but home-like environment for older adults and others who need added assistance with ADLs but might not necessarily require the skilled care of a nursing home (Park-Lee et al. 2011). In that regard, AL is often considered an intermediate step between independent living communities and nursing home facilities.

Although assisted living is household terminology today, the concept of AL has had a relatively short history, beginning in the 1980s. AL communities sought to fill a gap in the housing options for older adults. Until the advent of AL, as older adults or people with disabilities found themselves needing more help with daily activities or recognized need for long-term care, they were met with two options: move in with family members or move into a nursing home. For the first option, the informal care provided by family members often fell—and still falls—primarily on women. The option to move in with family has become less popular as women have increased participation in the workforce (Ettner 1995; Doty, Jackson, and Crown 1998). The second option was unpalatable for many families due to the reduced autonomy of the older family member as well as the bare, clinical environment of the nursing homes (Guberman, Maheu, and Maillé 1992; Wilson 2007).

One woman, Keren Brown Wilson, wanted to design an environment that would provide necessary care for individuals seeking increased help, but that would also allow them to maintain their living preferences, individual practices, and above all, agency. Her primary goal was to create a *home*, not just a facility (Wilson 2007; Gawande 2014). With Wilson's design, residents were given the autonomy to manage their own small kitchens, choose how to arrange their apartments, make their own medical choices, and plan their daily schedules to their liking. This was a novel idea, but eldercare advocates were slow to embrace the model. They worried that the

liberal ideas behind AL were dangerous to older adults at risk of injury and health-related disasters when given too much autonomy. In 1988, however, Wilson and colleagues presented data from the pilot AL facility demonstrating the safety of the model; resident health remained in stable condition, ADL and IADL functioning had improved, and residents exhibited improved cognitive states, lower rates of depression, and increased life satisfaction (Wilson, Ladd, and Saslow 1988 as cited in Wilson 2007, 14). Wilson's controversial ideas were a major success. By the mid 1990s, assisted living had mutated from a relatively contained vision to a national, million-dollar industry.

According to the National Center for Assisted Living, there are around 30,000 AL communities with close to 1 million residents nationwide today (NCAL 2020). The typical AL resident is a non-Hispanic white female widow who is 85 or older (Caffrey et al. 2014; Houser, Fox-Grage, and Ujvari 2012). Among RCFs, 72% of residents are female, which is due to the gender demographic trends highlighted in the introduction (see "Why Couples?"). A minority of residents receive Medicaid services, indicating that most residents of RCFs are financially independent. Approximately 40% of RCF residents live with diagnoses of Alzheimer's disease and other dementias. In RCFs with between four and twenty-five beds, that percentage rises to nearly 50% (Harris-Kojetin et al. 2013; Harris-Kojetin et al. 2019). Additionally, a pattern can be seen with need for assistance with ADLs, with the majority of RCF residents requiring some degree of assistance with at least one ADL, most often bathing and/or ambulating. Fewer residents require assistance with dressing, toileting, transferring, and eating (Harris-Kojetin et al. 2013 as cited in Caffrey et al. 2014; Harris-Kojetin et al. 2019).

In the United States, long-term services and supports (LTSS) tend to be unaffordable for most older adults, one-third of whom earn at levels below the poverty line. The median cost of

AL is approximately \$45,000 per year. Some AL communities charge residents using an “à la carte” pricing model, in which there is a baseline living fee, plus additional charges for extra services such as laundry, bathing assistance, safety checks, and transportation. Generally speaking, the more assistance with ADLs an individual requires, the higher the cost of assisted living (Houser, Fox-Grage, and Ujvari 2018).

Some assisted living communities are included in a model known as the continuing care retirement community (CCRC) approach. In these communities, it is understood that individuals, if given the opportunity, would rather stay in one location as long as possible throughout the various stages of the aging process (AARP 2019). Rather than move from independent living to AL and ultimately to a nursing home as their health declines, residents are able to “age in place” in their overall community but move to areas designated specifically for their needs.

Relocation can be particularly stressful for older adults, often leading to confusion, difficulty with adjustment, and feelings of social isolation and seized autonomy (Coughlan and Ward 2007; Ruess, Dupuis, and Whitfield 2005). CCRCs offer a sense of stability; residents and their families know that regardless of the changes to health and cognitive abilities, they will largely be able to avoid the disruption and uprooting that accompanies a drastic move. Of course, the transitions between each level of care come with their own stressors. Residents often feel forced to move when they are assessed as more dependent than their level of care can support (Shippee 2009). The same negative feelings often arise among residents in AL communities with attached memory or dementia care units (MCU or DCU) (Kelsey, Laditka, and Laditka 2008).

Several factors influence the pathways into and out of assisted living, as demonstrated by Ball and colleagues in their study of aging in place in AL (2004). In their study population of five AL communities in Atlanta, they found that especially in the lower-income AL

communities, increased ADL care needs often led to discharging the resident, either from the regular assisted living to memory care, or if the facility lacked a DCU, out of the facility entirely (Ball et al. 2004). State laws often guide these decisions. In Georgia, for example, Georgia Administrative Code section 111-8-63-.15 mandates that AL communities may only admit residents who: do not require continuous medical or nursing care, are capable of participating in transferring from one place to another, and have the ability to partake in the social environment of the community, among other stipulations. Many AL communities find ways to circumnavigate these regulations, allowing some residents to stay longer than others depending on the level of demand their care needs require. Thus, Ball et al. found that the ability of residents to remain in one community as they aged was based on “fit”—the success of the residents and AL communities in managing and responding to decline.

### **III. Relationships in Assisted Living**

It has been well-documented that close relationships are consistently important for people throughout their lifespans. Kahn and Antonucci developed the convoy model of understanding human relationships based on personal characteristics such as age, gender, and socioeconomic status, as well as situational characteristics such as cultural context and life history (Kahn and Antonucci 1980; Fuller, Ajrouch, and Antonucci 2020). Their aim was to understand the changes in relational roles and attachment to others in the scope of objective analysis of interpersonal relationships throughout the life-course. They also sought to create a model that would be applicable across cultures, not only in the hegemonic West (Kahn and Antonucci 1980). They recognized the importance of utilizing a life-course perspective due to the ways in which

dependencies change as people age and that “All individuals enter and leave a variety of roles” throughout their lives (Kahn and Antonucci 1980, 272).

In their heuristic model itself, the individual is presented in a small circle surrounded by three larger concentric circles that represent the different levels of the person’s convoy, or social network. The individual places characters in his or her life based on closeness of relationship. The first concentric circle represents characters closest to the person, which, depending on age, often contains family members such as spouse, children, siblings, and parents. In the circles further from the individual are often characters such as friends, co-workers, more distant family members, and other acquaintances or companions (Kahn and Antonucci 1980).

Analysis of convoy structure and composition allows researchers to gain insight into health, well-being, and quality of life based on the individual’s social network. Through the application of the convoy model, it has been shown that stronger, higher quality social networks serve as a protective buffer against declines in physical and mental health and well-being (Amieva et al. 2010; Blazer 1982). This theoretical perspective has been instrumental in the understanding of social relationships as people age, and it is particularly useful for studying social relationships of residents in assisted living communities (Antonucci, Ajrouch, and Birditt 2014; Fuller, Ajrouch, and Antonucci 2020; Perkins et al. 2013).

Living alone and in states of relative isolation is fairly common as people age, in part due to the deaths of spouses and close friends, the physical distance of grown children, and the rise in residential living at the expense of family-based senior care, particularly in higher-income countries in the West (United Nations 2005; Reher and Requena 2018; Grenade and Boldy 2008; Esteve et al. 2020). The COVID-19 pandemic has brought increased attention to the issue of

social isolation in older adults due to social distancing measures and shelter-in-place rules in the majority of long-term care facilities (Krendl and Perry 2020).

There is a large body of research surrounding social relationships among older adults. From the work of Laura Carstensen, it is widely understood that as individuals age, their social networks decline in size; older adults tend to exchange higher quantities of more superficial relationships for higher quality, more intimate connections with fewer people. Called socioemotional selectivity theory (SST), this framework suggests that people adjust the quantity of social relationships in later life due to their sense of time remaining and personal understanding of their mortality. This phenomenon explains the emotional meaning derived from social partners in later life (Carstensen 2006; English and Carstensen 2014). Interestingly, the findings of selective pruning of social networks in later life are mirrored in the studies of chimpanzees. Seeking to understand the origins of social selectivity in later life, researchers analyzed thousands of hours of footage of wild male chimpanzees in Kibale National Park in Uganda. They discovered that older males prioritized high-quality relationships, which were characterized by longer periods of reciprocal grooming. They also found that older chimpanzees spent more time alone than did their younger counterparts. These findings are the first to suggest that social selectivity in older age can be found in animals other than humans and that there may be an evolutionary basis to these behavioral changes (Rosati et al. 2020).

Evidence suggests that in assisted living communities, positive relationships between residents, particularly at mealtime, increase quality of life and psychosocial wellbeing of residents (Park 2009; Street and Burge 2012). Although many residents find positive meaning in their relationships with other coresidents, Kemp and colleagues found that multiple factors influence the quality and depth of these relationships, as well as the willingness to label the

relationships as friendships. These factors included functional status, reliance on family, personal characteristics, and general attitudes toward life in assisted living (Kemp et al. 2012). Because of these many factors, residents may experience challenges in forming these positive relationships.

Generally, a move into an RCF is associated with some degree of decreased contact between the resident and their external connections (Bear 1990). Even though residents find themselves spending most of their time with other residents, there is evidence that the time they spend with their family members is more meaningful and beneficial to their wellbeing. Perkins and colleagues, utilizing Kahn and Antonucci's social convoy model, found that a minority of residents included coresidents in their social networks. Instead, they "generally invest most of their emotional capital" in their close family members, with analysis results even indicating that family connections predicted well-being more than any other category of social relationship (Perkins et al. 2013, 504).

Consistent with Perkins and colleagues' analysis is the finding that while many assisted living residents actively maintain their connections with friends and family members external to the AL environment, many of them wish they could spend more time with the people close to them and secretly feel that the time spent with family members is inadequate. They appreciate what connection to family members they have but understand that their adult children and grandchildren are often too busy to give them more time. This understanding contributes to a sense of "losing control" and yearning for more among AL residents, especially when many residents are unwilling to share these thoughts with their family members (Tompkins et al. 2012).

#### **IV. Married Couples in Later Life**



As mentioned previously, married couples represent a minority among the “oldest old.” As the demographic age gap closes, married couples in later life are becoming more common (Mather and Kilduff 2020). As such, the topics surrounding older-adult couples have received increased attention in the past several decades. Earlier research largely focused on the influence of marital status (e.g., married, never married, widowed, divorced) on health and wellbeing. More recently, however, research has investigated the particulars of these later life relationships, utilizing ethnographic and other qualitative methodologies (Walker and Luszcz 2009). The following subsections will review the literature on selected aspects of the multifaceted nature of couplehood in later life.

#### **a. Couplehood and Health**

It has been well-established within the field of medical sociology that marital relationships have a protective effect on various health outcomes (Renne 1971), including mortality (Hu and Goldman 1990; Robards et al. 2012) and self-rated health (Zheng and Thomas 2013; Rohrer et al. 2008; Johnson et al. 2000). Several explanations exist for these phenomena, including differences in occupational health risks, lifestyle risks, and utilization of health services due to income and social pressure (Verbrugge 1979; Umberson 1992; Berkman and Glass 2000). The theory of “marriage selection,” which posits that healthier people enter marital unions in the first place leading to unequal levels of health between married and unmarried people, has also been a plausible explanation (DiMaggio and Mohr 1985), but has been heavily refuted by subsequent research (e.g., Waldron, Hughes, and Brooks 1996; Goldman 1993).

In later life, the relationship between marital status and health is complicated by several factors including caregiving burdens, ill-health of one spouse, and physical relocation (Adams

2006; Ahn and Kim 2007; Anderson, Earle, and Longino 1997; Walker and Luszcz 2009). Older adults generally report greater feelings of satisfaction with their social relationships, including with their spouses, compared to younger and middle-aged people (Carstensen, Gottman, and Levenson 1995; Luong, Charles, and Fingerman 2011), and studies have found that marital *satisfaction* is positively associated with health outcomes in older age (Margelisch et al. 2017).

### **b. Socioemotional Support**

Because social networks shrink as people age (e.g. Carstensen 2006), the few, close social connections become increasingly important in later life, especially for social and emotional support (Carstensen, Gottman, and Levenson 1995). In several studies, older adults were found to be more affectionate with one another even when presented with conflict-inducing tasks (Carstensen, Gottman, and Levenson 1995; Lauer, Lauer, and Kerr 1990). These findings have important implications for the understanding of mental health and emotional support among older couples.

Depression symptomatology, while less prevalent than in young people, poses serious consequences to older adults, including decreased cognitive and social function, increased morbidity, decreased self-maintenance, and an overall increase in mortality (Blazer 2003). The onset of depressive symptoms in older adults, while sometimes resulting from age-related neurobiological factors, often results from negative life events such as loss of loved ones and perceived decline in physical and cognitive function (Blazer 2003; Ko and Lewis 2011).

Based on research findings that emotional support is an effective protector against depression and depressive symptoms (e.g. Bruce 2002), Ko and Lewis examined emotional support among older couples and its relationship to these issues. Consistent with previous

research, they found gender differences in reported emotional care and support, with husbands reporting more emotional support from their wives than wives from their husbands. They also found that husbands and wives who perceived more emotional support from their spouses were less depressed. Reciprocal support—giving and receiving similar levels of support—was also an important factor of lower depressive symptoms. Additionally, their research highlighted the phenomenon that the emotions experienced by one spouse were “contagious” to the other member of the couple, which has been demonstrated in previous research (Ko and Lewis 2011; Tower and Kasl 1996; Goodman and Shippy 2002).

For most older adults, a spouse is the preferred confidant as they age, as opposed to the second best option of daughter or sister. Additionally, as spouses age together, they are able to provide consistency for one another, creating a predictable environment as the members of the couple age together (Wenger and Jerrome 1999). In their longitudinal study, Wenger and Jerrome (1999) found that for the vast majority of the oldest old with living spouses, their spouse was considered their closest confidant. In the minority of cases in which married people did not list their spouses as their closest confidants, their spouses were in poor health and required caregiving.

### **c. Caregiving**

As couples age together, it becomes more likely that one spouse will experience health concerns that require care from the other spouse. For many of these health problems, the caregiving responsibilities may end when the care recipient recovers from a physical impairment or is cured of a disease. However, for the oldest old, incurable age-related conditions, such as chronic diseases, vision or hearing loss, and Alzheimer’s and related dementias, comprise a significant

proportion of health concerns (Jaul and Barron 2017). When the care recipient suffers from a terminal illness, the experiences of caregiving reflect unique trajectories.

Patterns of caregiving trajectories at end of life have been well-researched. Penrod and colleagues document this trajectory, identifying four key phases and junctures of the caregiving process, beginning with a stage known as “sensing a disruption.” In this stage, a health problem is recognized that interferes with the individual’s ability to function normally, and the person and their loved ones seek out a diagnosis to explain the disruption to normal life. Once the person learns of their terminal illness or life-threatening condition, the person and those who care for them begin the process of coming to terms with the diagnosis and what it means for their collective future. This transition delineates two distinct periods, separating the old way of life or “steady state,” from an uncertain future. The second phase is “challenging normal.” In this phase, healthcare appointments and therapies dominate the lives of the caregivers and care recipients, and the caregivers must “take on the role of the assistant,” even though they are inclined to do more and try to help their loved one any way they can. In this stage, the caregivers begin to understand the limits to their power. The third phase, “building a new normal,” consists of increased caregiver responsibilities as they make end-of-life and comfort care decisions and care for their loved ones nearly full-time. In this phase, caregivers are forced to confront and acknowledge the inevitability of end-of-life. Once their loved one dies, the caregiver loses these caregiving responsibilities, and moves into the final caregiving phase, called “reinventing normal.” In Penrod and colleagues’ final phase, the caregiver grieves for their loved one and begins forming a new identity and a new life without the presence of the care recipient (Penrod et al. 2011; Penrod et al. 2012).

Caring for a loved one, while rewarding, can also have detrimental health effects, both physical and psychological, on the family caregiver (Schulz et al. 1997; Schulz and Sherwood 2008). When the care recipient has Alzheimer's or a related dementia, caregivers are often met with unique challenges that may further be detrimental to their health and wellbeing (Liu and Gallagher-Thompson 2009; Goren et al. 2016).

#### **d. Couplehood in Assisted Living**

As studies examining the social context of assisted living have become increasingly prevalent, the focus on couples in AL has also begun to receive added attention. Earlier research on couples living together in Canadian nursing homes suggested that the experiences of couples in long-term care (LTC) settings differed greatly from the experiences of residents without spouses. These differences included perceptions of space, social interactions, and privacy or lack thereof. Additionally, these studies examined the effects of the long-term care environment on quality of the marriage, concluding that couples benefit when they are able to remain together after their move into the LTC setting. Spousal obligations of caregiving were also considered and were found to be an important aspect of informal care provided within the nursing home environment (Gladstone 1995).

Following these findings, Kemp and colleagues conducted a large, exploratory study investigating the lived experiences of married couples in assisted living in the United States. Kemp found that the path to assisted living in couples often involved imbalanced rates of decline between the members of the couple, calling these divergent trajectories "asynchronous health transitions" (Kemp 2008). In many instances, the spouse who was more cognitively or physically impaired required higher-level care when the other spouse would have been able to remain

independent. However, due to the desire to remain together, both spouses moved into AL. Among other important findings, Kemp delineated a series of categorizations in couples' social integration in AL. *Independent couples* were those who "enjoyed one another's company but actively negotiated time apart" (243). These couples experienced some degree of physical disabilities but had minimal cognitive impairments. *Inter-reliant couples* were those who "were virtually inseparable and rarely left one another's side" (243). These couples ranged from being socially integrated within the AL community and participating in activities together to being isolated together in their own apartment. The final category was *restricted-independent couples*. In these couples, one spouse desired a certain degree of social independence but felt constrained due to perceived caregiving responsibilities for his or her spouse (Kemp 2008). These four categories were affirmed in a following study, and an additional four categories were delineated as well (Kemp et al. 2016).

In another study, Kemp analyzed the experiences of adult children providing support for their parents in assisted living (Kemp 2012). Adult children found comfort in knowing their parents had "built-in support" from each other's company but hoped that the move to AL would decrease some of the responsibilities on the higher-functioning spouse (648). Adult children additionally highlighted their parents' senses of purpose in caring for one another but were sometimes concerned that one parent, often the higher-functioning one, was not allowing themselves time to be alone or do other activities without the more impaired parent (Kemp 2012). Overall, Kemp found that spousal support was beneficial throughout navigating life transitions, as it provided "continuity in the face of change" and purpose in the AL environment (Kemp 2012).

## **V. Jewish Perspectives on Death and Dying**

### **a. *Pikuach Nefesh* in Practice**

For thousands of years, Jewish law has maintained strict rules and guidelines on all aspects of end-of-life planning, including the dying process, the definition of death, burial, and mourning. Jewish law makes it clear that the preservation of life is above all else, through the principle of *pikuach nefesh*. In essence, saving a life overrides all other Jewish rules, largely regardless of the context. Due to this principle, those who strictly observe Jewish law forbid euthanasia and suicide. But there is a distinction between “actions that hasten death from those that remove impediments to death” (Curlin et al. 2008, 5). Jewish tradition, while forbidding euthanasia and suicide if they hasten death, permits actions that remove the impediments to death, such as with terminal sedation and withdrawal of life support (Hamel 1991). Curlin and colleagues explored this nuance among physicians from different religious backgrounds. They found that compared to Catholic, Protestant, Hindu, and Muslim physicians, Jewish physicians had a very low likelihood of objecting to withdrawal of life support, terminal sedation, or physician-assisted suicide for their patients (2008). Of course, topics of this nature remain contentious within the Jewish community and there is no single answer to these debates.

### **b. Religious Practices**

Jewish law also provides guidelines for behavior during the dying process. According to the *Shulchan Aruch*, the Ethics of Our Fathers, a person on their deathbed should recite a prayer called *viddui*, meaning confession. The *viddui* prayer, which may be recited by the dying individual or someone around him or her, includes a plea for forgiveness, acknowledgement of death controlled only by God, and a request for a place in the *olam haba*, the world to come. The

final words of the *viddui* are from the *shema*, the prayer that says, “Hear O Israel, the Lord our God, the Lord is One.”<sup>3</sup> Following death, the body is covered and never left alone until burial. Someone who watches over the body is called a *shomer*, a guard. Many Jewish communities possess organizations that are responsible for this, called the *chevra kadisha*, which roughly translates to holy society. The *chevra kadisha* is also responsible for the holy preparation of the body, which is accomplished by thoroughly cleaning the body and wrapping it in a plain, white, linen shroud, known as *tachrichim* (Kolatch 2007; Diamont 1999). Any type of desecration of the body is strictly forbidden. This includes embalming, removal of organs or fluid, and even, in many cases, autopsy. Importantly, this law against desecration of the body also forbids cremation. Until very recently, as in the last fifteen or so years, it would have been nearly unthinkable for a Jew to request cremation. If someone did, rabbis would often force the family members of the deceased to betray the wishes of their loved one. Today, cremation has become more popular among Jews, but still likely represents less than a tenth of Jewish practice (Nathan-Kazis 2012).

Coffins are optional according to Jewish law but are, of course, mandatory in most cemeteries around the world. The coffin, then, is most frequently a simple, pine box. The coffin must be plain just like the *tachrichim*, because Jewish tradition maintains that the burial of a poor person must be no different from the burial of a wealthy person (Diamont 1999).

Simcha Fishbane, in his anthropological approach to studying Jewish mourning rituals, utilizes the framework of Victor Turner’s studies on rites of passage to understand the Jewish trajectory of mourning. Importantly, Jewish traditions holds that only the closest family members

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<sup>3</sup> The *shema* is one of the most well-known and common prayers in Judaism. Observant Jews say the *shema* multiple times a day, including upon waking up and just before falling asleep. The text of the *shema* is also included in *mezzuzot*, which are the small structures many Jews install on the doorframes of their homes.



be considered mourners; all others are technically supporters. The mourners, in their relationship to the deceased, include children, parents, siblings, and spouse. Fishbane explains that the role of the mourner changes throughout the different time periods after a death, following a trajectory of desocialization to resocialization. Prior to burial, the survivors (i.e. family members of the deceased) are known as *onenim*.<sup>4</sup> The only obligation of an *onen* is to prepare for the funeral; he or she is exempt, even excluded from most religious matters, highlighting the liminal state in this trajectory (Fishbane 1989). According to Jewish law, the survivors do not assume the role of mourners until the body is buried. This transition is marked by a recessional following the interment in which the supporters form two lines, guiding the mourners away from the graveside. Once the family members become mourners, a timeline of rituals prepares them for reintegration into Jewish and secular society. For seven days following the burial, the mourners sit *shiva* in the house of the mourner or in the house of the deceased. During the *shiva*, praying occurs, and supporters bring food for the family. Mourners and supporters often sit on the ground or on low stools to humble themselves. Mirrors are also traditionally covered. These seven days begin the period of *shloshim*, which is the thirty-days of semi-insular mourning. This is followed by the next eleven months of less-insular mourning, until the anniversary of the death, when the mourning period officially comes to a close. The following are examples of prohibitions during the periods of *shiva* and *shloshim*: haircutting, shaving, wearing new clothes, listening to live music, and getting married.

As Fishbane explains, the mourner's obligations systematically decrease throughout the three periods of mourning. This allows him or her to resume a life similar to life prior to the family member's death, easing into a different social world. Throughout this mourning year, and

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<sup>4</sup> *Onenim* is plural; *onen* is singular.

several times a year for the rest of the mourner's life, a prayer of critical importance is the mourner's *kaddish*.<sup>5</sup> Observant Jewish mourners recite the *kaddish* every day, often three times a day, for the duration of the mourning year. After the year ends, the *kaddish* is recited on each anniversary of the death and during select holiday services. It is recited only in the presence of ten Jews, a prayer quorum known as a *minyan*. The mourner's *kaddish* translates as follows:

May God's name be exalted and hallowed throughout the world that He created, as is God's wish. May God's sovereignty soon be accepted, during our life and the life of all Israel  
And let us say: Amen.

May God's great name be praised throughout all time.

Glorified and celebrated, lauded and worshipped, exalted and honored, extolled and acclaimed may the Holy One be, praised beyond all song and psalm, beyond all tributes that mortals can utter. And let us say: Amen.

Let there be abundant peace from heaven, with life's goodness for us and for all Israel. And let us say: Amen.

May the One who brings peace to His universe bring peace  
To us and to all Israel. And let us say: Amen.  
(Siddur Sim Shalom 2008)

Notably, nowhere does the *kaddish* mention death or dying. Rather, the prayer serves as an exaltation of God. In a service, only the mourners stand during the recitation of the *kaddish*. Fishbane understands the period of saying *kaddish* as a time of liminality—he argues that the act of saying *kaddish* “singles out the mourner,” but eventually allows him or her to return to regular society.

Of course, the mourning rituals among Jewish people are not homogenous. Abeles and Katz (2010) caution that Jews in modern times often observe some of these practices and not others. Depending on one's level of observance and local Jewish community, the rites and rituals

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<sup>5</sup> The mourner's *kaddish* is written in Aramaic, the language from which Hebrew arose.

differ substantially. The aforementioned mourning process provides a general outline of Jewish practices of death and dying.

## **VI. Concluding Thoughts on the Literature Review**

As demonstrated in the previous sections, there has been a wealth of research conducted that focuses on various aspects of aging, AL relationships, couplehood, caregiving, and end-of-life perspectives. Assisted living as a social world has also become more prominent in the literature over the recent decades. The published literature fills many niches, including aging and social networks (e.g., Wenger and Jerrrome 1999; Carstensen 2006), navigating assisted living as a couple (Kemp 2008; Kemp 2012; Kemp et al. 2016), and Jewish death and mourning practices (e.g., Fishbane 1989; Diamont 1999). This review, however, shows a gap in the existing literature: end-of-life perspectives of Jewish couples who live in assisted living. It is my hope that this thesis project fills this niche.

### **Chapter 3: Ethnographic Setting, Participants, and Methodology**

This honors thesis is part of a larger, 5-year, prospective longitudinal qualitative study conducted by my co-advisor, Dr. Molly Perkins and her colleagues, including my committee member, Dr. Alexis Bender. The larger study, entitled “End of Life in Assisted Living: Links Between Structure, Process, and Outcomes” (5R01AG047408) is funded by the National Institute on Aging within the National Institutes of Health. Data were collected between June 2015 and March 2020, and analysis is ongoing. For purposes of communicating with participants and study sites, researchers created a less official-sounding lay title for the study, “Trajectories of Life and Care in Assisted Living,” which they refer to as the “TLC Study.” The goal of the TLC study is to identify best practices for end-of-life care in assisted living from the perspectives of residents, AL staff, resident family members (informal caregivers), and external care providers, such as hospice workers, private aids, and other medical care providers.

#### **I. Ethnographic Site – Haber Gardens**

The larger TLC study included seven separate and diverse assisted living communities, including traditional assisted living homes as well as personal care homes, which contain fewer beds than the traditional AL communities. The study sites were chosen to reflect the diversity of assisted living communities in the United States, particularly the diverse racial and socioeconomic makeup of AL residents. For my study, I utilize the data from one of these communities, which I will call Shelly M. Haber Gardens to preserve the privacy of its residents.

Shelly M. Haber Gardens is a not-for-profit assisted living community located in a fairly upscale neighborhood in the metropolitan Atlanta area. Established in the late 1970s, the home is now under the leadership of Jewish HomeLife Communities, an organization that owns and

operates several Jewish long-term care facilities around Atlanta. While Haber Gardens has a Jewish affiliation and the majority of its residents are Jewish, being Jewish is not a requirement, and they accept residents of all faiths and religious affiliations.

Haber Gardens is characterized as a large-sized assisted living community, defined as a facility licensed for over twenty-six beds (Park-Lee et al. 2011). The home is licensed for forty-six residents between its assisted living and memory care sections, but it only housed around thirty residents at the time of the study.

Haber Gardens offers two levels of care: regular assisted living and memory care. In many assisted living homes, the memory care units are often physically separated from the main assisted living sections of the home. Memory care units may be located in different hallways or even different floors entirely, and they are often separated from the main areas by locked doors to prevent residents from wandering.

Alzheimer's disease and other forms of dementia are already stigmatizing conditions in and of themselves, and these segregated living arrangements greatly contribute to the stigma. Assisted living residents will often avoid the memory care area, because they do not like to be reminded of "those Zombies" among them (Riley Burgener, and Buckwalter 2014; Dobbs et al. 2008).

In Haber Gardens, however, these two levels of care are not quite segregated and are instead integrated as much as is safe and possible. Residents who require additional memory-related care live in the "Pathways neighborhood," described as an extension of the community but more intimate, with a higher staff to resident ratio and activities tailored to the cognitive abilities of the residents. The Pathways neighborhood is located on the main floor of the building, making it accessible to all residents. Pathways residents are invited to eat their meals in

the main dining room but have the option to eat in a more private setting called the Pathways Great Room.

This style of incorporation is similar to an approach called the Montessori-Inspired Lifestyle<sup>®</sup> (MIL), which seeks to increase the engagement of residents with different physical and cognitive abilities. In a previous quality evaluation project among AL communities that implemented this model, researchers found that inter-resident engagement did increase following the implementation of a MIL (Gaspar and Westberg 2020).

In addition to the typical activities of assisted living communities, Haber Gardens also runs a vegetable garden of which the residents are very proud. Consisting of eight residents and one staff member, the garden committee grows tomatoes, zucchini, radishes, and peppers, and Haber Gardens' in-house chef often prepares meals using fruits and vegetables from the harvest for all to enjoy. This chef seems to be highly popular with the residents, and they like to brag that she attended a Le Cordon Bleu culinary school.

Haber Gardens is located on a somewhat sparsely populated side street, and its closest neighbors are establishments like a horse farm, childcare center, and another assisted living community. The building itself is brick and beige, with horizontal vinyl siding. It was not as large as I was expecting, and I almost missed the entrance to the parking lot when I visited. During the pandemic, Haber Gardens has been practically closed down to outside visitors. Large posters were taped to the doors, reading "CORONAVIRUS PREVENTION IN PLACE: TO REDUCE THE RISK OF COVID-19 IN OUR COMMUNITIES, NO VISITORS WILL BE PERMITTED AT THIS TIME." Other signs declared, "Warning: Under Georgia law, there is no liability for an injury or death of an individual entering these premises if such injury or death results from the inherent risks of contracting COVID-19. You are assuming this risk by entering

these premises.” As of March 9, 2021, over a year into the pandemic, Haber Gardens had maintained its record of zero COVID-19 cases within its population of residents, a genuinely rare feat among long-term care facilities in Georgia (Georgia Department of Community Health 2021). Needless to say, there was not much visible activity at Haber Gardens while I was there sitting in the parking lot. A few staff members came outside and went back into the building, but nothing else. From my outdoor observations, I noted that Haber Gardens has a very pleasant surrounding environment. The building is surrounded by stands of pine trees; there were birds singing, and it seemed like a very peaceful place.

## **II. Participants**

Participants for the TLC study were recruited from seven different assisted living communities. With administrative approval from each AL community, the research team sent letters to resident family members introducing the project and its goals. The research team also posted flyers around each AL community with photographs of the lead researchers and information about the study. After the initial information pertaining to the study was presented to residents and their families, the team began making frequent visits to the AL communities to build rapport with the residents, staff members, and administration. Eventually, the team was able to select focal residents as the primary research participants for the study. To be considered for the TLC study, participants were required to be eighty-five and older. Additionally, they needed to be characterized by AL staff members as either *declining* or *dying*. Other focal residents were chosen based on other factors such as connections to focal residents, knowledge of the AL environment, length of tenure in their respective AL community, and end-of-life attitudes and

experiences. Following the process of acquiring consent from the participants, the residents were given unique, deidentified names for qualitative coding and organizational purposes.

In this thesis, I utilize the interview data recorded from residents at Haber Gardens. Within the Haber Gardens study population, there are two couples, so my research includes only these four primary participants who fit within its narrow scope, out of the original nine focal residents at Haber Gardens. I have created pseudonyms for my four participants in order to maintain their privacy and anonymity, but I have done so in such a way as to preserve their humanity and as well as their distinctly Ashkenazi Jewish backgrounds.<sup>6</sup> I will discuss my four research participants, Max and Edith Kopman and Abe and Freida Buchsbaum, in subsequent chapters.

### III. Sociodemographic Information

Table 1. Select Sociodemographic Characteristics of Thesis Study Participants\*

Surname	First Name	Gender	Race	Age	Education	Jewish Denomination**	Importance of Religion	Self-Rated Financial Well-being
Kopman	Max	male	white	87	some college or 2-year associate degree	Orthodox	important	Very well
	Edith	female	white	86	some college or 2-year associate degree	Reform	somewhat important	
Buchsbaum	Abe	male	white	86	bachelor's degree	Reform	important	Fairly well
	Freida	female	white	82	Some college or 2-year associate degree	Reform	very important	

\*Demographic information as reported at the time of enrollment in study

\*\*There are three primary denominations. Orthodox is most observant, followed by Conservative, then Reform, which is considered to be the least observant.

<sup>6</sup> There are many different types of Jews, as Jews have been spread out around the world for thousands of years. *Ashkenazi* Jews are those who trace their origins to Eastern and Central Europe and are the most common type today, making up approximately 80% of world Jewry.



#### **IV. Data Collection**

In the original TLC Study, both qualitative and quantitative research methods were used. My project, however, relies solely on the qualitative data collected during the pre-pandemic years of the study. The research methods employed in the TLC study included: semi-structured interviews, participant observation (from previously written memos), memo-writing, and what I call COVID-safe field trips.

##### **a. Semi-Structured Interviews**

A total of four semi-structured interviews were conducted with residents. The first interview contained questions about life histories and narratives. The second interview included a social network map, in which residents were asked to identify and explain their “bulls-eye” of relationships based on the Kahn and Antonucci (1980) convoy model.<sup>7</sup> The third semi-structured interview asked residents about their health behaviors and care/activities of daily living (ADL) needs, and the fourth addressed end-of-life perspectives and advance directives. In addition to these semi-structured interviews, research team members also administered the Montreal Cognitive Assessment (MoCA) test,<sup>8</sup> a measure of grip strength, and a demographic and health survey.

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<sup>7</sup> See literature review, section **III: Relationships in Assisted Living** for more information.

<sup>8</sup> The Montreal Cognitive Assessment, or MoCA, is a test designed to detect mild cognitive impairment and dementias such as Alzheimer’s disease, Lewy Body, and Frontotemporal dementia. Items in the test include: drawing a clock face at a specific time, recalling words on a list, and serial 7 subtraction starting at 100, among other tasks.

Family members of the residents and AL staff members were also interviewed, when possible, as part of the TLC Study. In interviews with family members, team members asked about their loved ones' backgrounds, the path leading up to assisted living, and their attitudes toward the care provided by the AL community. In interviews with AL staff members, staff were asked about prior experiences working with older adults, the social environment of the AL community, AL policies, their relationships with the focal residents, etc.

Different methodologies exist for the qualitative study of couplehood. Some studies conduct interviews with one member of the couple, while others employ a dyadic approach—gathering information from both members of the couple together in order to get a more complete understanding of the relationship. This method facilitates the process of “sharing and comparing” between participants, giving the researcher insight into the communication practices and miniature milieu between the members of the couple. The marital dyad approach operates under the assumption that couplehood exists in a unique state of two lives intertwined rather than simply two lives experiencing separate trajectories, such as in a small focus group or separate, individual interviews (Morgan et al. 2013).

In the TLC study, interviews of the couples were, in general, collected using a dyadic approach. One couple, the Buchsbaums, was able to complete their interviews together, because both were cognitively aware enough to process the interview questions and respond. The other couple, the Kopmans, although both members were living at the time, was unable to participate in the interviews as a marital dyad, because only Max Kopman was cognitively present. Edith was unable to participate directly, but the interviewers would often ask Max to answer particular questions using Edith's perspectives as well as he could. Undoubtedly, this was not a perfect

solution, because Max would usually revert to explaining his perspectives, but it did elicit some answers he might not have otherwise provided in his interviews.

Reading interviews that utilized a dyadic approach allowed me to gain an understanding of the ways in which the couples interacted with one another in conversation. In the Buchsbaums' interviews, they would often finish one another's sentences and add on to each other's accounts—correcting statements, asking for clarification, and reminiscing together.

Of course, during the COVID-19 pandemic, it has been impossible to enter any long-term care communities to conduct interviews, so I needed to get creative with my methodology to adhere to COVID-19 safety guidelines. I was able to speak with one of the residents, Max Kopman, over Zoom video conferencing software, because he is the most technologically-able of my research participants. Because I already had access to his initial interviews for the TLC Study, I used our Zoom conversations as informal, follow-up interviews, and I was able to ask specific questions related to my research goals. I was also given insight into the COVID-19 precautions at Haber Gardens, which allowed me to feel more connected to the current social and physical environment of the community.

### **b. Participant Observation**

In addition to the planned interviews, research team members visited each AL community at least once a week. During these visits, team members would catch up with the focal residents, AL staff members, and administration. In resident visits, the team member would check in with the residents to see how they were doing and occasionally meet the visiting family members. These visits were also excellent times to conduct participant observation, which included

participating in some recreational activities with residents (e.g., bingo and crafts), helping with meals, or attending memorial services and other planned events.

During the months prior to the pandemic, before I formally began research with Haber Gardens, I was able to visit another one of the homes in the study a few times. I was able to build rapport with some residents at this home, and I would sometimes join them for activities such as bingo or music performances. I would also sit in the common area with residents as they watched television or waited to be picked up by family members. If I did not see a resident out and about in the common areas or activity rooms, I would knock on their doors and visit with them in their own rooms. These visits to their rooms allowed me to get a sense of their lives external to the assisted living environment, because people enjoyed showing me family photos, old furniture, and objects from their previous homes that they incorporated into their small apartments. I could see that each apartment was uniquely decorated to highlight the most meaningful aspects of each resident's life. During my visits, I would take field notes, jotting down any observations or reflections I thought useful. Through this participant observation, I was able to gain a sense of the home's social milieu and general culture. From experience visiting the other assisted living study site as well as other Jewish assisted living communities in Atlanta, along with discussions with team members who have visited Haber Gardens, I believe there are sufficient similarities between these homes that I have an adequate sense of what Haber Gardens would be like if I were able to visit personally.

For this project, visiting resident rooms was not a possibility, so I had to find alternative methods for gaining this type of access to my participants' personal styles and interior design choices. During the pandemic, analyzing peoples' videoconferencing backgrounds has become a popular practice. In an article in *The Guardian*, fashion journalist Jess Cartner-Morley writes,

“The pandemic has forced us to make our private spaces into public ones...With a Zoom parliament, a Houseparty social life and a Microsoft Teams meeting schedule, our lockdown lives are being played out against a backdrop of bookshelves and kitchen cupboards” (2020). Whether sporting a virtual background, carefully curated bookshelf, or messy room, these little squares give others a small window into our lives. In my Zoom interviews with Max Kopman, I took note of the components of his Zoom background and was able to gauge the layout and aesthetic of his apartment. I was also able to witness some of his interactions with administrative and nursing staff, acting like a fly on the wall (or fly in the computer!) while he chatted with his visitors.

An additional, pandemic-friendly method of participant observation I employed was “liking” Haber Gardens’ Facebook page. As with many assisted living communities, Haber Gardens maintains a steady social media presence. Through the Facebook page, I saw photographs, captions, and comments relating to birthdays and other milestones, activities with residents, safety protocols, and holiday celebrations. The post captioned, “Our residents and staff had their first COVID vaccine clinic today!” was particularly exciting, and many family members of residents cheered on their loved ones with comments such as, “Way to go, Mom!” and “Awesome! Thanks for all that you do every day to keep everyone safe and healthy.” Through the Facebook page, I was also able to see photographs of the Buchsbaums, the couple with whom I have had no communication during my research. Seeing their photographs and being able to have a mental image of people about whose lives I have learned so much during these months was particularly meaningful to me. In general, having access to the Facebook page has been a wonderful way to see that despite the restrictions due to the pandemic, the residents at Haber Gardens have had opportunities to smile, laugh, celebrate, and live their lives.

In one of my conversations with Max Kopman, he suggested we become “friends” on Facebook so that I could learn more about his life. I was particularly honored by this suggestion, because, as he told me, he had fewer than 100 Facebook friends. By becoming his Facebook friend, I joined an intimate, virtual network of his close friends and family members with whom he shared memories and old photos, mostly of him and his wife. I was able to gain insight into his interactions with his friends and family members, a particularly unique opportunity during the pandemic.

### **c. Memo-Writing**

One of the important methodologies of the TLC Study was the practice of memo-writing following each visit. In each memo, the team member writes down thoughts on their encounters, summaries of their field notes, and other perspectives that are not found in the interviews. These were extremely useful to my analysis, because I was able to read about the thoughts and observations from the team members who worked closely with the focal residents. The memos provided me with insight and ethnographic detail that would otherwise be unavailable to me without being able to physically visit the research site. In my conversations with Max Kopman, I have also been writing memos. A sample memo can be found in **Appendix A**.

### **d. COVID-Safe Field Trips**

Although most physical aspects of this project were impossible due to the COVID-19 pandemic, I still found ways to have in-person experiences ingrained into my research process. After my initial read-through of the interview data, I identified places that were important to my research participants, whether a former place of business, place of interest, or place of significant personal

history. If the destination was within driving distance, I took COVID-safe field trips to visit. In the majority of these visits, I did not interact with anyone or go inside any buildings, rather I simply observed my surroundings from exteriors of significant buildings and spaces. These trips included a visit to several locations in Augusta, GA, to see the hometown of the Buchsbaums, a visit to the Northland Lake Library, a visit to the parking lot of Haber Gardens, and lastly a visit to a well-loved bagel shop near Haber Gardens.

## **V. Data Analysis**

All previously conducted interviews had already been transcribed by the time I began my project. The interviews and conversations I had with Max Kopman over Zoom, however, required transcribing, which I completed using the Otter.ai service that accompanies the Zoom cloud recording. I subsequently reviewed the inaccuracies and manually edited the transcript. The interviews were then compiled into a single folder, which was then transferred to NVivo, a qualitative data analysis software. Within the larger data corpus of the TLC study, my data set, as mentioned earlier, contained only the interviews pertinent to the two couples in my study, as well as the memos written by researchers during the data collection period.

I analyzed these data using an inductive thematic approach, a qualitative research method widely used in fields such as psychology, anthropology, and sociology. With inductive analysis, the themes do not derive from prior theories, frameworks, and preconceptions, rather the themes are determined from the particular set of data. Rather than using a ‘top-down,’ or theoretical/deductive analysis, employing an inductive thematic approach allows for data-driven analysis that is unique to the data set at hand, and conformity to prior assumptions and

theoretical frameworks is not necessary. Of course, my analysis does not occur in a vacuum, and my education and personal experiences do play a substantial role in my findings.

My inductive thematic approach largely followed the flexible process outlined by Braun and Clarke (2006). As is generally true with qualitative data analysis, I was not bound to any strict rules in timeline or structure, so my data collection and analysis were at times concurrent. As I read the previous interviews with my research participants, I was simultaneously reading existing literature on my topics, interviewing Max Kopman, and coding my data to find themes. Braun and Clarke describe the process as “recursive,” rather than linear, because the back-and-forth iterations allow the researcher to form a more cohesive picture of the data at hand without making inflexible conclusions too early in the research process.

Braun and Clarke argue that “Writing is an integral *part* [emphasis in original] of analysis, not something that takes place at the end” (Braun and Clarke 2006, 86). During my initial read-through of the interviews, I jotted down my thoughts, potential themes I was seeing, and further questions. These early writings guided my analysis throughout multiple readings and re-readings of my interview data. From these notes as well as from the previously completed TLC codebook, I generated my preliminary thesis-specific codebook, which I modified and updated throughout my coding, writing, and overall analytic process. The complete codebook can be found in **Appendix B**. I entered this codebook into NVivo 12 Plus (QSR International), a qualitative data analysis software that helps organize large quantities of data. I was able to use NVivo to highlight passages of my interviews and categorize them into specific themes and topics. NVivo automatically organized these categorized interview passages into code “buckets” that I was able to reference and review.



After coding each interview and recoding for completeness, I identified the code buckets that contained the most passages, and I created further ways to break these down for analysis, creating new sub-codes for passages within the interviews. From these codes, I identified and refined themes that addressed my research questions, as will be demonstrated in subsequent chapters. Word queries in NVivo were a useful tool for my analysis, as I was able to search for key words within buckets or interviews and pull particular quotes for my analytical exegeses.

My inductive thematic approach dovetailed with a narrative analysis approach. With narrative analysis, I was able to place value on the stories conveyed by my research participants, discern the meaning behind these stories, and understand my participants' roles as co-creators of their narratives (Reissman 2008). The analysis process outlined by specialists in narrative analysis (e.g. Catherine Kohler Riessman) does not differ substantially from the inductive thematic approach, but the emphasis on storytelling and dialogic analysis was particularly useful for my project.

The following three chapters report findings from this analysis. The fourth and fifth chapters outline themes related to each couples' shared life histories prior to their move to Haber Gardens. These histories provide important context for the sixth chapter, which focuses on themes related to the couples' end-of-life perspectives.

## **Chapter 4: Abe and Freida Buchsbaum**

### **I. Courtship and Marriage**

Abe Buchsbaum met Freida Lerman in 1955. At 23, Abe had already dedicated much of his life to the United States Army. He received his undergraduate education at the United States Military Academy, West Point, earning his Bachelor of Science in military engineering. Immediately following graduation, Abe joined the U.S. Army as a commissioned officer and found himself stationed at Fort Gordon, the military post just a few miles outside of Augusta, Georgia. Coincidentally, Freida Lerman and her teenaged friends from synagogue had plenty of contact with the soldiers at Fort Gordon. They would often bring cakes and cookies to the Jewish soldiers, and in 1955, Abe and Freida finally connected.

Freida Lerman had lived in Augusta for most of her life. She was born in Germany in 1936. Her father, a Jewish retail business owner, was instructed to paint “Jew store” on his store front, but he refused. He was arrested multiple times, and it was quickly becoming clear that Germany was no longer safe for Jewish people. With an aunt already living in Augusta, Georgia, Freida’s family was able to attain sponsorship and immigrate to the United States, and they fled from the Nazis when Freida was just a year old. Her father opened up another retail store called Lerman’s Home Fashions once the family had safely settled in Augusta.

In 1955, when Abe and Freida met, Freida was nineteen years old and in the middle of her first few years of college at the University of Georgia. She never finished college, because she married Abe six months after meeting him. By 1957, Freida and Abe had their first baby, a daughter, followed by two sons in the next six years. As they raised their three children, they always stressed the importance of education and community. As their children left for

universities, grew up, and started families of their own, Abe and Freida continued the patterns of their lives and were grateful for their good health and busy social calendars.

## **II. A Field Trip to Augusta**

Abe and Freida were still alive at the time of this writing, but given the unique circumstances of this year, I was not able to ask them more about their lives before they moved to Atlanta or about the places that shaped their narratives. I wanted to understand their lives in Augusta, where they lived for over fifty years, in a more complete way, so I decided to take the two-hour-long drive across the state to their hometown.

The drive was mostly a straight shot east with miles and miles of interstate lined with pine trees and grassy weeds. I navigated first to downtown Augusta, near the university. Abe and Freida had lived in the suburbs and worked in various parts of Augusta, and I wanted to get an idea of the geographical layout of their city. In the downtown area, I immediately spotted a street called Woodruff Road, and I recalled from my history search that Augusta had been home to one of the first Coca-Cola bottling plants. As an Emory University student, I felt right at home. In the next several subsections, I will recount the story of the Buchsbaums through the framework of my field trip to their hometown.

## **III. Business**

For the majority of his working life, Abe was in business with his father-in-law at Lerman's Home Fashions, selling curtains, drapes, and bedding. Eventually he became the full owner, and he expanded Lerman's to three locations around Augusta. Freida would help out around the store, but her primary role was taking care of the children when they were young. From

interviews with the Buchsbaums themselves, there was never any indication that Abe desired more from his work than what he had at his store. He seemed, from my understanding, perfectly content with his career, and he and Freida would often reminisce together about their times at the store. For example:

Abe: We had a good-sized store. In fact, we had three stores, when you come right down to it, in Augusta. I was involved with ‘em for 40 years with [Freida’s] father and her.

Freida: Mm-hmm. Yeah. *[Laughter]*

Abe: Cuz she was with me the whole time.

Freida: Yeah. Yep.

Abe: We owned ‘em and operated ‘em. It was more than a nine-to-five job, because we owned ‘em. Yeah. We were married to that, too.

They mentioned their store frequently in their interviews, and it was clear that it was a substantial part of their lives. Their accounts of their store were filled with a deep sense of pride—they were proud of the family they raised, and they were proud of the business to which they had almost equally devoted their lives.

In an interview with their son Michael, who lives in Atlanta, a more complicated picture of Abe’s relationship to his business developed. Michael discussed his father’s values of “Whatever you try, you try your hardest no matter what,” a philosophy that to Michael was “pretty damn impressive.” Abe and Freida worked in Lerman’s Home Fashions throughout Michael’s and his siblings’ childhoods, and the store was a constant in their lives. Michael acknowledged his parents’ pride in the store, but he also provided some necessary context:

There are times where I think he probably would have preferred to do something else, but that was the life he chose. I can think of one time when he really didn’t wanna do it anymore and essentially, he took a sabbatical and my mom took over the business...He was clearly burned out, and he needed a break. My mom wasn’t willing to walk away from the business just yet. She

took over while he was doing something else, and he did that for two years...He was selling stuff, products, wholesale salesman, and he was away from home three nights a week, driving all over Georgia and Alabama. It was—seeing him do that, it was a shock to all of us. Seeing him walk away like that was a bigger shock, because we had never seen him walk away from anything. Just another “show us you’re human [moment].” He learned a lot about himself and what he was doing, and we learned a lot from him by what he was doing.

Each transition in Abe’s life, it appears, had been straight-forward and fairly predictable. After West Point, army, then marriage, father-in-law’s business partner, then family. He had been awarded an engineering degree from one of the most prestigious universities in the United States. With that degree and years of experience as a commissioned officer, he entered a job as a subordinate to his father-in-law, making little use of his army leadership and hard-earned education. Whether or not that ever bothered him is not necessarily clear from the interviews, but from Michael’s reflections, however, it is evident that somewhere in Abe was the desire to break away from the predictable nature of his life.

His two years of near absence from his former life immediately reminded me of notable anthropologist Victor Turner’s concept of liminality. Turner’s work focused on rites of passage, ritual, and symbolism among the Ndembu people of Zambia, but his understanding of liminality is a useful tool with which to frame Abe’s temporary departure from his family and community. Borrowing from Arnold van Gennep (1960), Turner discusses the three stages of the rites of passage among the Ndembu people: separation, margin, and aggregation. To describe the marginal state, Turner writes that “Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial” (Turner 1969, 359). During the two years of partial absence from his family and his work, Abe was also “neither here nor there.” The three things that situated him securely in his life, at least according to Michael, were his family, his business, and his Jewish community, but during his

“sabbatical,” he purposefully interrupted the order of his established life. As Turner explains, “Liminality implies that the high could not be high unless the low existed, and he who is high must experience what it is like to be low” (Turner 1969, 360). From the interviews, it is difficult to know whether or not this represented a “low” point in Abe’s life, but it was certainly *different*. For one of the first times in his life, Abe chose to reject the structure and predictability that anchored him to his world. Like the initiates of Victor Turner’s fieldwork, Abe needed these few years away from the community and his family to learn about himself, his goals, and his place within his social world.

After Abe’s two-year sabbatical from his normal life, he returned. Once again, he devoted himself to his family business, his family, and his community. Whether or not it was a seamless transition, he made the clear decision to come back to his former life in full.

In the 1990s, Abe was diagnosed with lung cancer and made the decision to retire from his decades-long career at Lerman’s Home Fashions, passing the baton to his youngest son. His lung cancer was a short-term issue, however, because ten days after his surgery, he was declared cancer-free, remaining cancer-free to this day. Having worked in the same career for over forty years, his retirement understandably marked a momentous change in the Buchsbaums’ life, “all of a sudden, like being turned free.” Their son Michael told the post-retirement story of Lerman’s Home Fashions in his interview. After the Buchsbaums’ younger son took over from his father, he kept it up for around eight years, but ended up selling the business when he no longer wanted to be a part of it. This drove a serious wedge in the relationship between father and son that continued to the time of the interview, as Michael explained:

I just—there’s a part of me that wishes my brother and my dad could make peace before the inevitable happens. I don’t know that they will. I don’t know, but when that happens, my brother’s gonna regret it for the rest of his life. I don’t want that to happen.

Abe had spent forty-five years building the business with his father-in-law, and just like that, his son had let it go.

In downtown Augusta, I wanted to see if I could find the original location of Lerman's Home Fashions. I had one clue: I knew from an interview that it was located across the street from the old Sears and Roebuck building on Main Street, which, incidentally, had been owned by some of the Buchsbaums' best friends. I had an old photograph of the Sears building to guide me. Unfortunately, a lot has changed in Augusta since the Buchsbaums' original store was open. Main street used to be lined entirely with beautiful, nineteenth-century brick buildings. Today, many of the buildings still exist, but many have also been demolished. I tried to match the architecture of the old photo with the buildings I saw as I walked down the street, but I was unable to find the Sears building. Without the Sears building, there was no way I would be able to identify the building that used to belong to Lerman's Home Fashions. I walked around for a while, and the streets were fairly empty. Students had probably returned home for the holidays, and I would guess that the pandemic has not been great for Augusta's small tourism industry.

My next destination was another former location of Lerman's Home Fashions at an address that I was able to find on the internet. After a driving on a small stretch of industrial highway, I reached the Cottonwood Mall. The Cottonwood Mall seemed to be in the typical state of a retail establishment in the COVID-19 and Amazon era. There were few cars in the parking lot, and the Macy's, Dillard's, and J. C. Penney's anchor stores looked somewhat forlorn. To the side of the mall was the small strip of shops that used to include Lerman's Home Fashions. An armed forces career center had taken over the majority of the individual shops, leaving only an orthodontist at the end of the strip. The façade of the building clearly showed that the armed forces career center was not the original inhabitant of the property. The signs for the Army,

Navy, Marines, and Air Force branches were randomly spaced and off-center of the original molding. (See **Appendix C** for a drawing of the current state of the location.) As I sat in the car and observed, a few men in camouflage army uniforms walked into the parking lot, and I felt somewhat awkward sitting in my car taking notes. There were no relics of the Buchsbaums' home goods business anywhere in sight. Still, I felt strangely nostalgic visiting this place. This property, and the city as a whole, had been so important to the Buchsbaums. They were devoted to the business for generations, and all that was left of it were the memories Abe and Freida shared together.

#### **IV. Jewish Community**

It was useful for me to learn more about the history of the city the Buchsbaums called home for so many years of their life: Incorporated in the early nineteenth century, Augusta, GA, flourished due to the booming cotton industry. By the middle of the nineteenth century, enough German Jews had settled in Augusta to form the city's official Jewish congregation, which later became its first synagogue. These German Jews readily assimilated into Augusta's White, predominantly Christian culture. Rising in wealth and prominence in their city, they were not immune to what would be the South's deplorable legacy, as many participated in slavery through the cotton trade and fought for the Confederacy in prominent positions during the Civil War.

By the late 1890s, large numbers Eastern European immigrants had settled in Augusta just as they had in many other parts of the United States during this time. These Jews were generally more impoverished, less educated, and more religious. They opened dry-goods and retail stores in Augusta and formed their own synagogue that was separate from the synagogue of the German Jews. By the turn of the century, there were nearly one thousand Jews in Augusta.



The Jewish population peaked during the 1980s and has since dwindled as young people have left Augusta for Atlanta and other more populous cities (“Encyclopedia of Southern Jewish Communities”).

The Buchsbaums had an extensive network of friends around their community, which was largely composed of fellow Jews. Abe and Freida were active in their Reform synagogue—Freida was a leader of the sisterhood and the Ladies’ Jewish Aid Society, and Abe, though less involved due to his work, enjoyed spending time in the discussion groups, often remaining at the synagogue long into the evening with his friends. According to their son Michael, their synagogue had been their whole life outside of their business and family:

When they were in Augusta and their children were all grown up, that’s where they spent their time pretty much, at the temple. It was—I think they derived great comfort from being there and doing—being active participants there.

From an internet search, I learned that Abe won awards for his involvement at their synagogue. Returning to his roots as a young man stationed in Augusta, he had started a program in which volunteers from the synagogue would visit Fort Gordon, providing the Jewish service members with prayer services, Jewish education classes, and food receptions, called *onegs*. He maintained this program for over ten years, and the Union for Reform Judaism, the governing body of Reform synagogues in the United States, recognized his program as a “model of outstanding synagogue social action programs.”

The drive from the former location of Lerman’s to the Buchsbaum’s synagogue took only about ten minutes. The landscape in Augusta changes quite abruptly—once I left the downtown area, the scenes became industrial, and then quite suburban all in the span of the three-mile drive. I passed a lovely tree-filled park that I imagined Abe and Freida’s family might have frequented.

This neighborhood consisted mostly of older, ranch-style houses and plenty of yard signs for the Georgia senate run-off election's Democratic candidates.

Finally, I arrived at the synagogue. The large, mid-century style, light brick building sits on a tree-lined street. I pulled into the parking lot in the rear of the building, and mine was the only car there. It felt strange being at a synagogue during the pandemic. The synagogue likely would have been quiet on an ordinary Tuesday afternoon in December, but it felt especially eerie being there with the knowledge that congregants had not entered the building since March. Of course, I could not go in, so I just toured the property. I walked around the building to the side yard of the synagogue, an undeveloped flood plain, scattered with large oaks, pines, and maples, and little streams flowing through the grass. I figured that this tree-filled lot was probably an excellent place for children to play around during the grown-up services. As I turned the corner heading toward the front of the synagogue, a big raccoon ran out in front of me and disappeared into the bushes.

At the front of the synagogue, a large lawn separates the building from the street, with three large willow oaks planted in a row. From my elementary knowledge of tree growth, I guessed that the oaks had been planted when the synagogue was built in the 1950s. They provided some nice shade and acted as a barrier between the entrance to the building and the rest of the neighborhood.

I thought about these trees quite a bit. I had read that the synagogue used to be located in downtown Augusta when the congregation was formed in the 1850s. One hundred years later, the synagogue moved to the present location in the suburbs, just a few years after Abe and Freida began their relationship. Throughout their involvement with the synagogue, they had probably, without thinking about it, watched the trees as they grew. As sentimental as it sounds, the

Buchsbaums had been as deeply rooted to their Jewish community in Augusta as the massive oak trees that guard the synagogue today.

## **V. Leaving Augusta**

The Buchsbaums' complicated decision to move to Atlanta will be further discussed in Chapter 6, Findings on End-of-Life Perspectives. Here, however, I hope to provide useful context for that move and for their feelings toward Atlanta.

Michael's siblings travelled to Atlanta to visit Haber Gardens, and on a Friday afternoon, they decided that it was the right place for their parents.

We drove to Augusta Saturday morning. Got my mother and father, drove to Atlanta and brought them up to the place so they could see it, so that they could get an opinion, and I wanted to hear what they had to say. We all wanted to know what they thought. . . . [They were] very positive. My father was very positive. My mother needed some convincing, but it was less about the place than the fact that she was gonna have to pack up and leave Augusta. That was the thing with her, because everything she knew, everything was in her life, for...83 years, had been in Augusta. It's a big change. My father somehow managed—and I have never asked him how he did it—managed to convince her that this was what needed to be done at this particular point. Some questions, I just didn't wanna ask.

Their social life in Augusta was marked by steadiness and consistency. They kept the same friends for decades; Freida's best friends were those whom she had known since childhood. I cannot imagine the sense of uprootedness that Abe and Freida must have felt when they left Augusta for the suburbs of Atlanta. It seems that a majority of their world was within a twenty-minute driving radius—their friends, their store, their synagogue—all contained in the familiar environment that was Augusta. I especially cannot imagine how painful it must have been to leave the synagogue that had been their religious home for decades, and for Freida, generations.

By leaving Augusta, Abe and Freida left the close embrace of a community in which they had been integral members for nearly their whole lives.

It was interesting to think of the changes to the community since the Buchsbaums' departure from Augusta. As they discussed in their interviews, they had not been the only members of their community to leave Augusta. As their children and their friends' children grew up and left Augusta for the larger cities of the Southeast, many of the older Jews of Augusta also left. In Abe's words, it was as though they and everyone from their past had "fled" from their home.

The drive to and from Augusta was not difficult, although a bit monotonous at times. Despite the ease of the trip, it struck me that if Augusta was my home, making the drive more than once a month would be extremely daunting—especially if I no longer had my driver's license and needed to rely on others for my transportation.

For the Buchsbaums, Augusta was very clearly still their home, despite their transplant to Atlanta. They still referred to Atlanta as "up here," and Abe remarked:

Basically this is not our home... We're not looking at it as our—if we pass away, body's goin' right back home.

At the time of the interviews, Abe and Freida had only lived at Haber Gardens for a little less than a year. Compared to their lifetime in Augusta, it is no wonder that they saw Atlanta and Haber Gardens as only a temporary stopping place.

## Chapter 5: Max and Edith Kopman

### I. “The Mayor”

Max “The Mayor” Kopman was the only research participant with whom I had the opportunity of speaking in real-time. In the TLC study, he acted as a key informant, meaning that he was a particularly prominent source of information. He made introductions between the researchers and his fellow coresidents, and he helped the researchers understand the cultural contexts of his community. One reason Max made an excellent key informant was that he was basically an open book. In my first conversation with him, I was nervous about asking questions that were too personal; I did not want to be rude or intrusive, and I anticipated that it would take some time to build rapport between us. But Max had no such constraint. We talked about his special privileges at Haber Gardens, his many connections with local politicians and AL administrators, and even his IQ.

At Haber Gardens, he was known as “The Mayor,” and he took great responsibility in this title. He held many leadership positions, including leading a weekly Torah study group—“TorahTalks”—for the other residents. In these sessions, Max would make a small speech about the *parshat hashavuah*, the weekly Torah portion, and then the group would discuss it. In one of our conversations, he mentioned that his group had just discussed the portion called *Vayishlach*, which tells the stories of Jacob and Esau’s brotherly feud and Jacob’s experience fighting an angel sent from God. Max launched into a summary of the story:

If you didn't remember, [Jacob's] mother knew that if he had the birthright, he would handle it properly, whereas his brother Esau would piss it away. He was the kind that went out and gambled and did things that she didn't want him to do. So through subterfuge, she got him the birthright. And his brother Esau was a little upset. And after he had gotten married—married two wives, Leah and Rebecca, after 20 years, he came back. And Esau was approaching with 400 men. And he was very upset, he didn't know what to do. So he put his family on the other side of the river. And he laid down. And nobody

knows if it was a dream, or if it actually happened. But an angel came. And they had a wrestling match. He ended up with a damaged hip. And he had a limp after that. But he defeated the angel. And when he did that, he wanted the angel to give him a blessing. And the angel did, he changed his name. And he gave him the name of Israel. And that is the name that we all use today. And then he went across the river. And he was waiting for his brother. And what happened basically, he was still rather juvenile until after he wrestled. And he got this blessing from God through the angel. And it gave him a serenity that he didn't have before in that he was self-reliant. And he was going to stand up to his brother and ask his brother's forgiveness. And instead, he stood there, and his brother approached him and saw his demeanor was different than some ratty little kid, this was a man. And he was ready to take his punishment. And he decided there was no point in this. And that's when he ran towards him, and he gave him a kiss, and they hugged, and they were the best of friends after that.

I have grown to understand throughout this project that Max saw many aspects of himself—the self-reliance, the serenity, the connection with God, and the sagacity—in the biblical character of Jacob. As I will demonstrate in the following pages, these values guided Max's relationship with his wife as they built their lives together; they guided his caregiving years, and finally, they guided his mourning and coping process after Edith's death.

## **II. Courtship and Marriage**

Set up on a blind date, Philadelphia natives Max Kopman and Edith Silberstein started courting in the 1940s when Max was 16 and Edith was just 15 years old. Their relationship progressed without hiccups, and soon enough, Max had given Edith his high school ring. After four years of dating and courting, Max jokingly asked Edith for his ring back. "You're not getting it until I get a better one," she responded. "Okay, here," he said, having prepared for this scenario. And he proposed with the engagement ring she wore on her finger until she died. Their marriage was as perfectly sequential as their courtship. Max, who was completing his infantry training in Kentucky during the Korean War, came home to Philadelphia on a Saturday. On Sunday, the two

decided to get married. On Tuesday, they were married by a rabbi. On Friday, they were in New York for their honeymoon, enjoying night clubs, Broadway shows, and sparkling burgundy.

### **III. Career and Community Activism**

Max spent his career as a businessman and salesman in the furniture and clothing industries. For a while, he worked as a salesman for Edith's father's company, called Edith Dress Company, but quickly moved to other ventures. His career took the family from Kentucky, back to Pennsylvania, and finally to metro-Atlanta, where he was national sales manager for a local women's clothing company. Max was proud of his many accomplishments as a salesman and businessman, and in our conversations, he frequently highlighted the financial growth he oversaw during his tenure at these companies. Max retired more than once, but he was always drawn back to work, always wanting to keep busy. After a several more years working at Rich's department store and at Dillard's, Max finally retired at the age of eighty.

Edith went to college in Pennsylvania for two years in the early days of their relationship. She then held various positions as bookkeeper and librarian, following Max to the cities where his career led him. While their children were growing up, Edith was active in the parent-teacher associations at their schools.

Throughout these years and beyond, she dedicated herself to improving her community in any way she could. Max described her, in many separate interviews, as a "mover and shaker," and he provided plenty of examples of her hard work. In their long-time city in the suburbs of Atlanta, Edith noticed that a road commonly used by the school buses had too many potholes. After making countless calls with dismissive city workers who said things like "Yeah, we know, lady. It's on the list," Edith succeeded in getting the road repaved. This was the incipient victory

in her decades-long career in “getting things done.” In discussing Edith’s accomplishments, Max particularly enjoyed showcasing her pivotal work, and his assistance, in the establishment of a public library in their old neighborhood, which I will discuss further in the following chapter.

#### **IV. Jewish Life**

Max was raised as an Orthodox Jew. He had a bar mitzvah, learned to read and write in Hebrew, and had a very actively Jewish life as a child. When he was around ten years old, he became seriously ill with German measles, so ill that his parents and doctors would not allow him to read or play because they believed that light would have been harmful to his eyes. He was quarantined to his dark bedroom and was bored out of his mind. Inside his bedside table’s drawer, however, he found a copy of the King James Bible, the one book his parents forgot to confiscate. Not realizing that “it was a religious tome,” he read it cover to cover, multiple times, and he fell in love with its characters and the stories it contained. This somewhat traumatic period of Max’s childhood cemented his strong connection to Judaism and to the Torah that continued well into his old age.

Edith, on the other hand, was raised in a Reform Jewish family. She was confirmed in her family’s synagogue, a tradition in which Reform Jewish thirteen-year-olds affirm their commitment to Judaism in the tone of a graduation ceremony. Edith’s religious upbringing was far less strict than Max’s, but that was never a problem for their married life. Together, the couple created a “Jewish-style home.” Max described their religious arrangement as a life of compromise. They celebrated all of the Jewish holidays, raised their children as proud Jews, and were members of synagogues in all the cities they lived in. When they moved to Atlanta, they



joined a Conservative synagogue.<sup>9</sup> They never kept a strictly kosher home, but they never ate milk with meat “or anything silly like that.”<sup>10</sup>

## V. Family

Max and Edith had plenty of family members in their lives. They had two adult daughters two years apart in age. Max often marveled at how different two sisters could be, even when raised in the same house by the same parents. Their older daughter, Nancy, was “married to her work” in DC, while the younger daughter, Susan, chose to go the family route. Throughout most of the interviews, Max tried to maintain that he enjoyed them both equally, saying things like:

If you understand Yiddish, there’s a word called *nachas*. *Nachas* means enjoyment. I enjoy my children, Nancy and Susan. They’re two separate people, but they’re mine, and I can tell you right now, I know where Nancy is and what she’s doing. I know where Susan is and what she’s doing. I can get either one of ‘em on the phone in a heartbeat, because I know where they are and what they’re doing.

It was abundantly clear from Max’s interviews, however, that he held a distinct preference for his older daughter, Nancy. He spoke with her on the phone daily, and she visited him frequently, despite the long distance from D.C. to Atlanta.

Susan calls me when she wants me to take her to lunch or to dinner. Very rarely does she call—oh, wait. I shouldn’t say that. She called the other day. She went to Penney’s and used my credit card, so she wanted me to know the bill was coming. Okay, fine. Nancy calls every night. Every night without exception... and we’ll have a little discussion about how my day went. She’s really interested.

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<sup>9</sup> The Conservative movement of Judaism is often considered to be the intermediate level of religiousness and strictness between Reform and Orthodox Judaism.

<sup>10</sup> Keeping kosher, or adhering to the laws of *kashrut*, means that a person subscribes to the dietary laws written in the Torah. Among the many rules are not mixing meat with dairy, not eating shellfish, and not eating meat from non-kosher animals, including pigs.

Susan did, however, give Max and Edith two grandsons, a doctor and a lawyer. It is important to note that these two professions are held in high regard among most people but are particularly valued (and are the punchlines of many jokes) among Jews. For example: *A Jewish mother is walking down the street with her two young sons. A passerby asks her how old the boys are. "The doctor is three," the mother answers, "and the lawyer is two"* (Telushkin 1992, 86). For Max and Edith, the joke took a rather ironic turn. Both grandsons graduated at the top of their classes from their respective professional schools, but neither grandson established a career from his training. Instead, the doctor traded cryptocurrency in Southeast Asia, while the lawyer managed a bar and sold marijuana cookies in Washington, D.C. These career decisions, however, had very little effect on Max and Edith's pride in their grandsons, although Max occasionally let some judgement slip.

As wonderful a couple as Max and Edith were, they were not without their problems. According to their daughter Nancy, Edith was a difficult person while her daughters were young, very strict, and often anxious and frustrated. Nancy explained:

It's interesting...She didn't appear to like being a mother very much. She loved being a grandmother, and she loved having the grandkids over to sleep over, and she used to drive their carpools...My dad was always like, "Let things roll off your back." I think she trained a lot of her frustrations with him, that anyone would have in a marriage, on me, 'cause he just ignored it...My parents, when I was young, they bickered a lot. I remember in high school thinking, "God, I wish they would just get divorced." They just seemed they were bickering all the time. Although of course, they always really loved each other. As they got older, their relationship became a lot more affectionate.

Max never indicated any of this in his interviews. Although he would sometimes say, "we had our differences from time to time," he painted a mostly rosy picture of their life-long marriage. As Nancy explained, that they became more affectionate as they aged. After 65 years of marriage

(70 if you count their whole relationship), several interstate moves, and two daughters later, Max and Edith were self-described “two peas in a pod.”

## **Chapter 6: Findings on End-of-Life Perspectives**

Throughout the research period with the participants, there were six separate interviews that focused on different topics. Of these six, the last interview delved into questions about end of life. The participants were asked about their advance directives, such as Do Not Resuscitate (DNR) orders, Physician Order for Life-Sustaining Treatment (POLST), and medical powers of attorney (POA). They were also asked to reflect on their lives, their legacies, and how they wanted to be remembered in their communities after they died. In this chapter, I will explore several themes regarding these end-of-life perspectives, specifically addressing the couples' moves to assisted living, experiences with caregiving, perspectives on death and dying, and beliefs about burial traditions, mourning, and the afterlife.

### **I. Caregiving and Taking a Break**

For the majority of the Kopman's and Buchsbaum's lives as couples, they enjoyed independence and autonomy. They were leaders in their activities and careers, active in their social circles, and dedicated to caring for their families. As they got older, different health issues arose, and they were gradually forced to confront their aging bodies and minds. In the beginning of this decline, the couples did not yet need outside help, because they were able to rely on one another for support and basic assistance. Their care for one another allowed them to maintain the autonomy and independence to which they had been accustomed. When Max had rectal cancer in his 70s, Edith took him to his radiation appointments and drove him to work every morning. Her dedicated caregiving for her husband allowed him to continue his career throughout his cancer treatment and well into his remission.

When Edith was diagnosed with Alzheimer's by their beloved family physician, Max assumed the role as Edith's primary caregiver. He retired from his career for the last time, and he accepted more and more responsibilities around their home. Max's experience with Edith's decline followed the usual pattern of caregiving trajectories at the end of life.<sup>11</sup> As Edith's Alzheimer's progressed, Max understood that caring for Edith was not something he could do alone, and he gradually accepted help from others, including from a woman named Judy, a volunteer through the Jewish Federation of Greater Atlanta (JF&CS). In Judy's visits with the Kopmans during the first few years, Edith was still able to walk, feed herself, and use the restroom by herself, but her memory was "not good," and Max would "not leave her side at all." In those days, Judy was most useful when she gave Max time away from Edith to get things done. Judy would spend time with Edith, allowing Max to go grocery shopping, go to his Silver Sneakers exercise classes, or do whatever other errands he needed to do. Judy was interviewed as part of the TLC study, and she described these times:

The only time that he left her side is when we'd go on errands, and I'd be walking with Edith when she was able to, in the grocery store or whatever...[She would be] constantly asking 'where are we, why are we here? Why can't I go back to the house? Why can't I go to bed?' Just not understanding. It was constant. What I did was I took her with the carts, and I would walk around with her and let Max go and get whatever he needed.

Max cared for Edith so dutifully, that he never considered taking a break or made time for himself unless someone else temporarily took over the position of caregiver. This was undoubtedly a very stressful time for Max. He had transitioned from husband to caregiver in his life-long marriage and, just as in his approach to his career, he excelled at his new role and took charge of the situation in which he found himself. Luckily, he had good health throughout this

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<sup>11</sup> See literature review, section **IV: Married Couples in Later Life**, sub-section **c. Caregiving** for more information.

time, so he was able to take care of himself and his wife as they aged in place. Eventually, Edith reached a stage in her Alzheimer's in which it was no longer possible for Max to care for her alone, even with the help from Judy and his daughters, and Max had to hire an in-home aide. After Edith experienced a series of health crises, even a nearly full-time aide proved to be inadequate, and he and his daughters eventually recognized that assisted living was the logical next step.

In our conversations, it was sometimes difficult for Max to admit that he felt any kind of burden in caregiving for his wife. He was proud of his ability to pivot in difficult situations, and he spoke often of his advanced caregiving abilities and duty to reciprocate the caregiving for Edith.

People look at me and say "Max, I don't know how you do it." The answer is very simple. I've done it this way all these years, so this is no big deal. When I had double pneumonia, renal stress, and congestive heart failure all at the same time, I was in the hospital for a month. Edith was there for me.

He also never admitted that caregiving for Edith took a toll on his mental health, and he certainly never mentioned that he was ever resisted the idea of assisted living, but according to his daughter Nancy:

My father was really depressed because she (Edith) wouldn't go anywhere, and he wouldn't leave her. He is, as you can see, extremely friendly, gregarious, and social. He was just spending all this time reading or watching TV at home. I started talking to him about moving to assisted living about a year before he agreed to do it. His feeling was that they bought their house to be a place they could live till they died. It was one floor. They weren't leaving. You could carry him out on a stretcher.

Max was more than capable of living independently, but Edith needed the support of skilled professionals in a safe environment, and Max was willing to sacrifice aspects of his independence to ensure Edith had the best possible care and an environment conducive to their new normal. Max explained this time of transition:

[Edith] was what I consider fading. So we decided I couldn't keep her at home anymore. I had originally, someone came in from nine to five, five days a week. Then it was nine to five and five to nine. And when it got to be seven days a week, I said, you know, it's an awful burden. I don't mind cooking, but cleaning and doctor's visits and everything.

One of the most important things for Max was that he and Edith would be allowed to remain together. In some assisted living communities, Edith would have been required to live in the dementia care unit, and they would have been separated. That was an option Max would never have accepted. Haber Gardens, luckily, was more than willing to accommodate this stipulation. After they moved, he noticed immediate improvements in Edith's condition, both in her disposition and in her physical capabilities, and he expressed feelings of pride in his decision to move to Haber Gardens.

So we decided to come to assisted living. We went to several places, which we never really liked. And when we came here, Edith says, you know, this place is nice, let's stay here. So I said, fine. She was in a wheelchair. And because of the socialization, the regimentation of meals, eight and twelve and five, she was able to get up and get out. And after two months, Edith and I went to a birthday party at an Italian restaurant. And they had a man there who was playing the piano and sang, and we danced. We really enjoyed ourselves. And that continued for three years.

Max was confident that their move prolonged Edith's life and improved her quality of life. On our Zoom calls, he showed me many pictures of him and Edith living happily at Haber Gardens. On his Facebook page, he frequently reposted Facebook 'memories' of the two of them from the Haber Gardens page, often captioning them as "fond memories." In these photos, he and Edith could be seen wearing festive New Year's hats together, dancing in the dining room, eating lunch at Goldberg's deli on an outing, and smiling around a large table of friends on Rosh Hashanah.<sup>12</sup> Clearly, Max and Edith took advantage of assisted living. They enjoyed the social

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<sup>12</sup> Rosh Hashanah is a holiday that celebrates the Jewish new year according to the Hebrew calendar.

aspects, and Max was finally able to take some time for himself and take an occasional break from the enormous responsibilities of being Edith's primary caregiver.

I was able to take care of her a lot better than I would by myself. Or even with a woman that would come in and do what I needed done. Here it was done automatically. . . . She played mahjong. She played all kinds of board games. We had entertainment. So she lived a good life much better than we had when we were by ourselves. Being with people makes a big difference. And I'm a people person. So I enjoyed it.

Max continued to care dutifully for Edith when they lived together in assisted living, but he made sure to take advantage of the added help. He also began crafting a social life that did not necessarily always include Edith in it, especially as Edith's cognitive and physical function further declined.

She couldn't sit at the table and feed herself, but I still brought her downstairs, and I fed her. After I was finished [the CNAs] would bring her upstairs and put her in bed, and I would eat my breakfast with everybody else.

At Haber Gardens, Max became highly involved in the social scene, participating in Jewish life, the garden club, and having a clique-ish group at the dining room table known as the "Giggle Club" (because they don't stop laughing). Assisted living was invaluable to Max, not just for Edith's sake, but because it allowed him time to relax and regain a much-needed social life.

As Max became increasingly comfortable with his social life at Haber Gardens, his relationship with Edith became more centered around caregiving than on social fulfillment and companionship, it seems. After completing the social network map/convoy model with Max, one of the TLC study team members wrote in a memo:

I was surprised that in creating his network map, Max did not include Edith anywhere. At first, I thought he might say that it was because they were one and the same person—which he has said before. But instead, when I asked him about it, he said it was because their relationship has changed and he is now in a caregiver role towards her, and she doesn't participate in discussions anymore. Yet he always reassures me that she is "completely with it" and understands everything going on around her.



In caregiving for Edith at the end of her life, Max spent nearly 24 hours a day with her, and they shared an intimate relationship unlike the intimacy of their marriage before his caregiving duties began. Max described his responsibilities:

Her care includes her toiletries. Having been together all these years, I take care of her just like a CNA...I know how to do it. It doesn't bother me...Some people are very nervous about looking at somebody when they don't have clothes on. Doesn't bother me. Doesn't bother me at all, because it doesn't affect me...I have pads for the bed. I have extra clothes. I have extra pants...Not a problem. Some people say, "Oh, hoo, hoo." It's the human body. So what?

Even during this period, however, they still shared moments together of physical intimacy unrelated to Edith's care needs. As her Alzheimer's progressed, Edith spent more and more of the day sleeping.

Sometimes I'll take a nap during the day with her, and at night, she'll get in bed around 7:00. I don't get to bed until 11:00, but we will still cuddle and talk and go to sleep. She's still there, but she's not as much wide awake as she used to be.

At the time of our conversations, Max still did not need to be in assisted living. He chose to remain in Haber Gardens after Edith passed away two years ago.

When Edith and I came here she was in a wheelchair. We got up and we went dancing, and we got involved in everything that was going on. And after three wonderful years, the disease got her, she had Alzheimer's. And she's gone. And I could go into independent living someplace else. But what for? I have friends here. I get my laundry done. I get three meals a day. They clean up the apartment. And I'm relaxing. My daughter told me you've worked hard, raised two daughters.

After taking care of his wife for so long, it seems that he found it comforting to be the recipient of the care.

The Buchsbaums' path to assisted living followed a similar course as the Kopmans', beginning with loneliness and isolation. Freida had been diagnosed with Alzheimer's, and of course, her forgetfulness was not getting better. Abe was experiencing a severe loss in his ability to hear, which caused him to lose his driver's license. Due to these factors, the Buchsbaums

began to feel disconnected from their world, particularly from their beloved Jewish community.

Michael explained this disconnect:

Probably the last four or five years that they were in Augusta, they weren't able to [go to their synagogue] as much. My mom almost never went anymore, because she was—although she never said it, I think she was scared of what might come out of her mouth, because of what she was—she was seeing in herself the disease beginning, and she was scared of what was going on. She didn't wanna see anymore. She didn't wanna take any chances... She would talk about it, but she wouldn't go. She would never go. My dad would go, and then my dad, when he could no longer drive...he stopped going. I kept telling him, and my brother kept telling him, and my sister kept telling him, "All you have to do is call someone at the temple. They'll come. They'll be happy to pick you up." "I don't wanna be a burden on anybody. I've always done it myself. I'll keep doing it if I wanna go."

It was clear that they needed more help, but they were not yet at the point where they required assisted living or nursing home care. Michael and his siblings made the difficult decision to move their parents into a retirement community in the Augusta area, because public transportation was not easily accessible from Abe and Freida's home in the outskirts of town. After moving out of their home of 35 years, the Buchsbaums lived in this Augusta retirement home for around a year. At this time, they still had access to the credit cards for groceries, and Abe was still taking care of their bills. At one point, however, Michael discovered that his mother's credit card information had been stolen (likely through a scam targeting older adults), and within a few days, her account had acquired nearly \$20,000 worth of bills. Separately, Abe started buying hundreds of gift cards at Publix that totaled to thousands of dollars. After crises like these, Michael made the difficult decision to take over the financial responsibilities for his parents, and he "felt guilty as hell" about it. Michael explained that he saw this decline even before they moved out of their home.

As a business owner, my dad was pretty meticulous when it came to keeping records. I spent probably a year going through all of his papers trying to put everything together and trying to figure out everything. It was pretty obvious to

me at that point that at some point something changed mentally with him as well, with himself.

It pained Michael to see his father this way, and it pained him even more to be the one to “take all of this away and [take away] his independence.” After a health crisis involving Abe’s blood sugar, Michael knew they could no longer be left alone. In an interview, he recounted this terrifying event:

He was completely incoherent, he had absolutely no depth perception. He attempted to speak but what came out was nothing. It was gibberish, completely unintelligible. I was on the phone with my—I was in Augusta at the time anyway and [my mother] put him on the phone because she didn’t...know what to tell me. I couldn’t understand what he was saying, and I asked him to give the phone back to Momma. I asked her, “when we hang up, call an ambulance.” “Well, he won’t want me to do that.” I said—I told her, “I don’t care what he wants at this point ‘cause what he’s doing and saying doesn’t make any sense.” “What will the neighbors think?” “Mom, just call an ambulance.” “Well, I’ll talk to your father and see if we need to do that.” In the meantime, I’m driving like a maniac the seventeen-eighteen miles to where they are *[laughter]* not caring if there’s a cop around or not, because I have no idea what’s going on. I get there, and...I yelled at my mother to ask her if she called the ambulance and she said, “Well, no he didn’t want me to.” “It’s fine. Okay, fine.” I wasn’t gonna yell at her.

This crisis, Michael thinks, was essentially the beginning of the end. From the dialogue Michael conveys, it is clear that Abe and Freida greatly relied on one another when they made any kinds of decisions. They depended on one another throughout their lives, but it reached a point where as much as they wanted to depend on one another, it was no longer safe for them to do so. Michael no longer trusted his parents to care for one another, and he knew that drastic changes needed to happen. Although they had a local son in Augusta, Abe and Freida had a far closer relationship with Michael, and during their year in the retirement community, it became clear to Michael that it would be easier for everyone if they lived closer to him in Atlanta.

When they moved into Haber Gardens, Abe and Freida lived in the regular assisted living section. A few months later, however, they moved to the Pathways neighborhood of Haber

Gardens, which is, as mentioned earlier, the area for the more cognitively impaired residents who require more assistance with activities of daily living.

At the beginning, the Buchsbaums mostly kept to themselves. Freida did not want to interact with the other residents, and Abe did not want to leave Freida alone, so they would have their meals sent to the room. They did everything as a couple, never leaving one another's side. Eventually, as they grew more comfortable in their new home and vastly new city, they began participating in activities and forming new friendships and acquaintances. Abe began leading discussions with other residents, and he also read books to other residents who were unable to read. Although they had a rocky beginning, Abe and Freida made Haber Gardens feel like as much of a home as possible. Michael discussed the stark contrast:

My mom, she's much more willing to let him go out now. *[Laughter]* She will go out as well, and she talks. When she first got there, she really didn't wanna talk to anybody, and [now] she doesn't hesitate to say hello. Like the belle of the ball, she literally walks through the place saying, "Hello," waving to people, and she was not doing that before.

The care that Abe and Freida provided for one another was not as much physical support but rather emotional support. Haber Gardens took care of their meals, medications, personal hygiene and apartment cleaning. Freida still dressed herself but did not necessarily wear matching clothes. The rest of their needs were taken care of by their son Michael, as he described it, "like being a parent to your parents." Michael explained his parents' feelings about their inability to care for themselves:

My mom believes she can do all of it herself. She doesn't need anybody else's support, and she's told me that on several occasions...My dad is a little different, because he knows—and I've come to realize that I think this is the difference between Alzheimer's and dementia. He recognizes that he can't do the things he wants to do or has always been able to do. I don't think my mother has that same recognition. It's painful for him to know that he can't take care of himself by himself or that he and Momma can't live by themselves any longer. That—he's

resigned himself to the fact that he's being taken care of. He doesn't like it one little bit.

In interviews, it was clear that Abe and Freida supported each other emotionally. Whenever one of them was confused about a topic, they just bounced ideas off of one another and laughed away their confusion. For example, when asked where their other son lived, the discussion went like this:

Abe: Up in the Washington/Virginia area.

Freida: Yeah.

Abe: Doesn't he?

Freida: *[Laughter]* I don't know.

Abe: You know certainly more than I do.

It was wonderful to witness this dynamic through reading their previous interviews. Their loving and humor-filled relationship clearly shone through the text and through the pictures I was able to see of them on the Haber Gardens Facebook page. Michael also marveled at his parents' loving relationship and the ways they supported one another emotionally as they aged.

They still carry on conversations. I have walked in on them. Literally, I would stand at the door and listen to them talking and it sounds no different than it did 25 years ago. Yeah, they still support each other in almost any way possible that you can think. I know that my mother thinks she can support herself and my dad wants to support himself. . . . It is [sweet], 'cause they truly try to help each other, and they truly have this love that just is—it's obvious. She just wants to make him happy, and he just wants to make sure she's happy.

Despite the strong, caring, and loving relationship of the Buchsbaums, there were still times when they needed to take breaks from one another, as with the Kopmans. When Michael tried to help them take breaks, it was often to ease the perceived emotional burden of his father, who was more cognitively present than his mother.

I have tried—there are days where I know my dad just needs to separate himself. He needs his own time, and I have tried to take him out even if it's just for an hour or so...I'll leave work, get a cup of coffee, and come back and we'll sit and talk. Or we'll go...to [the bagel shop nearby]. They're really, really good bagels.<sup>13</sup> I have gone over there with him a couple of times just to get out and just so he has time alone, because they're together all the time...I don't know that he ever gets that unless I go and pick him up. I don't know that she ever gets that, or she even thinks about it.

Both the Buchsbaums and the Kopmans regularly demonstrated their devotion to one another any way they could. They expressed their values of caregiving and support for each other through different and unique ways, and their duties to one another continued well into their lives at Haber Gardens. Their responsibilities towards one another were shaped by their shared and intricate life histories, but as doting as they were, there were still times when they needed to be alone to ease the emotional burdens of caring for one another.

## **II. “It is what it is”**

In thinking about this project, I expected death to be an especially difficult subject for the participants. It is understandable that I, as a college student, would anticipate discomfort in end-of-life conversations with older adults. People my age seem to hold the belief that our deaths are far off in the future, although, and I hate to say it, I think climate change has somewhat complicated this notion. But in terms of health and well-being, we see ourselves as nowhere near death. Because of this, we young people feel a certain level of invincibility in our actions, as evidenced, for example, by our generation's cavalier attitudes toward pandemic health precautions. Similarly, we see older adults, particularly those living in long-term care, as

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<sup>13</sup> After I visited Haber Gardens, I stopped by the bagel shop Michael had mentioned in his interview. I can confirm—they make excellent bagels. I wasn't planning on buying anything other than a Coke, but something overcame me as soon as I walked in, and I ended up buying a loaf of chocolate babka, a tub of whitefish salad, and a dozen bagels. It was a truly thrilling COVID-safe field trip.

vulnerable, frail, and in their final stage of life before death. With this general view, it seemed inconsiderate to raise the topics of death and dying with people acutely aware of their advanced age.

I also imagined that the COVID-19 pandemic would be an inopportune time to discuss death with older adults, when Americans have been dying by the hundreds of thousands, 40% of whom lived in or worked in long-term care facilities (Kaiser Family Foundation 2021). Of course, the majority of the interviews with my research participants were conducted in the years prior to the pandemic, but when I had the opportunity to ask Max about Edith's passing, he was more than willing to speak candidly with me. In fact, in all of the interviews with participants, these conversations seemed not in the least uncomfortable. Death and dying were not nearly as taboo of topics as I had expected in this population.

I had feared that broaching the subject of death with the "oldest old" would only serve as an unpleasant reminder for them of their mortality. Not once, however, did I get the sense that these conversations caused any kind of distress or grief in the participants. On the contrary, it seemed that the participants even appreciated these conversations. Their advanced ages and relative proximity to experiencing death gave them the unique authority to express their acquired wisdom and beliefs, and they were more than happy to share their perspectives with me and the other interviewers.

I found was that my research participants exhibited an "*it is what it is*" attitude during these end-of-life discussions. The participants expressed this sentiment in ways that showed their individual personalities and their personality as a couple. Abe and Freida, in most of their responses, answered the interview questions together, often quite literally finishing each other's

sentences. When asked about the reactions of residents when a fellow resident dies in assisted living, they remarked:

Abe: We'll miss him or her, blah, blah, blah. That's life. It happens every day.

Freida: It is what it is.

Abe: You're born, you live, you die.

In justifying this attitude, Freida explained that she uses the phrase "it is what it is" to describe an event that "you just can't do anything about, whether it's good or bad." Both Abe and Freida had clearly internalized the inevitability of deaths in their community. They were well aware of the advanced ages at Haber Gardens, but this did not represent a tragedy to them in the sense that I would have expected at the beginning of my research. After long lives and experiencing their fair shares of joy, tragedy, pain, and love, the Buchsbaums saw death as a mundane reality, not something to be feared. Of course, they recognized that not everyone had the same philosophy.

Abe: I think everybody treats—everybody has a different way of reacting to death. If it were me, death is a fact of life. It happens. It happens everywhere, at all times, day or night. It's just an event, and it's—in many cases, it's sorrowful. It happens, and we have to accept it. We have no choice.

Freida: Most everybody that lives here is—I hate to say the word "elderly" 'cause I put myself in that, and I don't want to do that. *[Laughter]* They're here. We just hope everybody stays well.

In an interview prior to the pandemic, Max expressed similar sentiments to those of the Buchsbaums.

End-of-life, to me, is just an experience. Right now, I am experiencing life. One day I will experience death. To me, that's when you pull the chain and turn out the light. Bingo. I don't believe in the afterlife, and I don't believe in angels.

Max, with his practical and unemotional disposition, saw no reason to worry over death, just as he never saw a reason to worry about other aspects of his life. As it was for the Buchsbaums, death represented just another fact. Max had several moments in his life when he found it



pertinent to confront the inevitability of death. His parents died in their seventies, and in interviews, Max remarked that he considered himself to be “living on borrowed time.” In his early seventies, Max was diagnosed with rectal cancer, one of his most frightening “close calls,” along with double pneumonia and congestive heart failure. With these close calls, Max felt that there had been several times in his life in which he was “within thirty minutes of saying bye-bye.” These experiences undoubtedly made him examine his life, and upon examination, he found he was content. He had a supportive family, a fulfilling career, and a generally good life. He remarked:

I am very happy with where I am. It wouldn't bother me to get up from here, and walk through that door, and not make it downstairs...So I go with it. Go with the flow, enjoy it while you can. When you can't, so be it. That is my attitude. That is the way I live, and I am very happy with the guy I see in the mirror.

At one point during an interview, Max brought out a memory book with a picture of him, Edith, and a group of other co-residents on the cover. He displayed the picture and identified each person, candidly pointing to those who had died since it was taken.

This is Edith and I. He's gone. She's gone. He's gone. It's from all of the group. So, we made the front page, but in that particular case—he's gone too. What happens is we sit, and we eat dinner, and next thing you know, they don't show up.

In response to this, he was asked how people in the community react to these deaths and if people talk about the deaths among themselves.

If they see you, and somebody always mentions it—“I saw them go out in a gurney.” They're in the hospital, and they never come back. Okay, they're gone. It's no big deal, because it's very common. It's not unusual to have something like that happen.

Interestingly, the children of the couples had assumptions and notions about death that more closely aligned with mine. Michael, for example, figured that for his parents, hearing of a death

in their community must be “dreadfully painful.” He also guessed that each death represented “a reminder...that their time’s near or getting nearer.” As for his own fears for his parents’ deaths:

I know that the end is inevitable. I know what the end is going to be. When it happens, I can’t tell you. I try not to think—dwell on that ‘cause I don’t know what I would—I would be an absolute mess if I did. I try not to think about it.

This fear and unwillingness to think about the eventuality of death was the stark opposite of Max and the Buchsbaums’ “*it is what it is*” attitude. At their advanced ages, Max and the Buchsbaums saw no need to worry about and fear the end of their or anybody else’s lives. They were surrounded by death and dying in their assisted living community, and they had all lost many loved ones over the years. Their “*it is what it is*” attitude was useful for them likely as a coping mechanism, but also was also an indicator of their resilience and contentment as they neared the ends of their lives.

### **III. “I’m not interested in living a life that’s half a life”**

Their “*It is what it is*” attitude notwithstanding, the couples had quite definitive opinions regarding how they wanted their deaths to occur. In the interviews, the participants were asked about what “a good death” meant to them. They all answered, with only slightly different words, that a good death to them meant that they would not suffer. For Max:

No suffering. That is something I detest. As far as I am concerned, when the time comes, my number is up. Ding ding. Goodbye... While I was in the hospital they came, and they said, “Do you have an end-of-life wish?” I said, “Yes. I’ve got all the legal papers.” She says, “Well, you know, we have a purple band that we’ll give you that says DNR.” I said, “That’s fine.” Do not resuscitate. Why? Because A, I don’t want to suffer. B, I’m not interested in living a life that’s half a life. . . . I don’t want anybody pushing me around in a wheelchair. As far as my quality of life is concerned, I’d love to stay like this. I know in the back of my mind that it probably won’t be, but my father taught me what’s gonna be is gonna be. You just gotta go with it. That’s my attitude.

In Max's different descriptions of a good death throughout his interviews and our conversations, he used words and phrases like "bingo," "turn out the light," "number is up," "ding ding," and "close your eyes and you're gone." Max's ideal death was immediate and painless. He hoped there would be no decline in his health and that he would be able to function at his present level until the very end. Abe and Freida's thoughts on what constituted a good death were similar:

Abe: Peaceful.

Freida: Go to bed, go to sleep, and don't wake up.

Abe: Yeah, a peaceful death and, possibly, not unexpected—for the family, not unexpected.

Freida: We got a bunch of family.

Abe: The ones that really hurt is when it's a shocker.

For Max and the Buchsbaums, the deaths they wished for themselves reflected previous experiences with the loss of loved ones and others. They had all witnessed what seemed like a stark dichotomy of deaths in their lives, either the person died quickly and peacefully holding the hands of loved ones, or they died a slow and painful death full of fear and suffering. Neither Max nor the Buchsbaums seemed to observe any gray area, despite the fact that they were arguably approaching their ends of life somewhere in-between those two dichotomies. Max examined his experiences with dying family members:

I have been through this with Edith. I have been through this with other relatives. Edith and I, when we were first married, went to visit a cousin of hers who had stomach cancer. That upset me tremendously, because the poor woman was suffering, and they were keeping her alive for no reason at all. They knew they couldn't do anything. It was only a question of time. Let her go... That, to me, is a bad death. You're gonna go anyway, but why do you have to suffer needlessly? My grandmother, God rest her merry soul, died at 106. She was sharp as could be, but then she fell and broke her hip. Went into the hospital, and she wasn't happy. She called the family together, and they came to visit. Took two days. She said good-bye to everybody. Then she turned over and gave up the ghost, which, as far as I am concerned, is the way to go.

Abe and Freida thought about their experiences with their parents:

Freida: I've had a lot of—I don't know where my brain is today. *[Laughter]* Both my mother and father were in their older age when they died. I guess that's what needs to be. You don't wanna die at 50-something. They were really old, good and old. Your parents too.

Abe: My father was 75. That one's old.

Freida: Well my family was—my father was in his elderly *[Laughter]* eight years. He had always been healthy, and my mother too. Neither one of them was not healthy. Neither one of em' died when they were old. Is that right? Heart attack and that kind of stuff, just boom, you're dead.

In these anecdotes, the ideal death trajectories of family members were short and quick, exhibiting stark contrasts between alive (full functioning, both physically and mentally) and dead. As was true among all participants, nobody wanted the slow decline that is so often associated with Alzheimer's and other dementias. Even when personally experiencing these trajectories, as the Buchsbaums were, they still idealized that somewhat mythical, “Go to bed, go to sleep, and don't wake up” type of death.

The Buchsbaums' son Michael felt similarly, but because he understood the trajectory of Alzheimer's from past stories and experiences, he was more realistic:

My wife had lunch with a friend of hers the other day whose mother was diagnosed with Alzheimer's and lived-*existed* for...either 12 or 13 years after the diagnosis. The last five were spent in complete silence. She couldn't talk. She couldn't communicate, she could barely blink her eyes. She couldn't move. She had become completely incontinent, and I have to think, “What kind of life is that?” I don't know that I would want my mother to have that life.

The perspectives among the residents influenced—and were likely influenced by—the social dynamics and shared spaces between the regular assisted living residents of Haber Gardens and the Pathways neighborhood residents. Despite the nobly designed Montessori-Inspired Lifestyle

(MIL) model,<sup>14</sup> the integration of the more cognitively impaired residents into the general community seemed to be only mildly successful. AL residents still expressed that they did not wish to spend time in the Pathways neighborhood. As Max emphatically explained to me:

Pathways is one part of the building where the level three care people are. There, you have people that are getting fed by a CNA, or they're being taught what to do by a CNA, and they have a TV that's on all day long. So I don't go down there—or I don't go to that part, it's not down there, it's down the hall—because I have nothing whatever in common with them. They don't do conversations, whereas in the main dining room, we talk to everybody, because they are *with it*. And we're able to talk to them.

Max evidently felt far removed from the Pathways neighborhood, which he made clear from not only his sentiments, but also through his choices of words and grammatical constructions. He referred to the more cognitively impaired residents as “people that are getting fed” and “being taught what to do,” and although these were subconscious phrasing choices, his passive voice and use of “people that” instead of “people who” spoke volumes about his understandings of agency and humanity among his more impaired neighbors.

In describing the location of Pathways, he also made quite a telling *lapsus linguae*, or slip of the tongue. In saying “I don't go down there... it's not down there, it's down the hall,” he admitted that his perceptions of space at Haber Gardens differed from the reality. His mind held that the impaired residents resided on a separate floor from the “with it” residents, when in reality, these spaces (and the probable trajectories of decline) were far more ambiguous.

#### **IV. Burial, Mourning, and the Afterlife**

As discussed in the literature review, Jewish tradition maintains fairly rigid guidelines for proper religious procedures for death and dying, covering every detail from material of coffin to

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<sup>14</sup> See Chapter 3, Section I: **Ethnographic Site – Haber Gardens** for more information on the MIL model.

mourning rituals and understanding of the world to come. Here I will discuss the Buchsbaums' and Kopmans' perspectives on these end-of-life questions and examine how they align with traditional Jewish views.

### **a. Burial**

I was fascinated to learn that among the four participants in my study, only one held directives consistent with typical Jewish burial practices. From my Jewish day school education,<sup>15</sup> I was always instructed that Jews just do not get cremated. It was right up there on the list of unthinkable actions with getting tattoos and eating pork. The reasoning was twofold: First, our bodies are to be returned as we received them. Second, consider the crematoria of the Holocaust. Over the years, of course, I have come to understand more thoroughly the diversity of Jewish thought and religious observance, and besides my own parents, I would never pass judgement on anyone's personal, end-of-life decisions, even if they do contradict the lessons I was taught in my religious upbringing.

Of the two couples, Max and Edith Kopman's directives were the most startlingly non-traditional. Max explained:

Edith was cremated. Because even though that's against the Jewish religion, Edith and I decided, Nancy was not going to come down from D.C. to visit with her. And the daughter that lives here (Susan) is not going to come and visit her... Why don't I have a hole in the ground like everybody else? Now if you go back in Bible days, it was very common to go visit, but today a cemetery is a total waste of time and effort... So why spend the money for a plot that nobody's going to bother with, for a stone that nobody's going to look at?

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<sup>15</sup> Through elementary and middle school, I attended a strict, Orthodox-leaning Jewish day school in Atlanta despite my family's Conservative Jewish practices.

Hearing this seemingly pessimistic outlook from Max saddened me, at first. He knew, as much as I did, how much a presence he had in his community and how important he was to his family and closest friends. He further explained that he had evidence that no one would visit:

My daughter Susan belonged to a synagogue that had plots in the ground. Based on my experience with her mother-in-law, when she passed away, I knew that she wasn't gonna come visit.

I eventually understood that to Max, this realization did not represent a tragedy. As Max frequently expressed to me and to the previous interviewers, he never stressed or worried. Why? To this he would give the same answer as to why he did not choose an in-ground burial—"It does not pay." Always a man of practicality, Max saw no need to forfeit his sensibilities for the sake of others' approval.

This is not to say that Jewish tradition was not valued by the Kopmans. Max was quite aware of the non-traditional route he and his wife chose, and he felt little discomfort in this. He frequently expressed his confidence in his level of religious observance, reminding me that he was raised Orthodox, went to Hebrew school and synagogue, lived in a Jewish assisted living community, led the Torah study group and Friday night services, and prayed multiple times a day. He and Edith were not wanting for Jewish values in their life. And while I'm sure their decision to be cremated was far more complicated and contentious than he conveyed in his interviews, his and Edith's decision was based more on practicality than on religious responsibility.

One particularly interesting aspect of this practicality was the symbolism of his inurnment plans.

So, Edith was cremated; her remains are in Washington with my daughter. And when my time comes, I'm going to be cremated. And the two ashes will be mixed together. And the reason for that is Edith and I have been together for 70 years.

In the funeral industry, the practice of mixing together ashes is known as “comingling.” In traditional Jewish burial practice, there is no parallel to this, because although couples are usually interred beside one another and may share a headstone, the bodies are buried in separate caskets. It seems like being physically reunited with Edith after he died was a very attractive prospect of cremation to Max, especially after the difficult years of caregiving for Edith at the end of her life. Max longed for the physical closeness he shared with her for so many decades. With the reunion of their ashes, they could share a level of physical intimacy that would finally be uncomplicated by Edith’s Alzheimer’s disease and his caregiving responsibilities.

Additionally, it was curious that Max instructed his daughter Nancy to keep Edith’s ashes after her death instead of keeping them himself. In Nancy’s interview, she was asked if she knew about her father’s thought process with this. The answer was no, and that he had just said so. When I tried to ask about this in my conversations with him, I never quite got a straight answer.

The Buchsbaums, on the other hand, were unique in that their burial plans differed from one another’s. Freida wished to be cremated, while Abe wished to be buried with traditional Jewish burial practices. Again, this was surprising, because Freida was clearly engaged with the Jewish community and was highly involved in Jewish life in Augusta, not to mention the fact that she and her family had narrowly escaped Nazi Germany. Unfortunately, there is not much explanation of this in their interviews, but their son Michael discussed it briefly in his. If it were his decision, both would have traditional Jewish burials, but he acknowledged their autonomy to choose:

My mother has said that she doesn’t want a burial; she wants to be cremated. While I don’t necessarily agree with her because of religious beliefs, I’m not gonna do anything that goes against her wishes. She has spelled that out.



Where Abe and Freida were in agreement was that after they died, his body and her ashes would be taken back home to Augusta, where they would be buried in their pre-paid plots in their synagogue's section of the cemetery.

### **b. Mourning and Legacy**

The prevalence of the “*it is what it is*” attitude toward death did not mean that the death of loved ones occurred without great sadness. Max had been aware since Edith was diagnosed with Alzheimer's that her condition was incurable. Throughout his caregiving process, he gradually accepted new and varying states of normalcy in their relationship, and as Edith slowly declined in health and in presence, he was able to craft a social world in which she no longer had a prominent role. Max described the moments leading up to his wife's passing:

Finally, she couldn't get out of bed, and we gave her an ice cube for moisture. She was cognizant, and the last thing that happens in that stage is your hearing. One day, after about a little over two months the [hospice] nurse said “Max, she is transitioning.” I looked at her. She says, “She'll be here for another 30 minutes or a week, but that's it...[After she died], they brought in a chaplain, which I didn't need because what's happened, Edith has had Alzheimer's for quite a number of years. Alzheimer's from my understanding, is fatal. There is no way to get around it...Now we had conversations. She was still aware of what was going on. Every night up until maybe a week before she passed away, she and I would hug and kiss before we went to bed. That was us, because we had been together for 70 years. We were married 65. It was a wonderful relationship, which I enjoyed, which I miss like crazy. It's life, and there's nothing I can do about it.

After Edith's long and drawn-out decline from Alzheimer's, it seems that Max felt a complicated mixture of grief and relief. When TLC team members visited Haber Gardens after Edith's death, Max told them that “life was not going to be as good without Edith.” He also mentioned that he had been sleeping next to a body pillow so that he would not feel alone in Edith's absence.

He grieved the loss of his partner of 70 years, but it is clear that he also felt relief that she was no longer suffering and that she had passed away peacefully. Considering the complicated nature of her death, Max had to choose carefully how to mourn for her. He explained:

When Edith passed, we did not mourn per se, because in Judaism, you're supposed to sit, they call it *shiva*, for seven days unless it happens on a weekend.<sup>16</sup> Then it can be reduced to three days. What we did is we had a party. We celebrated Edith's life. We celebrated her legacy which we celebrate today.

This legacy, Max specified, was centered around her work establishing the Northland Lake Library.

Edith started an organization called People for the Northland Lake Library. We raised money, and we politicked. Edith was president, I was vice president, and we worked on it. We had a book sale... We'd do that every year. We raised \$10,000.00, \$15,000.00. It was fun. We always enjoyed that. It was Edith's idea. She persevered, and after 14 years, we got a library built.

Again, I wanted to get an in-person feel for the places that were so important to my research participants during their lives prior to their move to assisted living. Based on Max's evident pride in his wife's work with the library, I decided to pay it a visit. I had been hoping that I could peek inside and perhaps spot a plaque of some sort dedicated to Edith and Max. Of course, however, like most establishments during the COVID-19 pandemic, the library was closed to patrons and only offered curbside services. Without residence in that county, however, I was just left to observe. I watched several patrons collect their books from the librarians, and the curbside pickup was consistently busy the whole time I was there. I noted the librarians' use of face shields, nitrile gloves, reflective vests (presumably for parking lot safety), and N95 masks. As mundane as these accessories have become during the pandemic, I still marveled at the fact that librarians, of all people, would be dressed this way.

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<sup>16</sup> See section **V. Jewish Perspectives on Death and Dying**, subsection **b. Religious Practices** for a more in-depth explanation of this important Jewish practice.

I walked around the parking lot and took note of the appealing architecture and landscaping. Five large boulders were situated in a semi-circle around the entrance, and the large awning was held up from the ground by pillars that looked like branching trees. Although the building was tastefully designed and the property was well-kept, what struck me about the library was how ordinary it looked. I figured it could have easily been any one of the hundreds of public, county-run libraries around the Atlanta area. This was just the type of legacy that Max and Edith wanted, as Max explained, “I don’t need a monument, neither does Edith. Her legacy is that library.” They fought for ordinary measures in their communities. Edith was a “mover and shaker,” but that did not necessarily mean that the Kopmans had to be the center of attention with their names plastered on the sides of buildings. Rather, they, as a couple, were leaders for the sake of leading, not for the sake of being noticed.

Max’s idea of his personal legacy, aside from his and Edith’s accomplishments with the library, was more abstract.

I have a legacy. I know that there will be people that will say, “Oh my, Max is gone. What will we do about this or that?” But that’s always been the case. I’m building that legacy now. I’ve done it ever since I’ve been a kid. I have done things for people, and I enjoy them, and I have a load of friends. . . . Actually, the only legacy that I will have is somebody will remember here what I did and say, “You know, if Max were here, this wouldn’t be that way.” I’m serious.

Max wanted to be remembered by his dedication to his community and his eagerness to make his voice heard. He wanted to be remembered by his leadership and expertise. More directly, however, he just wanted to be missed.

Max and his daughters held their celebration of Edith’s life at the home of his local daughter, Susan. Around 100 people came to pay their respects, and the family showed a video slideshow of photographs from Edith’s life. The TLC team members noted that Max was particularly proud of the large amount of food they received from guests. Food plays a

substantial role in Jewish mourning practices. According to custom, mourners should not prepare their own food; instead, the food should be prepared by friends who care for them. Round foods, including eggs, bagels, and lentils, are customarily served to symbolize the cyclical nature of life. From both the outpouring of support from friends and family members and from the large quantities of condolence food they received, Max found great comfort in the celebration of life for Edith.

When Edith died, as is the practice when any resident dies, Haber Gardens placed a memorial candle embossed with a Star of David and a note of her passing at the entrance to the building. In Jewish terminology, this was a *yahrzeit* candle, meaning anniversary candle. In Hebrew, this candle is called a *ner neshama*, which translates to soul candle. The use of a *yahrzeit* candle is a central custom in Jewish mourning rituals, practiced by observant and non-observant Jews alike. The incorporation of a *yahrzeit* candle into their mourning rituals for residents was a notable way that Haber Gardens honored the Jewish backgrounds and tradition of their community.

Another opportunity for religious and communal mourning at Haber Gardens was at the resident-led Shabbat services every Friday night. These services were usually led by Max or his friend, a male resident who was also raised Orthodox.<sup>17</sup>

On Friday night, I lead services. There's another member here who is also Orthodox, so to speak. And we share the services. We do the candles if we don't have a woman to light them.<sup>18</sup> We do the blessings over the wine; we do the blessings over the bread. There are several prayers that we do. We will read the readers' *kaddish*. And at the very end, we do the mourners' *kaddish* for those people. We do the *misheberach* for those people that need help.<sup>19</sup> So we have a service that runs about 15 minutes... We have about 20 people that are in the main

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<sup>17</sup> In more Orthodox Jewish contexts, it is rare for women to hold leadership positions, including leading prayers and services.

<sup>18</sup> Lighting candles on Shabbat is one of the few *mitzvot*, or commandments, specifically given for women to fulfill. A man is allowed to fill this role if no woman is available to light the candles herself.

<sup>19</sup> The *misheberach* is a prayer that asks God to heal the sick and injured.

dining room when I do the services and light the candles, and they bring some people in from Pathways to listen to the services.

The mourner's *kaddish*, as discussed in the literature review, is a prayer in Aramaic that is traditionally recited in memory of the dead. In Jewish practice, the *kaddish* prayer is never said alone. Instead, it is recited among a quorum of ten people, called a *minyan*,<sup>20</sup> partly so that the mourner is surrounded by a support network and must return to the embrace of the community even when it is emotionally difficult to do so.

The Buchsbaums approached the topic of communal mourning in Haber Gardens with some amusement. When asked what type of support they might like after the passing of a fellow resident, Abe responded:

If it was a relative or a member of my family or something, yeah, I would like to have, I guess, some support in that respect. [Laughter] Now, I'm gonna use the term "fellow inmate." [Laughter] A fellow occupant of this place, I think we would all be sympathetic to anybody's needs.

Unlike Max Kopman, the Buchsbaums had not experienced any close, personal deaths while at Haber Gardens, and at the time of their interviews, they had been living there for around eight months. At first they expressed that they did not have many friends at Haber Gardens, and that it would not matter to them whether or not the community held a service in their honor after they passed away, but that ultimately, it was up to Haber Gardens. Then they changed their minds slightly.

Abe: If we have enough friends here, I would hope that they would be very—I would be very appreciative—

Freida: If it was here.

Abe: If they recognized us for something.

Freida: Absolutely, yeah.

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<sup>20</sup> Or ten men, depending on level of strictness

Abe: The fact that we were residents here.

Interestingly, in the majority of the interviews, whenever Abe and Freida discussed their own deaths, they never discussed the prospect of one of them dying before the other. All events with death, including mourning, involved the two of them experiencing the event together, almost as if they expected to die simultaneously and that loved ones would mourn for them as a couple, rather than as two separate individuals on two separate occasions. Michael, however, understood things differently, expressing that:

This is gonna sound awful. If one of them has to go before the other, which is more than likely to happen, I don't want my dad to go first, because my mother won't understand.

As difficult as it was to read this, I reminded myself that, at the time of writing, Abe and Freida still lived together at Haber Gardens, as devoted to one another as ever judging by their pictures on the Haber Gardens Facebook page. Often wearing themed hats or posing with colorful holiday decorations, they were always shown together with silly grins on their faces.

When asked about their legacies, Abe and Freida took time to brag about one another and offer words of wisdom.

Freida: Well, he hasn't said anything, but he's been generous. He has helped out at the synagogue and [been] generous with money. What else you want?

Abe: Well, it's hard for me to say. I think to become—to make friends easily—

Freida: Yeah, that's good too.

Abe: And to be good to people.

Freida: We did it. We do that.

Abe: Stay with the good folks, treat them the way you wanna be treated by them, and everything else will follow naturally, really.

Between their work at the synagogue, their family business, and their strong network of friends in Augusta, they certainly made a name for themselves. When they first came to Atlanta, they may have felt disconnected from their accomplishments and active life back home. Through their conversations with one another, with their children, with friends, and with the interviewers in the TLC study, they had opportunities to cement their legacies, even if some of the key places in their lives, including the Lerman's Home Fashions location I visited, no longer bore their name.

### c. The Afterlife

Because Edith died during the TLC study, there were many opportunities for Max to discuss his perspectives about the afterlife with study team members and with me. Abe and Freida, however, did not share their views on the afterlife (other than to make a joke about haunting their children if they misbehaved), so this section focuses largely on Max's perspectives on Edith's continued presence and the afterlife following her death.

In interviews prior to Edith's death, Max expressed a purely pragmatic view of death, remarking, "I don't believe in the afterlife, and I don't believe in angels." Max's end-of-life beliefs, however, seem to have shifted substantially since then. In my interviews with him, he expressed a much more spiritual and religious perception of death, dying, and mourning. The following story he told me provides valuable insight into this realm of his thinking:

I wanna tell you a story. This may be listed as a *bobbeh myseh*,<sup>21</sup> but years ago, when a cousin of mine died, we went to sit *shiva*. And I met a woman there who was one of her best friends. And she told me this story: She and her husband were travelling through Ireland. He had rented a car, and they were driving. And they're driving and driving, and she says her husband, "I think you ought to stop here. I've been here before." So they stopped the car. And they go up and there's a farm. And they go to the farmhouse and they talk to the farmer. And he says, "no idea what you're talking about." She says, "Well, isn't there a barn behind the house?"

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<sup>21</sup> *Bobbeh myseh* is a Yiddish expression for a story without much truth to it, sometimes translated as an "old wives' tale."

And he says yes. So they go behind the barn. She says, “look on the corner of the entrance to the barn. Go see these initials.” And sure enough, there's initials that she says. And she says, “Do you know who put them there?” And he says, “Yes, there was a 16-year-old girl that rode this horse and was thrown, and she died, and her boyfriend put those initials up there as a remembrance to her,” and she turns to her husband. And she says, “You see, I told you I was here.” Don't ask me how she knew, or why she knew or what she knew. But she had a lifetime experience that was actually brought out by them driving down this little old road in Ireland. I have a theory, for what it's worth. When you are born, you get some DNA, whatever, from your parents. And they got theirs from their parents, who got it from their parents, who got it from their parents. And apparently, some of the memory genes are passed down from one to the other. Until finally, it was awakened by this woman seeing this thing that was familiar. They refer to it quite often as *déjà vu*, and I believe in that; quite often you will get the feeling I've been here before, and that's what it's from. Now, you may think that I am off the wall and I'm crazy, or whatever.

Max combined this quasi-scientific understanding of life after death with a more Jewish perspective:

I'll tell you this: Jews believe in the afterlife. God breathes life into you. And when you're finished, he takes it back. And you go to a little place somewhere. Some people refer to it as heaven. And that's where you stay. And if you read the Torah, you'll find that there are people who come back having lived that way.

These two grounds of science and religion guided Max's continued relationship with Edith after she passed away. They enabled him to make peace with her death while also justifying his feelings toward the continuity of her presence in his life. He explained to me:

Every once in a while, I get into a situation, and I think to myself, what would Edith do? Sometimes I even get a nudge on my shoulder. Don't laugh.<sup>22</sup> I get a nudge on my shoulder for no reason. And it will tell me that Edith is still sitting on my shoulder telling me [what to do]. Upon occasion, I will tell Edith to wait. I'll be there one of these days. Because we do communicate. It's not about end-of-life, it's about what my daily activities are, because she's still sitting on my shoulder. Every once in a while, I can feel a nudge. That's me. Whether it's imaginary, or maybe a muscle twitch, or whatever. I don't know, and I don't care.

By saying “Don't laugh,” “That's me,” “and whether it's imaginary...,” he left room for doubt from me and the other interviewers and acknowledged the possibility of his ideas being untrue.

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<sup>22</sup> I wasn't laughing.



At the same time, these qualifiers indicated that he felt confident in his beliefs, and that our doubts would not influence him to change his mind. He continued:

That's one of the reasons that I say, "Bless Edith." If she hears me, fine. If she doesn't hear me, that's okay, but it makes me feel good.

As Max mourned the loss of his wife of nearly 70 years, his belief in the afterlife and in her continued presence in his life brought him great comfort. With these beliefs, he would never truly be by himself and alone; he could still rely on her when he needed the support of his loving wife; and their relationship would endure across the margins of life and death.

## Chapter 7: Discussion and Conclusions

Chapter 6 provided insight into the end-of-life perspectives of the Kopmans and the Buchsbaums, focusing on four key matters: caregiving and taking breaks; attitudes toward death; aversion to suffering; and burial, mourning, and the afterlife. At the root of this project was a dedication to the narratives and shared life histories of these couples. In this chapter, I will discuss these complicated and sometimes contradictory perspectives within the context of the couples' life histories and legacies as well as reflect on the personal meaning of this project.

An important aspect of existential anthropology is the understanding that a single human life is inherently complicated and not without its contradictions (see Jackson and Piette 2015). I found this to be true in the couples' opinions and ideals surrounding death. When they expressed their "*it is what it is*" attitudes, they often imagined non-specific deaths. Although they did not insinuate that everyone experiences the same death, the concept of death, in these conversations, was somewhat homogenous and nondescript—it was just generic death—"you're born, you live, you die," "just an experience," "He's gone. She's gone," etc. This nondescript death presented no problem for the couples, because it did not require them to consider the sometimes painful and drawn-out realities of specific experiences.

When asked about their views of good deaths and bad deaths, the fear and aversion to suffering were evoked, because the couples had to recall the experiences of death they had witnessed in their lifetimes. Sherwin Nuland wrote that "While so many of us hope for a swift death or a death during sleep 'so I won't suffer,' we at the same time cling to an image of our final moments that combines grace with a sense of closure; we need to believe in a clear-minded process in which the summation of a life takes place—either that or a perfect lapse into agony-free unconsciousness (Nuland 1994, 8). This "clear-minded process" and "agony-free

unconsciousness” was evidently the hope of these couples as well. Unfortunately, these types of death are somewhat rare for the oldest old (Kafetz 2002). More often, especially for people with Alzheimer’s and other dementias, the trajectory is relentlessly slow (Nuland 1994; Kafetz 2002). As Nuland wrote, “We rarely go gentle into that goodnight” (1994, 9). The couples in my study were averse to this possibility even though they were surrounded by—and for the Buchsbaums, living—this trajectory.

These findings of accepting death but being averse to the actual realities of many peoples’ experiences with death are consistent with previous studies (e.g., Myerhoff 1978; Nuland 1994; Fleming et al. 2016). In Myerhoff’s ethnography, these topics arose frequently. She wrote about the Center members: “Their efforts were directed at convincing others, and then themselves, that they were in charge of their life...Underlying this was the unspoken, enormous fear of senility. Clear-mindedness and self-possession were signs of being intact” (Myerhoff 1978, 181). These fears were exemplified by Max’s perceptions of the Pathways neighborhood. In Max’s mind, the “main” residents and the Pathways residents represented two stark dichotomies: those who were “with it” and those who were far gone. The reality, of course, was far more ill-defined. Max and the Buchsbaums did not revolt against the inevitability of aging and death, as some of Myerhoff’s participants did, but they did hope to be “with it” until the end.

Although they did not revolt against these eventualities and maintained their “*it is what it is*” attitudes, they still occasionally made reserved attempts to conceal or ward off their age, declining health, and increasing deficits, both mental and physical. When Freida was asked to say her age, and she thought she was an age far younger than her true age, she laughed, saying that she supposed she wished to be younger than in real life. Max often remarked that he was pleased with his age, for he was “living on borrowed time” and would be content to die when it

was his turn. Simultaneously, Max was somewhat of a vitamin junkie, and he was certain that they were “keeping him young,” or at least keeping him as healthy as he was. These slight contradictions serve as reminders that there are layers of complexity within every person, and that aversion to and acceptance of death and aging can and do exist simultaneously. They also remind us of the capacity to change one’s mind—Max’s eschatological convictions, particularly about the afterlife, shifted during the study period. While Edith was alive, he understood death as a stark end, reporting: “I don’t believe in the afterlife, and I don’t believe in angels.” Following her death, as I explain in chapter 6, Max assumed a more spiritual outlook on the question of the afterlife, and Edith’s continued presence in his life brought him great comfort in the lonely period following her death. The couples, in their contradictions, perceptions, and actions, were, as Nuland so eloquently wrote, just “yearning to achieve a graceful triumph over the stark and often repugnant finality of life’s last sputterings” (Nuland 1994, 10).

In their quests for this “graceful triumph,” they placed great value on portraying themselves in the light in which they hoped to be remembered. Their interviews, especially the life history interviews, served as spaces in which they could reminisce, review their accomplishments, and take stock of their lives. I often noticed that my participants would repeat stories several times, even within the same interview. At first, I interpreted these repeated stories as indications of short-term memory loss, even with Max, who exhibited the least degree of cognitive decline among the four participants. While memory loss was almost certainly a factor, these story repetitions served to establish their legacies, both in my and the other interviewers’ perceptions of them as well as in their own understandings of themselves. Myerhoff explained, “Reviewing one’s life and reminiscing, much practiced by the very old, are expressions of their

attempt to find themselves to be the same person throughout their lifecycle” (Myerhoff 1978, 108). For the Buchsbaums, emphasis was placed on their business, their family, and their synagogue. These three entities shaped the trajectory of their active, adult lives as well as their perceptions of themselves into their retirement and toward the end of their lives.

It was particularly interesting to see what aspects of these three categories Abe and Freida did not mention in their narrative and what was only elucidated in Michael’s interviews. For example, Abe and Freida never mentioned the period of Abe’s life in which he essentially deserted his position at Lerman’s Home Fashions. In the stories about Lerman’s, the Buchsbaums described it as a constant in their lives—the picture-perfect, family-owned business. To include the details about Abe’s sabbatical would have potentially muddled their fond memories of their beloved family business, because they “were married to that, too.” They also never mentioned the rift between Abe and their younger son over his actions with the business. It may have been too painful to discuss. Either that, or they strove to remember their family as a cohesive unit, not one made complicated by divisions and guilt. As for their beloved synagogue, Abe and Freida did not discuss the relationship they had with it in the last few years before their move to Atlanta, when Freida’s memory was failing her, and Abe avoided asking for rides so as not to burden his fellow congregants. Instead, they remembered their time spent with other couple friends at the synagogue and being “involved in everything at the synagogue.” Their reminiscence was an act of collecting their special moments, projects, and relationships and presenting them as cohesive and meaningful stories of their lives.

In interviews with Max, he repeated his stories so predictably that I could almost anticipate the words and phrases he would use in his telling of them. His stories addressed a wide range of topics, everywhere from his relationship with his wife, their community activism, his

D.C. lawyer daughter, and his influence at Haber Gardens. Again, it was interesting to see which aspects of his life he chose to emphasize and which he chose to not include. He never talked about the difficulties he and Edith had due to their clashing personalities, which Nancy discussed in her interview. Instead, he portrayed their lifelong relationship as filled with sweetness, adoration, teamwork, and affection—they were “two peas in a pod;” they were “one.” As Myerhoff wrote about her participants, and is, I believe, true of the Buchsbaums and Kopmans as well—“The work they were doing was not a cosmetic operation; it was the search for pattern and continuity amid the accidental features of their life. Always in these stories, they sought evidence that they were still the same people now that they had once been, however transformed” (1978, 36-37). The Kopmans and the Buchsbaums had navigated many transitions throughout their long lives, and it was important to them to find continuity—and form their legacies—through the stories they told.

In their need to find continuity, they often alluded to the cyclical nature of life and death. Desires to return—to someone or somewhere—permeated their thinking. These personal hopes for return spoke to their most painful losses as well as their desires to reestablish the familiarity that had characterized their lives. For example, when Abe remarked that “if we pass away, body’s goin’ right back home,” he not only indicated that Haber Gardens was not their home, but also that he and his wife were determined to one day return to the comfort of their world in Augusta, even if it would only be possible after they had died. Max, on the other hand, longed to return not to a place, but to his wife. In multiple interviews, Max repeated this desire to return to Edith through the mixing of their ashes. Like Max, he also understood that this reunion would only take place after he died. The prospects of return undoubtedly brought them comfort in their analyses of their lives and the relationships, both spatial and personal, that filled them with

meaning and purpose. Their desires for future returns and reunions allowed them to anticipate renewals, in some sense, of the happiest years of their lives.

I found the above aspects of my project, and many others, sincerely heartwarming. I have never quite believed in an afterlife—most Jews typically don't, although as I have shown, Jewish cultural beliefs are quite diverse when it comes to the end of life. Instead, when asked, I often consider the nebulous, vague concept of *olam haba*, the world to come. One comforting aspect of the vagueness, I realize, is its allowance for people to make of it what they wish. Although neither Max nor the Buchsbaums mentioned the Jewish concept of *olam haba* by name, they all used the vague framework to envision a return to the happiest periods of their lives.

As I have worked on this project, some have asked me how I have immersed myself in the end-of-life perspectives of the oldest old without becoming depressed, especially when thousands of older adults like them have lost their lives to the COVID-19 pandemic. To me, bearing witness to the age-old dream of lifelong love and learning about these couples' searches for meaning and fulfillment in their lives could not possibly be depressing. I have had the opportunity to learn about their joys, hardships, and hopes for the future. There have absolutely been times, especially while reading interviews or going on my COVID-safe field trips, when I have shed tears—usually not because I feel sad thinking about people approaching the ends of their lives, but rather because I think about the resilience of these couples as they navigated difficult life transitions and caregiving responsibilities. After a lifetime of marriage, they still adored each other—As Freida so heartwarmingly put it, “Well, the best thing that happened is him.” Throughout their lifetimes, they made sacrifices for one another, remained devoted to each another, and grew old together. They reflected on the lives they had built together with dignity, humor, pride, and gratitude, and it was a privilege to learn from them.

## **Chapter 8: Implications, Limitations, and Future Directions**

### **I. Implications and Recommendations**

My research findings have implications for anyone who spends time with older adults, whether adult children, grandchildren, care providers, friends, or community members. First, assisted living seems to be a viable option for easing spousal caregiving burdens and improving the general quality of life of both spouses, even if one is more independent than the other. The AL environment provides social opportunities for both spouses and can provide the more independent spouse with the opportunity for “taking breaks” from his or her caregiving responsibilities.

Broadly, assisted living communities should anticipate an increase of coupled residents. Previous studies have indicated that couples often have difficulties finding large enough units in AL to accommodate two people (Kemp 2008; Kemp 2012). Although my findings did not specifically address issues of space, the need for occasional privacy and “taking breaks” did arise, which was consistent with previous studies (e.g. Kemp 2012). To account for this, AL communities should diversify the sizes of apartments. AL administration and staff should take time to become familiar with the emotional needs of their couples as a unit as well as the emotional needs of the individual spouses. In couples with varying levels of cognition and social engagement, AL staff should be particularly aware of the need for “taking breaks” and provide opportunities for the more social spouse to have time for themselves. This could be accomplished by occasionally providing extra care for the more disabled spouse.

AL communities should find ways to decrease the stigma of cognitive decline. Haber Gardens was clearly trying to achieve this with their MIL model, but residents still felt the divide between the “with it” and the cognitively impaired residents. From the Buchsbaums’ story,



synagogues should work to make programming more accessible and actively strive to include members with dementia. Withdrawal from communal life due to dementia has been well-documented in previous studies (e.g., Riley, Burgener, and Buckwalter 2014; Dobbs et al. 2008). Assisted living communities, religious institutions, and other community organizations should take steps to address this stigma and ensure members and residents are given the opportunity to participate and feel included in the social environment. Additionally, these organizations might consider educating community members without dementia about the realities of Alzheimer's and related dementia in order to decrease stigma.

## **II. Limitations**

As it did with most plans made during this past year, the COVID-19 pandemic forced me to reassess many of my plans for this project. Limitations arise from my study design, the reality of the pandemic, and from my positionality. Due to my small sample size, I am unable to make generalizations about the end-of-life perspectives of Jewish couples in assisted living other than to comment on my specific participants. Because of this, generalizability was not a goal of this study. I am aware that there is nothing quite comparable to in-person, ethnographic research. A major limitation was that I was never able to meet the Buchsbaums, and I had to rely on previously collected interviews. Because the previous interview guides were not designed for my project, there were certainly aspects of their life about which I was never able to learn. My internet searches and COVID-safe field trip to Augusta partially accounted for this, but not completely. Another major limitation was that I was never able to enter Haber Gardens and experience the social and physical environment myself. While I was able to read the memos from previous researcher visits, observe the outside of the Haber Gardens building, and see brief

interactions between Max and the staff members during our Zoom calls, proper participant observation was largely impossible. Lastly, my own biases likely had an effect on my analysis and findings. As a Jew with substantial Jewish education, I may have easily taken aspects of my participants' accounts for granted, missing key cultural and religious aspects of their end-of-life perspectives.

### **III. Future Directions**

Many potential avenues exist for further research following the completion of this project. Future research should investigate the end-of-life perspectives of couples with a larger sample size, as was the original plan of this project. Ideally, this future research can be conducted in person to gain a better ethnographic understanding. Another interesting path would be to conduct a comparison study of couples in different faith-based assisted living communities, which could also focus on the end-of-life perspectives among these diverse couples.

Additionally, further research could explore the end-of-life perceptions among AL couples using a long-term longitudinal study design. This would provide insight into the ways their attitudes change over time, potentially comparing perspectives before the move to assisted living to those following integration into the social environment. This work could also explore the impact of religion on these attitudes, because as has been demonstrated by previous research, religiosity tends to increase with age (e.g. Idler 2006). Because most research with older couples focuses on traditional and heterosexual marriages, researchers could also investigate 'non-traditional' couples who age together in assisted living. Lastly, future research should focus on the retrospective experiences and end-of-life perspectives of couples in LTC during the COVID-19 pandemic, assessing factors such as isolation, privacy, and coping mechanisms.

## Appendix A (Sample Memo)

**PPL20210207IZC, Interview with Max Kopman, Sunday, February 7, 2021, 2:45PM-4:50PM (125 Minutes)**

**Team Members Present: Isabella Cantor**

Mr. Kopman and I had agreed that we would get on the Zoom link at 2:00PM for our informal interview, and at 1:55PM (at the last minute), I tried to figure out how to do “cloud recording” on Zoom. I was frazzled thinking I would be late, so I logged into the meeting while I fiddled with the Zoom settings. Mr. Kopman did not show up on the Zoom for a long time, so I had enough time to work with the Zoom settings while I waited. I wasn’t surprised that Mr. Kopman was late, because the first time I met with him, he was over two hours late to our Zoom meeting. At 2:40PM, I texted him letting him know I was ready and on the link. He entered the Zoom room a few minutes later. He was wearing a brown plaid/checkered shirt, and he had papers and a pen in his shirt pocket. I could see behind him in his Zoom background he had a vacuum cleaner on the ground and what looked to be Shabbat candles on a table. The countertop in his kitchenette was mildly messy, but not messier than it was in previous meetings we’ve had.

Whenever we start our Zoom meetings, Mr. Kopman always asks me if I came prepared with a list of questions, in the manner which I feel implies that I usually don’t, and that it’s such a burden for him to have to fill the time with his talking. It’s as if to say, ‘enough of the chit-chat, let’s get down to business.’ It’s really funny how he says this, because I know he enjoys talking about himself during our interviews. It’s also funny, because when I do ask questions, he rarely answers them and instead starts talking at length about topics that are only marginally related, and it’s really hard for me to interrupt him to get him back on track.

He started off by telling me about the dedication that is going to take place at the Northland Lake Library in the coming weeks for a statue in honor of Edith. I told him I’d be interested in seeing a Zoom recording if they make one available, and he was excited that I’ve included so much about the library in my thesis.

Then we talked about the vaccine distribution at Haber Gardens. They got their first dose a few weeks ago, and their second doses are scheduled for next week. He seems really mild and collected about the whole thing, not very excited, but also fairly optimistic. I guess that’s right in line with his general demeanor, because he “never worries” and also meditates. He told me his daughters are relieved that he’s been vaccinated, and that they are looking forward to a loosening of “visitation rights”—I’m sure!

He talked a lot about the great food he gets to eat. He mentioned that they make bacon, just for him! I laughed, because he was acting so sneaky about it, but he told me it was chicken bacon, and that his daughter has it shipped to Haber Gardens just for him. Whenever he tells me something that is mildly incriminating, he uses the phrase “off the record,” but I’ve come to realize that he uses this phrase somewhat unofficially. He told me about the chicken bacon “off the record,” but it sure seems like that’s his way of being coy about his privileges as “The Mayor.”

Later, he was talking about his visitor from One Good Deed, and he said the word “attitude” many times in reference to his consistently positive attitude about life, and he pronounced the word like “atty-tude.” I thought that was pretty funny.

Most of our conversation was repeated stories that I’ve heard from him or read about five or six times. It’s gotten to the point where he’ll say one word and I’ll know exactly what story he’s about to tell, and I can even predict what he’ll say at a certain point in the story, word for word. This could also be indicative of senile dementia, but honestly I think he just likes telling stories. He is generally quite sharp/ He is really good at finding ways to avoid answering my questions. He doesn’t do it intentionally, but I guess he wants to give me the most complete answer, so he’ll start from the very beginning and get carried away and side-tracked.

I like that as we’ve had our interviews, he has gotten more comfortable using Yiddish and Hebrew words with me. At the beginning of our interviews, he would usually avoid using the Yiddish and Hebrew, because he figured, I guess, that I wouldn’t know what he was talking about. I often felt like I needed to convince him I was Jewish, so that he didn’t have to define things for me. Today, he said things like *treif*, *cheder*, *bobbeh myseh*, and *kaddish*, and he didn’t even hesitate. I was pleased!

At 3:40, a CNA knocked on his door, and she took his temperature—98.4. She was very cheerful, and he was perfectly happy allowing her to come in. I’m sure they’ve gotten very used to the precautions that Haber Gardens has taken during the Pandemic. He already explained to me the sanitation and distancing procedures they have learned, and I think it is incredible that the Haber Gardens has not seen any COVID-19 cases, especially considering the caseloads in the other communities operated by Jewish HomeLife.

I tried so hard to ask him about the mourning practices he did after Edith passed away, but he talked about her work with the library instead, as well as all of the other “mover and shaker” things she did. While he was telling me these stories, another staff member came into his room at around 3:55 with some Super Bowl snacks (cheese, crackers, and a can of beer). He was quite excited to get those snacks, and he voiced his appreciation to the staff member, repeatedly calling her “dear.” He said, “They take very good care of us, I mean it!” after she left.

A few times during our conversation, we got to talking about Facebook. He knows exactly how many friends he has on Facebook (86), and he asked if I might like to be his Facebook friend. He told me it would be a good way to learn more about his life. I said sure, why not. As it turns out, we have two mutual friends on Facebook, one is my seventh-grade English and social studies teacher, and the other is a rabbi who often leads services at different locations around Atlanta.

Overall, I didn’t get much new information from this interview, because he just wouldn’t answer any of my questions as I hoped he would. Regardless, I loved talking to him as usual, and I am glad that I got to speak with him after his first dose of the vaccine. I feel like this is a historic time to be interviewing someone living in a long-term care facility.

## Appendix B (NVivo Codebook)

**AL FACILITY CODE** (all documents will be coded in their entirety based on the facility where data were collected)

**Haber Gardens** – Haber Gardens

**AL FACILITY NAME (PEOPLE) CODES** (Codes will be applied to all individuals in the facility and used for any mention of them)

**AL RESIDENT NAMES** (applies to any mention of a resident)

**AL STAFF NAMES** (applies to all DCWs, administrators, owners, medication managers, etc.)

**AL-LIFE** (any general reference to life in AL e.g., from Interview 1, including residents' attitudes about living in AL, whether it is "home", what a typical day is like, etc.)

**AGING IN PLACE** (any reference to resident's desire or practice of aging in place)

**MOVE-OUT** (any reference to a resident's move or decision/preparation to move out of a study site)

**MOVE-WITHIN** (any reference to moves within the facility e.g., from AL to DCU)

**PATH-AL** (any mention of the move to the current facility, including decision-making and multiple moves i.e., from more than one facility prior to moving to the current facility)

**CARE-OUTCOME** (any mention/observation of care outcomes e.g., participant's satisfaction with care, discussions/observations regarding quality of care, results of therapy e.g., for pain, depression, PT, hospice intervention, medication, etc.)

**ATT-CARE** (any reference to stakeholders' attitudes regarding quality of care, care processes, etc.)

**RESPECT** (any reference to feeling respected or not feeling respected by care providers will be coded "RESPECT")

**CARE-PROCESS** (any reference to care processes/activities/interactions)

**ACCESS** (any reference to residents' lack of access to health care, hospital care, etc.)

**ADL-CARE** (any mention of activities of daily living e.g., eating, bathing, dressing/undressing, grooming, transferring, getting in/out of bed, toileting)

**COMMUNICATION** (any reference to quality/ nature/mode of communication among participants)

**C-ROLE** (anything pertaining to a specific participant's role in care, including self-care, caregiving, and end of life decision-making)

**HEALTH-IN** (any mention of health care activities/processes involving licensed health care professionals other than hospice personnel provided inside the facility e.g., MD/NP visits, podiatrist, OT/PT, therapy, dentist, etc.)

**HEALTH-OUT**(any mention of health care activities/processes involving licensed health care professionals other than hospice personnel provided outside the facility e.g., MD/NP visits, podiatrist, OT/PT, therapy, dentist, dialysis, surgery etc.)

**IADL-CARE** (any mention of instrumental activities of daily living other than medication assistance or transportation e.g., assistance with finances, shopping, reminders to attend meals,)

**MEDICATION** (any reference to medication, including medication use, dispensing of medication, adherence, side effects of medication, etc.)

**TRANSPORT** (any references to care-related transportation and problems related to transportation should be coded "TRANSPORT")

**EOL CONTEXTS** (Resident Interview 6 and EOL sections of all participant interviews should be coded in their entirety with the code "EOL" in addition to other codes that may apply, such as "DIRECTIVES" or "HOSPICE")

**BEREAVE** (any reference to bereavement experience as well as policies, procedures for managing grief and bereavement, including memorials, etc.)

**DIRECTIVES** (any reference to advance directives/advance care planning in participant interviews or in field notes, includes facility policies and procedures related to advance care planning, living will, healthcare power of attorney, POLST, etc.)

**DEATH** (any reference to resident death, including after death activities and reactions as well as participant attitudes about death, including good or bad death, conversations regarding etc.)

**HIST/EXPERIENCE** (any mention of previous experience with death and dying, from parents, other family members, etc.)

**DECLINE** (any mention/observation of a resident's physical or cognitive decline)

**DYING** (any reference to someone who is imminently or actively dying)

**SELF-REFLECT** (any type of reflecting on life decisions, relationships, goals, telos, etc. in the context of EOL discussions; may overlap with “P-value” and “Death” code)

**IT IS WHAT IT IS** (any exhibition of “it is what it is” attitude toward death)

**WHAT KIND OF LIFE** (any sense of aversion to dementia/non-communicative residents/suffering)

**HOSPICE** (Any reference to hospice, hospice workers, etc.)

**FACILITY-LEVEL CONTEXTS** (any reference to facility-level factors, including aspects of facility culture, that can influence care processes, structures, and outcomes)

**ACTIV-PROGRAM** (any reference to facility activity program)

**SOLO-PROG** (any reference to activity that participant goes to alone, without spouse; should be coded along with “ACTIV-PROGRAM”)

**COUPLE-PROG** (any reference to activity that participant goes with spouse; should be coded along with “ACTIV-PROGRAM”)

**C-ENVIRON** (physical and sociocultural characteristics of the neighborhood/community surrounding the AL)

**FAC-CHARACTERISTICS** (facility size, ownership, location, years in operation, care philosophies/mission statement, use of technology, etc.)

**MEALS** (any reference to meals, food service, nutrition)

**P-ENVIRON** (characteristics of the AL physical environment, including space, noise, smell, lighting, privacy)

**POLICY** (any reference to facility policies, practices and procedures not captured under staffing. ONLY Include facility level policies and not local, state, or federal policies-regs - code those at AL-REGS)

**S-ENVIRON** (characteristics of the AL social milieu, sociocultural context, social connectedness/social distance, etc.)

**COVID-19** (any reference to facility policies regarding COVID-19 pandemic, temperature taking, sanitation, special procedures; to be coded separately from “Policy”, although there may be some overlap)

**HEALTH CHARACTERISTICS** (any reference to a participant’s personal health, including mental/cognitive/emotional and physical health, including ADL/IADL ability, diagnoses, and symptoms)

**COGNITIVE** (any reference to cognitive function)

**LIFE-ALZ** (any reference to diagnosis with specifically Alzheimer’s disease, cognitive decline, function; can use this code in addition to “Physical”, “Mental”, “Function”, “Decline”, and/or “Cognitive”)

**DIAGNOSIS** (any reference to a specific diagnosis/diagnoses e.g., breast cancer, COPD, schizophrenia; can use this code in addition to “Physical” and/or “Mental”)

**FUNCTION** (any reference to function other than cognitive function, including ADL, IADL abilities)

**MENTAL** (any reference to mental health/mental illness/psychiatric conditions)

**PAIN** (any reference to pain and its impact, includes treatments and strategies used to manage pain)

**SYMPTOM** (any reference to symptoms of illness/health conditions other than pain e.g., fatigue, nausea, shortness of breath and their impact, includes strategies used to manage symptoms)

**HEALTH TRANSITION** (any mention of care/health/illness transitions)

**HEALTH CRISIS** (any mention of health-related emergency e.g., acute health events such as fall, stroke, heart attack, manic episode, urinary tract infection, pneumonia, etc.)

**HOSPITAL** (any mention of hospital/emergency room visits and hospitalization)

**IMPROVE** (any mention/observation of improvement in a resident’s physical or cognitive function)

**REHAB** (any mention of resident’s move to or use of a rehab facility)

**INFORMAL/FORMAL CAREGIVER CODES** (Codes will be applied to informal/formal caregivers and used for any mention of them)

**AL-DCW** (all AL direct care workers and medication managers will be coded AL STAFF in addition to their name code)

**FORMAL CARE PROVIDER** (all formal/external healthcare provider transcripts (other than hospice “HCW” and MEDICAID providers) will be coded in their entirety with the code “FORMAL”; and reference to these formal caregivers in field notes also should be coded “FORMAL”)



**INFORMAL CAREGIVER** (all informal caregiver (family, friend, neighbor) transcripts will be coded in their entirety with the code “INFORMAL”; any reference to informal caregivers in field notes also should be coded “INFORMAL”)

**SPOUSE CARE** (any specific reference to caring for spouse--in a physical/ADL/health-related manner--should be coded here)

**CHILD CARE** (any specific reference to the care from children--in a physical/ADL/health-related manner--should be coded here)

**SPOUSE BREAK** (any reference to children separating their parents from one another to give each parent a break from the other)

**OTHER** (any specific reference to care of/from friends or other community members--in a physical/ADL/health-related manner--should be coded here)

**AL-MGMT** (all managerial staff, owners and operators, executive directors will be coded MGMT in addition to their name code)

**OTHER** (any reference to individuals providing care who do not fall into other care categories listed above should be coded “OTHER”)

**OTHER-ALSTAFF** (all other staff who work in the facility (e.g., housekeeping, kitchen staff, maintenance workers) and are not management or DCWs will be coded in addition to their name code)

**LOCATION** (refers to locations where observations or interviews take place)

**COMMON** (refers to observations or interviews that take place in common areas of the facility)

**DCU** (refers to observations or interviews that take place in the dementia care unit or DCU)

**OFF-SITE** (refers to observations or interviews that take place off-site e.g., at a hospital, family home, restaurant)

**OFFICE-EMPLOYEE SPACE** (Refers to observations that take place in staff offices, kitchen, staff breakrooms or anywhere on-site that residents are typically not present or allowed.)

**OUTSIDE** (refers to observations or interviews that take place in outdoor areas of the facility, such as a patio)

**RES-ROOM** (refers to observations or interviews that take place in resident rooms)

**PERSONAL MEANING** (any reference to personal or subjective experience/meanings)

**EMOTION** (any reference to participants' expression of emotions/personal feelings e.g., sadness, depression, grief, anxiety, guilt, hope, stress, anger, relief, empathy, sympathy, loneliness, joy, confidence, apathy, disgust)

**IDENTITY**(any reference to social, personal, group identity or sense of self not captured under other personal characteristics e.g., sexual identity, identity as a veteran, identity as an artist, identity as a caregiver, includes loss of or maintaining valued identities/roles)

**P-VALUE** (e.g., participants' caregiving beliefs, values for self-care, autonomy, independence, what matters most in life now, hopes for the future, values/definitions of good care/quality of life, etc.)

**RELATIONSHIP** (any reference to quality/ nature of participant's personal, social and/or care relationships or the quality/nature of relationships among participants)

**SOCIAL-NETWORK** (all Interview 2 transcripts will be coded in their entirety with the codes "SOCIAL-NETWORK" in addition to any other applicable codes.)

**WE/US** (Any use of the pronouns we/us in the context of shared life histories and narrative)

**MARRIED-CURRENT** (all references to current married life (this might be a big code): emotions associated, companionship, difficulties; may overlap with "Socemo-Spouse" and others)

**ON BEHALF** (coded whenever one spouse speaks on behalf of the other spouse for cognitive reasons or otherwise, taking command of story, etc.)

**SOCIOEMOTIONAL CARE** (any reference to comfort, companionship, etc. provided by staff members, family members, and spouse)

**SOCEMO-NF** (any mention of socioemotional care provided to participants by staff members and other non-family members e.g., spiritual care, encouragement, advice, etc.)

**SOCEMO-FAM** (any mention of socioemotional care provided to participants by family members other than spouse e.g., spiritual care, encouragement, advice, etc.)

**SOCEMO-SPOUSE** (any mention of socioemotional care provided to participants by spouse e.g., spiritual care, encouragement, advice, etc.)

**RESEARCH** (refers to all aspects of the research process reflected upon in observations/field notes, including any reference to relationships researchers/the study team have with study participants and any mention/observation of these relationships e.g., RED HOME'S initial negative attitude toward Emory—includes participants' attitudes toward the research and the research process)

**MEMO** (any reference to researcher interpretation of events e.g., bracketed material within field notes; larger memo text e.g., included at the end of field notes; theoretical memos, insight related to evolving theory, insights linking evolving findings to the literature)

**METHODS** (any notes regarding methods, problem with equipment, problems related to consenting, issues surrounding interviews, suggestions for sample selection, etc.)

**SOCIOCULTURAL CONTEXTS** (any reference to a participant's (resident, staff, administrator, owner, formal/informal caregivers) or the AL community's sociocultural characteristics)

**AGE** (any reference to age or its impact e.g., experiences, perceptions related to age e.g., ageism, infantilism, wisdom related to age)

**BACKGROUND** (any reference to education/education level, employment, work history, life history/family history, family life)

**JEWISH** (in reference to the AL community's shared Judaism and Jewish values, growing up Jewish, current Jewish practices, culture, food, traditions, beliefs, roots; may be used in place of "Faith" and "Culture")

**CULTURE** (any reference to a participant's or the AL community's ethnicity/culture or its impact; also can include aspects of /mention of regional culture "southern culture" etc. or U.S. /western culture e.g. cultural value for independence and autonomy etc. )

**FAITH** (any reference to religious background/faith/spirituality/spiritual health)

**FINANCE** (any reference to economic class, economic circumstances, poverty, and affluence)

**GENDER** (any reference to gender e.g., experiences, perceptions related to gender, references to gender and its impact/influence, gender dynamics among the couples)

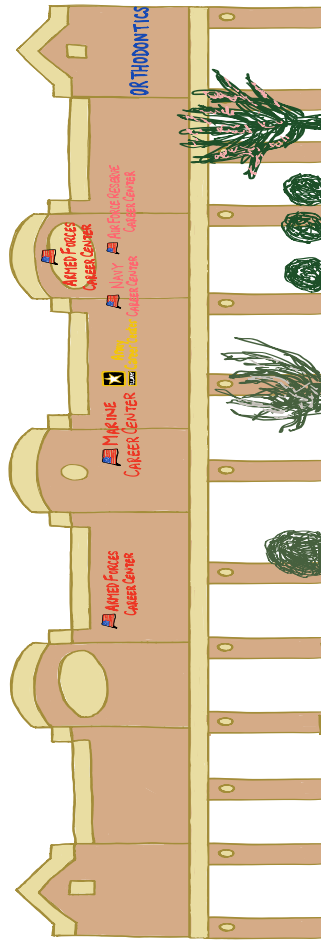
**HEALTH-LIT** (any reference to knowledge or lack of knowledge regarding health and health conditions i.e., one's own health conditions and those of others)

**LIFESTYLE** (any reference to lifestyle behaviors, e.g., smoking, alcohol use as well as strategies participants use to maintain/improve health e.g., exercise, healthy eating)

**RACE** (any reference to race/ skin color/racial identity or its impact e.g., racism, discrimination)

**TO BE CODED** (used to note sections where coders have questions regarding the appropriate code or where a "people" code needs to be determined, etc. Is a placeholder for information that needs to be added later) – Use Annotations or Memo feature to indicate what you think it should be called.

# Appendix C (Lerman's Home Fashions)



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