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WHAT WE CAN LEARN FROM EACH OTHER: A MULTI-SITED ANALYSIS OF LAY EXPERTISE AND CAREGIVING FOR PEOPLE LIVING WITH ALZHEIMER'S AND DEMENTIA IN EMILIA-ROMAGNA AND THE UNITED STATES

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You must go on. I can’t go on. I’ll go on.

– Samuel Beckett, *The Unnamable* (1954)

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ABSTRACT

This dissertation examines the experiences of informal caregivers for individuals with Alzheimer's Disease and Related Dementias (ADRD), focusing on how they develop lay expertise. Employing a multi-sited ethnographic approach, it compares caregivers in Emilia-Romagna, Italy, and the Midwest, United States. The research draws on in-depth interviews, participant observation in support groups, netnographic analysis of online caregiver forums, and secondary data analysis of large-scale surveys like the National Study of Caregiving (NSOC). Through the lens of grounded theory, this study identifies key themes and patterns in caregivers' experiences, including biographical disruption, the process of "becoming" a caregiver, the development of practical skills and emotional intelligence, and the importance of social support. The dissertation conceptualizes lay expertise as a dynamic and evolving form of knowledge that integrates experiential, embodied, formal, and evidence-based approaches. Caregivers continuously blend these forms of knowledge to meet the complex demands of caregiving, navigating complex medical systems, social networks, and personal challenges. Findings reveal that becoming a caregiver often marks a profound biographical disruption, forcing individuals to navigate new roles and responsibilities while confronting emotional pain and logistical challenges. Caregivers describe a continuous process of learning by doing, marked by both triumphs and setbacks. Support centers emerge as crucial spaces for reducing caregiver burden and fostering a sense of self-efficacy. The research argues that lay expertise extends beyond practical skills and proficiency in memory care techniques; it encompasses a holistic understanding of the caregiving experience, informed by personal growth, resilience, and a deep sense of empathy. Flourishing caregivers actively seek support, engage in peer-to-peer learning, and prioritize self-care, demonstrating a reflexive awareness of their own needs and limitations. Through the lens of situational analysis, the study examines the social ecologies surrounding caregiving, mapping the interplay of cultural norms, support networks, healthcare systems, and non-human actors in shaping the caregiving experience. By exploring the lived experiences of caregivers across diverse cultural and social contexts, the dissertation offers valuable insights into the dynamic interplay between individual narratives, social support structures, and healthcare systems. It highlights the need for policies and practices that recognize and empower lay expertise in caregiving, emphasizing the crucial role caregivers play in providing compassionate and effective support for individuals living with dementia. This dissertation argues that lay expertise is not a secondary or inferior form of knowledge but a vital, deeply nuanced way of knowing that emerges from the lived realities of caregiving. By situating caregivers as key agents in the management of dementia care, it challenges us to think critically about the intersections between care, knowledge, and power, and to envision new ways of supporting those who are at the forefront of this global health challenge.

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Introduction

This dissertation presents an in-depth and meticulously argued examination of the cultivation of lay expertise in the context of dementia caregiving, an issue of critical global importance given the rapid increase in dementia diagnoses worldwide. Despite their indispensable role, informal caregivers are often overlooked, with both their contributions and the vast, nuanced knowledge they develop through caregiving rarely acknowledged or adequately supported by healthcare systems and policy frameworks. Within this research, lay expertise is conceptualized as a dynamic, evolving form of knowledge that caregivers cultivate through lived experiences, emotional labor, and continuous interactions with medical professionals, formal support systems, and informal caregiving networks. This dissertation frames lay expertise as a hybridized, multifaceted body of knowledge that integrates experiential, embodied, formal, and evidence-based approaches, with caregivers continually blending these forms of knowledge to meet the complex demands of caregiving.

By drawing on Epstein's conceptualization of lay expertise, this work underscores that caregivers not only acquire practical skills—such as managing symptoms, coordinating medical care, and navigating bureaucratic healthcare structures—but also develop affective capacities for preserving the dignity, emotional well-being, and quality of life of those under their care. The central research question guiding this dissertation is: "How do caregivers for individuals living with dementia cultivate lay expertise, and how does this expertise evolve in response to diverse sociocultural, familial, and institutional contexts?"

The dissertation is structured into five chapters, each offering a distinctive yet interwoven contribution to the central theme of caregiving expertise.

Chapter One, *Sociological Theory of Health and Illness* sets the intellectual stage for the research by engaging deeply with sociological and theoretical concepts such as social mechanisms, stigma, the sick role, identity, and narrative theory. These concepts provide a framework for understanding caregiving as not merely a set of practical activities but as an embodied, socially structured process through which caregivers navigate complex expectations and constraints. The chapter establishes caregiving as a dynamic process in which individuals engage with societal norms, healthcare systems, and their evolving personal identities, constantly reshaping their sense of self and expertise. The chapter's intellectual scaffolding draws on foundational thinkers in sociology and medical anthropology, offering readers a comprehensive theoretical lens through which to view the emergence of lay expertise in caregiving.

Chapter Two: *Conceptual Contours of Caregiving, Burden, Expertise and Flourishing* builds upon this foundation by critically examining the specific socio-cultural constructions surrounding Alzheimer's, dementia, and caregiving. The chapter unpacks how these conditions are framed through life course theory, exploring how aging, memory loss, and cognitive decline are socially constructed phenomena that shape caregivers' roles and experiences. The chapter delves into key issues such as family dynamics, stigma, social isolation, caregiver burden, and the notion of flourishing, particularly in relation to gendered caregiving roles. Gender emerges as a focal point of analysis, given that caregiving remains a predominantly gendered activity, with women often bearing the primary responsibility for caregiving in both familial and institutional settings. The chapter also engages with the intersections between lay expertise and formal scientific knowledge, exploring how caregivers' practices and knowledge interact with, resist, or complement formal medical approaches. This chapter provides a broad conceptual framework that positions caregivers as active agents whose expertise is shaped not only by their immediate caregiving contexts but also by larger societal structures and cultural norms.

Chapter Three: *Caregiving as Process: The Social Ecology of Support and Burden* offers a detailed account of the research design and methods employed to investigate the cultivation of lay expertise in dementia caregiving. The dissertation adopts a multi-sited, multi-method approach, combining ethnographic fieldwork with participant observation in caregiver support groups and netnographic analysis of online caregiver forums. In-depth interviews with caregivers in Italy and the United States form the qualitative core of the research, capturing a wide range of experiences across different sociocultural contexts. The dissertation's methodological rigor is further strengthened by the use of grounded theory, which allows for an emergent, data-driven analysis of caregivers' experiences, and situational analysis, which maps the broader social ecologies that caregivers must navigate. Secondary data from the National Study of Caregiving (NSOC) offers a quantitative comparative perspective on caregiving practices. The methodological diversity employed in this research allows for a nuanced understanding of how caregivers develop and apply their expertise across different sociocultural settings, providing a robust empirical foundation for the dissertation's broader theoretical claims.

Chapters Four and Five: *Data Collection and Procedure*, and *Development of*

Lay Expertise in Caregiving presents the key findings from this comprehensive analysis, highlighting how caregivers cultivate lay expertise through a combination of lived experience, peer learning, and reflective practice. The findings reveal that caregivers draw on both formal medical knowledge and their own practical, hands-on experience to navigate the complexities of dementia care. Central themes such as emotional resilience, adaptability, and the ability to manage the dual demands of physical and emotional labor emerge prominently from the data. Moreover, the findings underscore the importance of both formal support systems, such as healthcare professionals, and informal networks, including family members and peer communities, in shaping caregivers' capacity to develop and apply expertise. This chapter underscores the collective and relational dimensions of caregiving, revealing how caregivers' knowledge is continually enriched through interactions with others and how caregiving is far from an isolated, individual experience.

Chapter Six: *Interactions of Lay Expertise and Situated Knowledge* provides a more in-depth analysis of these empirical findings, directly addressing the theoretical and conceptual arguments introduced in Chapter One. This chapter critically engages with the concept of embodied knowledge, exploring how caregivers' lived experiences and emotional labor contribute to the development of their expertise. It also considers how caregiving practices are shaped by broader social and cultural factors, such as gender, social support networks, and healthcare infrastructures, offering a nuanced exploration of the interplay between individual agency and structural constraints. By weaving together the empirical findings with sociological and theoretical insights, Chapter Five not only deepens the analysis of caregivers' lived experiences but also extends the theoretical conversation, offering fresh perspectives on the role of caregiving within the wider field of medical sociology. The chapter concludes by reflecting on the implications of these findings for healthcare policy and practice, particularly in relation to how formal systems can better support caregivers and recognize the value of lay expertise.

In conclusion, this dissertation represents a significant contribution to the academic literature on caregiving, expertise, and the sociology of health. Through its multi-method approach and cross-cultural analysis, the research provides new insights into how caregivers develop, refine, and deploy lay expertise in response to the complex, evolving demands of dementia care. The findings have profound implications for future caregiving policies, suggesting the need for more targeted interventions that support caregivers not only in the practical dimensions of care but also in the emotional and relational labor they undertake. This research underscores the critical role that informal caregivers play in addressing the global dementia crisis and highlights the need for policies that recognize and support the full spectrum of expertise that caregivers bring to their roles.

As we confront the growing prevalence of dementia in an aging global population, the insights generated by this dissertation invite us to reconsider how we think about expertise, care, and the boundaries between formal and informal knowledge. Lay expertise, as this research shows, is not a secondary or inferior form of knowledge but a vital, deeply nuanced way of knowing that emerges from the lived realities of caregiving. By situating caregivers as key agents in the management of dementia care, this dissertation challenges us to think critically about the intersections between care, knowledge, and power, and to envision new ways of supporting those who are at the forefront of this global health challenge. In this sense, the work not only advances academic debates but also offers actionable insights for policy, practice, and future research, positioning caregiving as a central concern for social equality and public health in the twenty-first century.

Chapter 1

Sociological Theory of Health and Illness

1.1 Introduction

“They’re all right.” My classical theory professor gave me this response when I asked her who they thought was the most reliable and valid sociological theory. Similarly, when asked plainly what her own opinion on theory was, she responded dryly, “Theory of what?”. These pithy lessons have indelibly impacted my research and understanding of sociological theory. There is a tendency in most disciplines to assign great leaps in collective knowledge to specific thinkers and individuals. History of Science, Technology, and Medicine scholars’ critique of the Great Man theory posits that, while certain discoveries and inventions attributed to certain thinkers and scientists irreversibly changed societies in radical ways, these abrupt shifts in collective behavior were inseparable from their context and the countless unidentified or overlooked contributions of others.[1] This seems to have been largely forgotten within much of the later 20th century with regards to sociology; as undergraduates and graduates, we sit in hallowed halls learning of the shining brilliance of singular figures whose discoveries founded our discipline; Marx, Simmel, Weber, and Durkheim, to name a few. This chapter serves as both an overview of these great thinkers and seeks to connect them to the contemporary theorists they inspired. To do this, this chapter draws inspiration from Fabio Rojas’ interpretation of Neil Gross’s Social Mechanism,

> A social mechanism is a more or less general sequence or set of social

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[1] The work of Bruno Latour effectively demonstrates this through their ethnographic study of sites associated with the formal production of credentialed knowledge (production which both Latour and Woolgar argue are not removed from the social interactions in which they are generated) (Latour and Woolgar 1979).

> events or processes analyzed at a lower level of complexity or aggregation by which - in certain circumstances - some cause X tends to bring about some effect in the realm of human social relations. (Rojas 2017:xvii)

Alternatively, Rojas (2017) refers to as “a chain of events” (Rojas 2017:xvii). Every link within this chain of events is simpler than its total process, which is far greater and more complex than its total sum of parts. To that end, exploring social mechanisms rooted in health and illness is both a nuanced and concise way to understand great thinkers, their context, their ideas, and how those went on to influence contemporary social theory (this dissertation included). To that end, this chapter is divided into five subsections, each engaging with a theoretical current, paradigm, or social mechanism within social theory. The first is devoted to classical sociologists, who, whether acknowledged overtly or not, inform the sociological theories which follow. The next section explores health outcomes concerning social determinants of health, building off of the larger paradigm of social conflict theory. The subsequent section explores institutions more theoretically, examining the role of medical practices and medicine more broadly and the various mechanisms at play which serve to contribute to the health outcomes analyzed in the previous section. The fourth section explores social behavior as it relates to health and illness within narrative—which, in other words, for the sake of terseness, can be described as theoretical perspectives from interactionist paradigms. The fifth section expands on these perspectives, exploring how social theorists have applied those same principles to issues concerning this work; culture, illness, aging, and caregiving.

1.2 Classical Sociological Perspectives on Health and Illness

The only way the American public realized that ‘health’ was something that was, in fact, shared was through a lethal global pandemic. The months following the first waves of lockdowns, social movements and mass demonstrations calling for a veritable laundry list of institutional changes became the norm. From Main Street to Pennsylvania Avenue, all walks of life were ‘on the march.’ The United States is not unique in this sense; through a public health crisis emerged pockets of fervent social action throughout the globe, yet, regardless of ideology or the political leanings of these movements, what can be noted from these social actions is solidarity. In no unclear words, from a classical sociological reading of contemporary events, it is evident that sociologists hold to benefit from sharing Durkheim’s interest in social cohesion and solidarity.

Writing predominantly on social movements, religious ceremony, and social identity, a theme throughout Durkheim’s work on social cohesion or lack thereof. Perhaps the most obvious example of Durkheim engaging with health would be in his work Suicide. Published in 1897, ‘Le Suicidé’ presents a groundbreaking sociological analysis of the social causes and implications of suicide. At the core of Durkheim's analysis is that suicide is not simply an individual act but rather a social phenomenon reflecting broader social structures and patterns (Loyal and Malešević 2021). In his examination of suicide, Durkheim identifies four distinct types: egoistic, altruistic, anomic, and fatalistic. Each type of suicide is linked to particular social conditions, such as individualism, excessive social integration, social instability, and excessive regulation. Highlighting the importance of studying the social context of health and illness illustrated the ways in which social factors shape individual behavior and experiences (Cockerham and Scambler 2021). Durkheim's classification of suicide types was the first to explore how social conditions can contribute to different health outcomes, alongside the role social integration and regulation plays in shaping mental health (Durkheim [1897] 1951). Durkheim's emphasis on the impact of social integration and regulation on mental well-being connects to his theory of "collective effervescence," referring to the heightened sense of excitement and energy that arises when individuals come together and engage in shared experiences, such as religious rituals or group celebrations (Durkheim [1912] 1995). Durkheim argued that these collective experiences strengthen social bonds and reinforce social norms. In terms of the social nature of health and illness, Durkheim's concept of collective effervescence highlights the role that social interaction and shared experiences can play in promoting health and well-being. Arguing that individuals strongly connected to their social group are less likely to experience feelings of isolation, anomie, and hopelessness that can lead to suicide, Durkheim identifies several social factors that can promote or hinder social integration, including family structure, religious affiliation, occupational status, and educational attainment. Durkheim furthers this argument by asserting that social institutions such as religion and education play a crucial role in promoting social integration by providing individuals with a sense of belonging and shared purpose.

In short, the social cohesion found in groups provides members with sense of self and shared identity beyond that of the individual. Durkheim was undoubtedly the first social theorist to not only provide a rigorous methodological approach and structure (the monograph) to present his findings (both of which we still use today) but also to point out the importance of group dynamics and the role of social integration in health outcomes. Thanks in part to Durkheim, health can be viewed as both 'public' and inherently relational – with a sense of belonging and purpose stemming from social cohesion and solidarity. Durkheim's work connected macro-level social events and their effects on health in several ways, all of which could be eased through social support (Cockerham and Scambler 2021:25). Social cohesion, however, does not exist independently from the infrastructures, institutions, and practices within a given context. For Durkheim, social institutions played a crucial role in shaping social integration. Exploring the significance of these institutions in shaping behavior and health outcomes represents an essential theme in the sociology of health and illness. To that point, Weber provides the framework to explore how these larger structures behave and possibly answer 'why.'

For Weber, Sociology was at heart " a science concerning itself with the interpretative understanding of social action and thereby with a causal explanation of its course and consequences" (Weber 1968:4). Operating within this framework separates Weber significantly from his contemporaries – where debate at the time focused on whether social sciences should follow different sets of methodologies (anti-positivists) and those that disagreed, arguing that sociology had to follow the same guiding principles as natural science (positivists). Weber posits that sociology is a discipline that is inherently interpretive in nature, with a primary focus on comprehending the intricate meanings that underlie social actions. This process involves recognizing the identifiability of human actions, which nevertheless do not adhere to the mechanical causality that characterizes the natural world (Loyal and Malešević 2021:173). For Weber, social research had to do away with positivist absolutism, whereby all individual subjectivity in research had to be stamped out, and the extreme subjectivism in studying social actions and within the researcher themselves. To create intellectually honest research, Weber developed the concept of the ideal type. For Weber, Producing qualified objectivist frameworks meant using a benchmark to measure empirical cases – with the benchmark being entirely theoretical, generalized, simplified, or exaggerated. The ideal-type, then, is a contextualized tool by which empirical reality is measured against. As Loyal and Malešević explain,

> the ideal type of bureaucracy would include such features as a consistent and uniform system of abstract rules, impersonal order, transparent hierarchies, professional relationships between employees regulated by written technical rules, a meritocratic system of promotion and a clearly defined division of labour. (Loyal and Malešević 2021:176)

In this point, Weber's ideal-type and its contextual fluidity allows research to turn its focus to organizations and bureaucratic mechanisms. One of the qualities which an ideal-type is measured against to analyze social behavior and organization is formal rationality. Ways of thinking and behavior characterized by applying formal and abstract rules to achieve outcomes are 'rational,' calculative, efficient, and teleological. Modern hospitals, specifically the semi-privatized or fully-privatized hospitals found in the United States, operate under Weber's ideal-type of bureaucracy, a formally rationalized 'ideal-type' which Weber himself warned against being dehumanizing. In order to accomplish the daily tasks and coordinate activities of work, hospital's authority and hierarchies are exceptionally well defined (Cockerham 2015). While patient care is the center of hospital services, rules and regulations within hospital settings are established to benefit personnel in treating large numbers of patients, running as efficiently as possible (Cockerham 2015:133).

The ideal-type of the American hospital maximizes efficiency and is a formally rationalized bureaucracy. Since American hospitals are beholden to shareholders, boards of trustees, and a veritable laundry list of interest groups (from private insurers and state insurance agencies to small business groups and lobbying associations), medical practices and care administration is not only dictated by medical professionals. Studies identify countless trends and managerial restructurings of public and private hospitals in and outside the United States (Cockerham 2015; Freidson 1985; Manchikanti et al. 2017; Wilson 1959). However, an underlying and preeminent super-structure dictating, guiding, and directing decisions on the hospital floor is economics. Luckily, a formidable social theorist wrote extensively on that issue.

Marxist perspectives on medical care concentrate on issues of political power and dominance. Sociologists studying health and medicine from a Marxist paradigm see healthcare systems mirroring larger class structures in capitalist society. In a capitalist society, humans are compelled to be producers and consumers of commodities. These commodities are created by capital and are not created for the benefit of humankind because, according to Marx and Engels', commodities, as products of human labor, are produced to satisfy human needs; all of which are socially and historically determined (Collyer 2015). Individuals are inherently 'social beings' and, therefore, "the ensemble (aggregate) of social relations." (Marx [1888] 1983:157). Marx expands on this key point in Capital Vol. 1:

> The capitalist process of production, therefore, seen as a total, connected process, i.e., a process of reproduction, produces not only commodities, not only surplus value, but it also produces and reproduces the capital-relation itself; on the one hand the capitalist, on the other the wage-labourer. (Marx [1867] 1976:724)

The flip side of the same coin is that labor itself is sold as a commodity whose price is determined by dire circumstances and need – not individual freedom or choice, inherently connecting capitalist modes of production with individual health and disease. Marx and Engels' conceptualization of health and illness is deeply embedded in their analysis of the interplay between commodities and human labor, contending that the capitalist system, with its focus on production and consumption, engenders a world in which individuals' health is intricately tied to their capacity to perform as productive workers (Marx 1977). Consequently, health becomes commodified and traded rather than viewed as a fundamental right or requirement for all individuals. This perspective highlights the crucial role that historical processes and preeminent superstructures play in shaping needs, social structures, and material conditions. Marx and Engels assert that prior historical events shape society's economic and political structures and that these structures determine individuals' needs, the formation of social relationships, and material conditions that influence health and illness. Applying this concept to health and medicine, Marx and Engels noted the poor health and working conditions of wage laborers working across Europe's industrial centers. From their perspective, the ill health and disease of the working classes could not be reduced to poor housing design, improper waste disposal, and lack of plumbing. Instead, they argued that these issues were all products of human organization within a particular type of society (Collyer 2015). For Marx and Engels, the relationship between abject poverty and disease was not an individual phenomenon but a social one (Engels 1887). This served as a departure from popular liberal theories of the time – frequently arguing that disease resulted from inherently weak bodies, or the Malthusian Social Darwinism, which argued that disease was inevitable and necessary.

Marx and Engels' theories on the relationship between poor health and poverty influenced countless social theories of health and illness. In the context of medical sociology and medical anthropology, while our respective vernacular may have some differences, key reference points, framing, and theoretical grounding remain the same. Stratification, social determinants of health, medicalization, and intersectionality; all fall under the same lens and within the large umbrella of social conflict theory – in essence (harkening back to the introduction), exploring the mechanisms that pertain to exploitation and injustice.

1.3 Social Determinants of Health, Conflict Theory, and Stratification

"Medicine is a social science and politics nothing but medicine on a grand scale," (Virchow [1848] 2009). Marxist reading and interpretation of medicine and health expanded beyond orthodox analyses concerned solely with material and economic terminology relegated to production and shop-floor relations. However, medical sociologists in the United States largely rejected Marxist interpretations (or even Marxist vocabulary) before the early 1960s (Navarro 1985). Opting instead for an entirely separate understanding of individuals, interests, and power, with the state operating entirely independently, with the underlying assumption being that no one interest group could hold complete sway over the neutral arbitrator that was the government – e.g., pluralist perspectives such as those adopted by Anderson (1972). Following critical reflection of pluralist frameworks, the 1960s and 70s witnessed the growth of "power elite" theories, arguing that the concentration of wealth and power within a specific interest group reduces competition to a small group of 'elites' that dominate the branches of the state. Power Elite perspectives follow the following method of analysis:

First, identification of the groups of elites that play a dominant role in the different sectors of medicine and of the state; second, analysis of how that power is exercised and through which mechanisms of state intervention; and third, description of the nature of the benefits those groups obtain as a result of their intervention [...] the actors (hospitals, universities, medical associations, insurance companies, etc.) are seen as power groups competing in their quest for dominance of, or influence in, the different agencies of the state. (Navarro 1985:529–30)

Marxists argue that Power Elite perspectives have limited explanatory power, as “power groups” exist within the parameters defined by larger power categories (class, gender, colonial). Accordingly, orthodox Marxist perspectives of health and illness posit that medicine “[is] the interplay of power conflicts that operate within a matrix of social power categories (class, race, gender, and others), of which class is the organizer of those conflicts, including the professional-patient conflict, take place.” (Navarro 1985:531)Health outcomes connected to economic inequality inherently carry a class-based perspective of social conflict theory.

Inasmuch as orthodox theoretical Marxist perspectives on medicine relegate any and all conflict to class, there are just as many variations in interpretation and application of Marxist frameworks, albeit implicit. Simply put, a Marxist reading of medical care explores political power and the health system’s mirroring of larger class structures (Waitzkin 1978). In essence, the explanatory power of Marxist paradigms adopts what Waitzkin (1978) calls “nonreformist reforms.” Link and Phelan’s (1995) work on social conditions and disease demonstrates the need to reassess the role of the individual and risk factors. Link and Phelan (1995) call for researchers to contextualize risk and the individual in relation to social conditions if they are to call for medical reform (Link and Phelan 1995). As such, social conditions and inequality act as “fundamental causes” of disease – that inequality “affects multiple disease outcomes through multiple mechanisms.” Understanding social conditions and inequality is the primary concern for conflict theorists – from a variety of framings, turning their attention to what orthodox Marxist perspectives such as Navarro (1985) would refer to as the ‘matrix of power categories”. Where, for Navarro, class and economic disparity being the category which all others rally around, a number of scholars that fall under the umbrella of ‘conflict theory’ differ. From feminist perspectives on health, race and ethnicity scholars, and the rejection of Marx’s implicit power dynamics through intersectional approaches, social conflict theory stands as a rich paradigm to explore health outcomes and illness in society.

Social epidemiologist Nancy Krieger’s (1999) extensive work on the relationship between systemic inequality and health outcomes, transcends Marxist orthodoxy to explain how inequalities (regardless of power category) can become “biologically embedded” in individual bodies, resulting in health disparity, e.g., Embodiment (Krieger 1999). For example, individuals suffering chronic stress resulting from discrimination can lead to higher rates of heart disease or gender-based violence resulting in higher levels of mental health disorders among women; all stemming from socially constructed categories imposing biological events. For causal analysis of these medical realities, R.W. Connell (1987) points towards gendered-based exploitation systems in Western society. Raewyn Connell coined the term 'multiple masculinities' as an explanatory tool for gender disparity. While for Connell, gender relations are not fixed social categories and are inherently fluid, Connell's multiple masculinities framework proposes five categories that are essentially measured against that which is not masculine (e.g., feminine). Among Connell's categories, that which could be considered in line with Weber's "ideal type" (albeit anything but ideal) as a benchmark for masculine behavior is "Hegemonic Masculinity" (Connell 1987, 2005, 2008). For Connell, hegemonic masculinity refers to Western cultural practices surrounding gender, which affirm certain traits and characteristics as desirable 'masculine traits.' These could be proclivity to violence, lack of emotion, impulsivity, and disregard for personal health (Scott-Samuel, Stanistreet, and Crawshaw 2009). In essence, smoking is higher among men because of an internalization of hegemonic masculinity; e.g., concern for personal health is connected to femininity – to perform masculinity effectively, men embody this trait (Scott-Samuel et al. 2009). From multiple masculinities frameworks, social researchers are better equipped to understand performative masculinity and its perpetuation through a variety of social mechanisms. Social reproduction theorists, on the other hand, exploring the gendered nature of capitalist modes of production, posit that which is 'masculine' is contextual based on the relations of production. To benefit capitalist modes of production, the devaluation of gendered wage labor is considered inherent to capitalist production (Fraser 2017). For capitalist structures to be maintained, it requires the reproduction of the next generation of workers; forcing women to be 'temporarily waged' and economically precarious, dependent on men. This process reinforces the male-dominant order made of husbands as providers (Bhattacharya 2017; Mohandesi and Teitelman 2017; Weiss 2021). For social conflict theorists, the reality of being in non-dominant groups inherently affects health outcomes, from maternal and child health outcomes to reproductive rights and heightened economic precarity and exposure to various antagonistic social determinants of health.

Paul Farmer (2004) explores social determinants of health at a global scale. Through Farmer's Pathologies of Power: Health, Human Rights, and the New War on the poor, (2004), Farmer elaborates on the concept of 'structural violence' and its relationship to global institutions that perpetuate suffering (formally introduced and operationalized by [Galtung and Höivik 1971]). Farmer's work explores the extremes of marginalization through the matrixes of race, gender, class, and a complete denial of agency. This sort of oppression, for Farmer, is innate within stable institutions and is rendered invisible through normalization and regularization (Farmer 2004:307). Sociologists of health and medicine have extensively engaged with institutions' roles and behavior, thereby further developing theoretical frameworks for understanding social mechanisms. Social theorists exploring social mechanisms surrounding institutions and their role in shaping individual behavior, particularly concerning medical practices, was instrumental in the emergence of Medical Sociology as a distinct field of study.

1.4 Institutions, Mechanisms, and Medical Sociology

Social determinants of health, marginalization, and their associated health outcomes address social mechanisms concerning inequality. While the sociologists in the previous sections explore the lattices and matrixes of oppression exhaustively, the role of institutions and the medical profession more broadly in shaping individual behavior and society were not their primary concern. To illustrate social practices from "Macro" positions into "Micro" social interactions, attention needs to turn towards Talcott Parsons and, by default, Davis and Moore, and Durkheim. The Davis-Moore hypothesis serves more as a strawman for sociological critique than a theory. Arguing that social stratification results from "functional necessity," Kingsley Davis and Wilbert E. Moore posit that professions or skills are rewarded based on their value to larger society and the sheer number of individuals capable of performing them (Davis and Moore 1945). Upon publication, Davis and Moore justifiably received endless critique – not accounting for class structures, properly defining "reward," or even how professions or skills are deemed "valuable" by larger society. That being said, it does hold merit to explore the role of physicians from Davis and Moore's framing. Their reading of the social mechanisms behind physicians in contemporary society would lead researchers to believe that doctors' behavior is dictated by professionalism and that their arrival to that profession results from a meritocratic process. In the terms of Davis and Moore , the most challenging societal positions demand the highest reward, filling roles and permitting the division of labor to function (Davis and Moore 1945). Through structural-functionalist paradigms, power dynamics and social stratification take a very different shape.

"In sociology, we have been so deeply involved in self-criticism that we are in danger of self-destruction." (Parsons [1951] 2005:xv). This quote, attributed to Bryan Turner (2005), can be found in the preface to Talcott Parsons, The Social System, and the reason it is included is that, out of all "classical" sociologists, Parsons has received a steady stream of criticism. An avid student of Weber, Parsons is formally considered part of the functionalist school of sociology. Parsons' main goal (using his terminology) was to delineate the "principle components of a social system from the structure of a social action," in other words, "value-orientations" and the cultural patterns of action, therein exploring their connection with the drivers of social processes (Parsons [1951] 2005:xix). The operationalization of cultural patterns of action can be demonstrated through Parsons' structuring of role-definitions, representing a confrontation with action as a system of conflicting choices (Parsons [1951] 2005:xix). Pattern variables for Parsons apply directly to the doctor-patient relationship.

Much of Parsons' work concerns social order and the pattern variables dictating it. In this sense, social relations are inherently structured, with social actors morally coerced into action by the internalization of fundamental value patterns. As such, Parsons' work concentrates heavily on deviance. It is through Parsons' analysis of deviance and social values that his most significant contribution to medical sociology lies. For a well-functioning social system, "too low a general level of health, too high an incidence of illness, is dysfunctional [...] because illness incapacitates for the effective performance of social roles." (Parsons [1951] 2005:289). Medical practice (which Parsons describes as a "mechanism") includes institutionalized roles filled by professionals concerned solely with providing care. Medical practitioners for Parsons then represent a specific sub-class of highly trained professionals. Working within that role requires high levels of technical competency. Taking Davis and Moore (1945) a step further, Parsons applies his patterns variables to argue:

> One basis for the division of labor is the specialization of technical competence. The role of physician is far along the continuum of increasingly high levels of technical competence required for performance [...] There is an intrinsic connection between achieved statuses and the requirements of high technical competence, as well as universalism and competence. (Parsons [1951] 2005:292)

Parsons stresses the distinctiveness of the medical practitioner using the pattern variables of self vs. collectivity-orientation. There is, harkening to Weber's understanding of bureaucracies and occupations, an inherent "ideology" of professionalism, characteristic to the physician; as such medical practitioners abide by collectivity-orientation, putting patient welfare above personal benefit. Parsons' work was written during the post-war era, a time of immense prosperity for the United States, with massive leaps in technological developments in medicine. During this time, the physician's role was changing abruptly as medical practices were starting to be performed within the organization's context (vis-à-vis formalized bureaucracy) (Cockerham 2015; Wilson 1959). Within this framing, Parsons expanded the concept of social role to the patients themselves, illustrating the sick role. Parsons highlights four specific characteristics concerning the sick role. The first is the exemption of the sick from 'normal' responsibilities (relative to illness severity). Exemption, in turn, requires legitimation from "various alters involved and the physician often serves as a court of appeal as well as a direct legitimatizing agent." (Parsons [1951] 2005:294). The second, is that the sick individual is not expected to recover by themselves – it is not a lack of willpower that makes them ill. The third is that the ill individual must, however, desire to heal. In turn, this serves as the impetus for seeking help, denoting the sick role's fourth characteristic. The ill individual must seek "*technically competent* help, namely, in the most usual case, that of a physician, and to cooperate with him in the process of trying to get well" (Parsons [1951] 2005:294). The sick role is contingent, meaning that regardless of an individual's status, they may find themselves in it. It is also "deviant" in that it deviates from the norm of being healthy. Only through the neutral and "sacred" arbiter being the physician is the sick person deemed legitimate and not sanctioned for their behavior, provided they abide by the characteristics illustrated above.

There are many aspects of Parsons' theories that can be criticized but one in particular stands out for medicine and medical sociology. Parsons, perhaps implicitly referring to an 'ideal-type' for operationalization, states that the physicians' ideology stresses the need to

> put the 'welfare of the patient' above his personal interests, and regards "commercialism" as the most serious and insidious evil with which it has to contend. The line, therefore, is drawn primarily vis-à-vis "business." The "profit motive" is supposed to be drastically excluded from the medical world. (Parsons [1951] 2005:293)

Understandably, while many things in the social world are immensely complex and excruciatingly sophisticated, social scientists know that, given the systems in which we operate, the "profit motive" is an indisputable feature of medical practice, specifically in the United States. That being said, Parsons' work served as a cornerstone for theoretical perspectives on medicine, albeit limited. Parsons' was the first to conceptualize medicine as an institution of social control. His concept of the "sick role" gave way to studying the mechanism of legitimizing illness which would otherwise be considered deviant (Twaddle 1973). Having been given these newfound tools that grew from emergent constructionist perspectives, thinkers such as Conrad (1975), Zola (1972), Freidson (1970), and Illich (1976) explored how medicine at an institutional level works as a form of social control from an explicitly sociological framing. Turning their attention to how once non-medical conditions or issues come under medical influence, a process known as medicalization (Conrad 1992). Most scholars of medicalization imply an inherent "overmedicalization," the driving forces attributed to which are exceedingly varied depending on scholars' framings and fieldwork.[2]

The relationship between medicalization and social control is twofold. Initially, social control stems from the power "to define behaviors persons and things" (Conrad 1992; Conrad and Schneider 1980:8). For medical social control to take hold, it must be adopted, on the one hand in practice, and on the other, in spirit. That is to say that, for medical social control to be meaningful, a category must carry a shared definition in the field, with fixed procedures for caring for it, stemming from a legitimate authority, authority which refers to that of the physician "excusing" deviance (illness) (Conrad 1992). This process carries elements of labeling theory,

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[2] For further reading on medicalization and its driving forces within the medical profession see; Halpern (1990), Maturo (2013), Maturo, Esposito, and Tognetti (2020) Pawluch (1983).

inasmuch as it refers to deviance and social identity regarding illness, inherently shaping individuals' experiences and behaviors.

The following section delves into the intricate relationship between social deviance and illness, highlighting the crucial roles of stigma and collective meanings in shaping health outcomes. By exploring the interplay between social mechanisms, such as social control, doctor-patient relationships, and identity, and illuminating the significance of meaning, interaction, values, beliefs, and cultural norms in comprehending illness, a more nuanced understanding of the complex interaction between subjectivity, social factors, and health outcomes can be achieved.

1.5 Interactionism and Narrative

Social mechanisms that shape the experiences of individuals and groups are the main concern for sociologists and social scientists adopting interactionist paradigms. Interactionists apply their concern to mechanisms such as socialization, labeling, stigma, doctor-patient interactions, narrative, and social support. These mechanisms stress the agency of individuals, an aspect of the social world that medical sociology appropriately began to turn its attention to. What sets interactionists apart from constructionist perspectives, while the two paradigms share an abundance of similarities, is their focus on micro-level exchanges, exploring the symbols and meanings attached to behavior and narrative (Blumer 1969). While constructionists seek to discover social processes' effect on experience, interactionists find social realities from behavior (Berger and Luckmann 1966; Blumer 1969). For that reason, medical sociology as a distinct field of study, with its traditions and methodological toolboxes, owes a great deal to the work of Mead (1934) in stressing the significance of how individuals form identity and make sense of their world through language and the development of the self (Belgrave and Charmaz 2015). Building on Mead's work on the self and socialization, Goffman's (1963) ideas on stigma and the management of social identity can be seen as an extension of Mead's concepts.

By growing from illness as a form of social deviance, resembling labeling theory, stigma stresses societal definitions of deviance as opposed to Parsonian perspectives of deviance attributed to inherent properties of an individual feature or the behavior itself (Monaghan and Williams 2013). Irving Goffman (1963) builds off Lemert's (1951) distinction between 'primary deviance' (original infraction and societal reaction to it) and 'secondary deviance' (the individual's response) and the resulting 'master-status' whereby any other sources of a person's identity are moot in light of society's reaction to their infraction. Goffman's (1963) Stigma: Notes on the Management of Spoiled Identity refers precisely to the internal manifestation of stigma when society's reaction to deviance 'spoils' an individual's identity (Goffman 1963). Identifying three culturally, historically, and socially variable distinct forms of stigma, Goffman classifies 1) stigmas of the body (deformities or blemishes), 2) stigmas of character (mental illnesses); and 3) stigmas of social collectivities (racial) (Goffman 1963; Monaghan and Williams 2013). Individuals facing stigma are excluded from crucial participation in society, therein disqualified from full social citizenship (Pescosolido 2015:280). For Goffman, Stigma management is exercised by anyone that operates in a social context with norms of identity from which to deviate.

Scholars inspired by Goffman's work on stigma and interactionist framing have explored exclusionary practices in state policy and medical practices. Disability theorists turn their attention to the labelers, as opposed to the labeled, moving from Goffman's focus on personal tragedy to focus on the social structures at play in marginalization. Whether those social structures be neo-liberal ideologies of personal responsibility (Scambler 2009), perceived social value, and discrimination in health care settings (Link and Phelan 2001; Reidpath et al. 2005), stigma and interactionist paradigms offer unique ways to explore the fluidity of identity and context within broader social schemas.

For Medical sociologists, where broader social realities and the fluidity of identity converge can be illustrated by narratives themselves. Anthropologist and practicing M.D. Arthur Kleinman's seminal work, The Illness Narratives: Suffering, Healing, and the Human Condition, had a profound impact on understanding the subjective experiences of illness and the cultural factors that shape them. Arguing that medical systems often focus too narrowly on the biological aspects of illness, neglecting the broader social, cultural, and personal dimensions of the experience, Kleinman posits an alternative to biomedical perspectives on illness. Kleinman's work emphasizes the importance of listening to patients' narratives and understanding the meaning they attach to their illness experiences (Bury and Monaghan 2013). By actively voicing their experience and having a 'witness to suffering,' patients can provide practical management of disorders in the clinical setting. Outside the clinical realm, illness narratives allow individuals to explain the profound disruption illness can create.

Kleinman contends that the experience of illness is not solely a medical or biological occurrence but is deeply entrenched in social and cultural contexts. The manner in which individuals comprehend and react to their illness is influenced by a multifaceted interplay of personal, social, and cultural factors, with these elements being crucial for a comprehensive understanding of the experience of illness and the dynamics of recovery (Kleinman 1988). Researchers seeking to incorporate the various social factors present in narrative strive to communicate knowledge to audiences in different settings, therein implying the comparative nature of illness narratives. Through Kleinman's work in global health, the social, historical, and above all, cultural components of stigma can be illuminated (Keusch, Wilentz, and Kleinman 2006).

Illness narratives also inform individual experiences and community practices within global social forces and contexts. Beyond serving researchers as a methodological tool for data collection, illness narratives also aid in healing, permitting patients and participants to make sense of their illnesses and the world around them.[3] People can interpret their suffering by turning their diseases into stories (Frank 1995). The benefits of illness narratives are twofold: they can inform and be used in tandem with other methodologies, but also as an overarching epistemological framing. As Charmaz (1995) illustrates through her work on impairment, ' adapting' and identity, seeking to explicate key processes of how people untangle the intersection of body, identity, and the self through illness; all social mechanisms which manifest through narrative (Charmaz 1995).

Interpretive, interactionist, and constructionist perspectives all emphasize the importance of understanding the agency of individuals in constructing social reality. These perspectives reject the notion that individuals are passive recipients of social norms and structures and instead focus on how people actively shape and create meaning in their social interactions. By doing so, they provide a valuable framework for analyzing complex social mechanisms, such as doctor-patient communication or the interplay of culture, aging, and caregiving, in a way that accounts for the rich and diverse experiences of the individuals involved (Kleinman 2013; Waitzkin 1984).

Relating to the substance of this project, it is essential to note that the theoretical perspectives listed above are employed widely to study the intricate relationship between culture, aging, and caregiving. Through their emphasis on communication, interaction, and culture, these perspectives reveal the complex social processes and power dynamics that shape health outcomes and healthcare experiences among older adults and caregivers. Additionally, by highlighting the impact of cultural beliefs, life course transitions, embodied experiences, and biographical disruptions, perspectives stressing participant voices and agency offer a comprehensive framework for understanding the social and cultural dimensions of aging and caregiving.

1.6 Culture, Aging, and Caregiving

Medical sociology, specifically concerned with studying social mechanisms inseparable from a milieu of cultural practices and institutional forces, benefits from interacting with diverse epistemological disciplines. Borrowing from medical

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[3] For social scientists seeking to employ Illness Narratives, regardless of theoretical orientation (interpretative, constructionist, interactionist), there is a balancing act to be done between celebrating personal narrative or "testimony" of participants, and a thorough analytic interrogation of data (Atkinson 2009; Atkinson and Delamont 2006). This critique of narrative inquiry is elaborated in the methodology section of this work.

anthropology, seeing sickness as "culturally constituted networks that link symbolic meaning to physiological and psychological processes and the personal experience of sickness, on the one side, and to social situations, relationships, and stressors on the other," permits analysis to identify and understand cultural forces, acting to shape health, ideas, and actions (Kleinman 1978:663). This perspective interacts with culture dynamically and fluidly, as opposed to viewing it as a static system to be untangled through the "cultural competency" of the researcher. Additionally, Kleinman's underlying thesis bridges some sociological theories that precede it. By analyzing illness as a biological event and an appendage of a much larger manifestation of a milieu of fluid structural, cultural, and interpretive forces, the meanings the sick ascribe to themselves, but also broader interconnected forces, can be illuminated (Byron 1994; Farmer 2003; Maio and Fernando 2015). Therefore, social mechanisms concerning cultural practices such as cultural capital, scripts, values, and norms can be explored in the context of aging, caregiving, and the life course.

Tamara Hareven's (1982) work on aging and the life course in *Family time and industrial time: the relationship between the family and work in a New England industrial community* interacts with the historical context related to the social structures and cultural contexts of a site. Hareven posits that aging (adopting a life-course perspective on standard sets of transitional phases throughout an individual's life) is deeply embedded in the historical context, rendering it a fluid and dynamic process (Hareven 1982). Neugarten's (1996) work throughout her career also emphasized the complexity of the life course, rejecting the preexistent fixed-nature of life course perspectives of the time, arguing instead that life trajectories were exceptionally varied across time and place, mediated by cultural values, expectations, and historical events (Neugarten 1996). Exploring aging and the life course further, Lock (1995) examines how aging relates to "embodiment" through menopause. In Western societies, the body is to be managed and controlled to resist the effects of aging; in Japan, the emphasis on rights and obligations the young have towards the old influences collective perception as aging is a natural and inevitable process. Connecting stigma to aging with society's emphasis on youthfulness, the diversity of culturally fluid life-course perspectives are expressed in individuals' internalized views based on societal expectations for the body (Lock 1995). Lock further denotes the role social structures and institutions have in aging, all of which implicate the care for older people. Aspects of the cultural practices present in Japan, with perceptions of old adults having intrinsic wisdom and value, translate into formal policy and social support systems.

Stressing the significance of cultural attitudes toward aging, Lock also stresses the complexity of caregiving. Involving physical, emotional, and practical labor, caregiving relies on effectively negotiating a complex web of social expectations of aging, illness, and death. The social reality of caregiving means that caregivers are bound to the social, cultural, and economic conditions in which caregiving occurs. Inasmuch as Life-course perspectives represent internalized expectations individuals possess of their life trajectories, caregiving can represent a rupturing of these expectations. As Bury (1982) writes on the biographical disruption that accompanies sickness where, “sickness produces feelings of derailment in achieving life goals” (Nowakowski 2021:448). Related to the concept of the ‘sick role’ in extrinsic behavior, biographical disruption explores the internal; in how individuals seek to reconstruct their narratives in response to sickness (Bury 1982). This process is referred to by Gareth Williams (1984) as ‘narrative reconstruction’ (Williams 1984). Untangling a series of non-linear “ruptures” within a personal narrative means examining these narratives within the broader expectations of the life course and how expectations are mediated by social forces present in the milieu of cultural context.

1.7 Conclusion

This chapter provided an overview of sociological theory surrounding social mechanisms concerning health and illness by connecting the relevance of classical sociological theory in contemporary medical sociology, aiming to uncover the influence of the former on the latter, exploring the various ways in which the seminal ideas of classical theorists have been reinterpreted and reworked by medical sociologists of the latter 20th century. Through an examination of the works of prominent scholars, the chapter highlights the continued importance of classical theory in shaping our understanding of health and illness while also providing a comprehensive overview of the evolution of medical sociology as a field of inquiry. This chapter then sought to show the coalescing theories of social conflict and how they interrogate social determinants of health and global inequalities from structural perspectives with identifiable antagonists. The second section shifted the focus to social conflict theories and their relevance to health and medicine. These theories provide a framework for understanding how social structures and power dynamics influence health outcomes, connecting to global health inequalities. From this perspective, the works of scholars such as Navarro, Link and Phelan, Bhattacharya, Waitzkin, Kreiger, and Connell have contributed to critical perspectives on health and medicine.

In the third section of this chapter, attention was turned to the examination of similar phenomena through separate epistemologies. With a focus on the immense contribution of Talcott Parsons to the field of medical sociology in his study of the sick role and its relation to social order, the discussion explored the structural-functionalist perspective. This theoretical framework delves into the contribution of social structures and institutions to the health and illness of individuals and how deviations from societal norms can disrupt social order. Parsons’ seminal work on the sick role provides valuable insights into the social expectations that surround illness and the role played by healthcare institutions in maintaining social order. From that point, the third section reflected on some critical points of medicalization as a form of theoretical bridging between two explicitly different ontological framings.

Departing from Parsons, institutions, and pattern variables related to social order, while retaining the point of sickness as social deviance, the following section explored the role of Stigma and the contributions of Irving Goffman to the study of identity, the self and his emphasis on language and communication. This perspective then served to touch on some important epistemological debates; debates inherently connected to methodological practices. By examining culture and the nature of illness through narrative, Arthur Kleinman's work is summarized as vital to medical sociology in stressing individual agency in constructing identity.

From Kathy Charmaz's extensive work on narrative and methodology, the nuances of Arthur Kleinman's illness narratives, alongside Byron Good's careful attention to context and structural forces, the final section connects those concepts outlined in the preceding to those explicitly related to the subject of this paper: Caregiving. Among the issues discussed, Hareven and Neugarten's interpretations of life course perspectives served as the background of analysis, examining Bury's concept of Biographical Disruption and how it relates to the lived experiences of caregivers for older adults. Numerous theorists made invaluable contributions to the field of medical sociology that significantly impact and inspire contemporary sociologists today, which unfortunately did not have a section devoted to their work. From Andrew Twaddle's (1968) Disease, Illness, and Sickness Triad, Pierre Bourdieu's (1984) Habitus and bridging health and social structures, Robert Merton (1957) and the socialization of physicians, to Foucault (1973) and his contributions to biopolitics and power - numerous authors were omitted solely for the sake of brevity. Those lucky authors who were included at length were explicitly chosen because their work aids in analyzing the concepts and social mechanisms surrounding caregiving, all of which will be elaborated and expanded on in the next chapter.

Chapter 2

Conceptual Contours of Caregiving, Burden, Expertise and Flourishing

2.1 Introduction

In Medical Sociology, we are taught to understand the social behaviors of biomedical conditions. We are instructed to expand our field of vision beyond the individual's body and understand what, for medical practitioners, lies at the periphery. Our 'gaze' or lens is determined by sets of theoretical paradigms, many of which were explored in the previous chapter. We see, we write, we publish – our efforts illuminate what is invisible or unnoticed to the untrained eye. Nevertheless, what if, once we have our lenses and look onto the field, that which lies in our immediate field of vision is numerous, its boundaries hazy, and our own vision foggy? To clean our lenses, pinpoint what is relevant, zoom in and zoom out, and carefully fine-tune our eyes to bring our field of vision into focus, conceptualization does just that.

Departing from the abstract theoretical paradigms of the previous chapter, this section dives into the theoretical concepts and ideas that inform the subject of this dissertation: Alzheimer's, Dementia, and Caregiving. As inherently social diseases, Alzheimer's and Dementia sociological research is largely concerned with understanding it through families of patients and their caregivers. Since Alzheimer's and Dementia have no known cure, therapies, and treatment regimens primarily focus on palliative care and respite care, aiming to enhance comfort and support individuals as they navigate the progressive decline of their cognitive abilities. This emphasis on palliative approaches, rather than actively seeking a cure, is influenced by the prevailing social constructs surrounding these diseases. Alzheimer's and Dementia are, in some respects, irreversible conditions, meaning a prioritization of symptom management and maintaining quality of life.

This chapter is therefore divided into four subsections. The first engages with sociological literature on Alzheimer's and Dementia more broadly from various perspectives and theoretical paradigms. This section touches on interrelated concepts surrounding the disease: the social construction of Alzheimer's and Dementia (Hashmi 2009; Lock 2013), Aging and Life Course perspectives in neurodegenerative diseases, and the cultural dimensions of care (Barg et al. 2014; Cipriani and Borin 2015; Cohen 2000), family dynamics, stigma, and social isolation (Honda et al. 2013), before focusing on the concepts and perspectives in Caregiving and practice.

The second section focuses on Caregiving, culture, and experience. This section draws heavily on the role and function of care work in contemporary society and the gendered reality of care work (Bhattacharya 2017). Departing from structural perspective analysis, this section connects with cultural interpretation and collective meaning-making in caregiving roles (Kleinman 1988, 2013; Montgomery, Rowe, and Kosloki 2007; Scheper-Hughes and Lock 1987). From there, exploring one of the main concepts concerning this works being burden and burnout through a critical lens.

Following the section on Caregiving, the subsequent two sections focus on the interconnection between Lay-Expertise and Empowerment, first, by understanding lay-expertise and how it relates to science and society more broadly, focusing on its connection with culture, knowledge, perception, and interpretivist readings of lay-expertise (Arksey 1994; Herzlich 1973; Williams 2013).

Since lay-expertise is deeply interrelated with empowerment in literature regarding health and illness, the following section explores empowerment in medical settings and potential institutional pitfalls. From Foucault (1979) to Freire (1970) to Giddens (1984) and Prior (2003), this section seeks to illustrate the ambiguity of empowerment in medical encounters and the hazy boundaries of the 'lay-expert.' Following empowerment, an expanded and operationalized form of empowerment in lay-expertise is introduced via the concept of "Flourishing" by Beach et al. (2022) and VanderWeele (2017).

2.2 Alzheimer's and Dementia in Sociology

> "Before too long, we may all be required to engage in what could well be thought of as 21st-century divinatory practices in an attempt to avert our respective destinies. The key signifies of the future will no longer be cracked turtle plastrons or heated ox, sheep, or deer shoulder bones [...] but rather molecular substances known as"biomarkers."

In *The Alzheimer Conundrum: entanglements of Dementia and Aging,* Margaret Lock (2013) illustrates the ethical complications that follow early ADRD detection methods. Throughout the past two decades, scholars of medical sociology have been increasingly sounding the alarm bells of the medicalization of risk, whereby biomarkers themselves are diagnosed and treated as diseases in their own right. For ADRD, the process of diagnosis (today being pushed into ever-earlier presymptomatic schemas- more than 20 years before the onset of irreversible effects of ADRD) is problematized through extending the calculation of aging in delineating "normal" aging and "pathological"; but normal risk and pathological risk. The method used to identify the early biomarkers of A.D. are amyloid depositions in the brain; however, the correlation between amyloid deposition and A.D. is not entirely reliable (Balard 2022). Theoretical positions on biomedical conditions differ significantly on a varying scale, one camp exclusively viewing molecular structures and protein folds, schemata of symptoms and biomarkers, and the other seeing emergent processes, fruit of contextualized biologies and experiences, culminating in the clinical expression of ADRD. I argue that most medical sociologists are not purists, instead falling along the spectrum of ontological positions, whether overtly or not. Medical sociologists should prioritize the critique of social reality of examination of disease development and prevention and the exploration of the historical context and evolving impact of ADRD. This includes investigating the structural changes in family dynamics and the interpretative understanding of subjective experiences, which are crucial in providing a comprehensive understanding of the phenomenon.

2.2.1 ADRD and the Cultural Dimensions of Selfhood

Throughout the last century, advocacy spearheaded the medicalization of A.D. From their inception in the 1970s, Alzheimer advocacy groups sought ADRD to be recognized as a medical condition and not dismissed as "senility" and an inescapable part of aging. Hoping this advocacy would lead to increased research funding, activists were soon disappointed. As Peter St. George-Hyslop writes, "Alzheimer's is not that sexy. [it's not] hot like breast cancer or HIV," and efforts to drum up funding fall dismally short when "affected people cannot speak for themselves" (Abraham 2010). Before medicalization, ADRD was simply part and parcel of aging, classified under the offensive catchall of "senility," a symptom of being old, and something which needed to be kept private, hidden from the general public, and managed by the family. This body of conceptual theories resides within that longstanding care network - as does a majority of social research on ADRD, stressing the "loss of self" and the subjective experience of Dementia.

Perceptions of the body and autonomy are culturally varied. Western Cultures are largely cited as having individualistic views of the self, whereby individuals experience the world "as autonomous and bounded entities within quite separate bodies" (Hashmi 2009:207). Scheper-Hughes and Lock (1987) illustrate the individual vs. society dichotomy in Western epistemology, a separation emerging in the late 17th century (Hashmi 2009; Scheper-Hughes and Lock 1987). Embedded within this epistemology lies the process of gradual estrangement from an individual's family "individuation," which psychologists consider a critical aspect of psychological development. This process, however, is unarguably a culturally-bounded notion, aligning with the prevailing Western epistemological framework of perceiving the individual and society. A number of non-western cultures can be cited as having contrasting notions of selfhood to Western individualism, whether it be socially relative (individuals acting within the context of social relationships) or cultures lacking perceptions of self entirely; individuals are non-existent outside their social roles (Barg et al. 2014; Calia, Johnson, and Cristea 2019; Cohen 2000; Mahoney et al. 2005; Sun, Ong, and Burnette 2012). Sickness in these latter examples is frequently attributed to bad social relations.

Aging and Caregiving in the context of culture ties directly to notions surrounding individualism. Two decades ago, In India, for example, dementia diagnosis was significantly lower than in the United States (Cohen 2000) and among Chinese Americans (Sun et al. 2012). This reality is not to say that ADRD does not exist in these spaces and communities; instead, its recognition is significantly delayed. Pathological aging and "normal aging" are increasingly difficult to differentiate: how many amyloid deposits mean Dementia, and how many are normal aging? A dementia diagnosis requires two bodies: a "sick" body (dealing with memory loss) and a body that notices symptoms. Timing of diagnosis therein connects with caregiver stress, as opposed to the clinical or biomedical severity of the disease. As ideas of personhood are innately centered around autonomy, individuals unable to exercise agency are, as Hazen (1994) argues, "culturally ambiguous entities lacking some of the properties of human beings". In this sense, those with dementia experience the "death of selfhood" (Hashmi 2009). Simultaneously, the carer experiences a serious threat to 'selfhood.' Using the U.S. as an example, the intensity of suffering is a culturally constructed reality. Given the importance of individuation and departure from parents as inseparable parts of the journey of adulthood, caring for a dependent parent threatens children's selfhood. The parent with Dementia becomes an "agent of disease" while their caregivers experience the "endless funeral, the around the clock ordeal, the 36 hour day" (Cohen 2000) and "being chained to a corpse, the naked truth of the shattered lives" (Longmore et al. 2010). This acute suffering is culturally varied, and its relevance is equally important in understanding the social character of neurodegenerative illnesses.

To that end, cultural values surrounding autonomy, agency, expectations for aging, and "normal" aging trajectories greatly influence diagnosis, inasmuch as they influence perceived caregiver burden.[1] Moreover, internalizing the role of 'caregiver'

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[1] The term "perceived" is utilized here as a significant distinction (AKA Subjective Burden

or the perception of being one largely depends on cultural practices of rites and responsibilities to the family (Cipriani and Borin 2015). The transformative process and reevaluation of familial roles (e.g., spouses caring for spouses – children caring for parents) signify a reappraisal of identity; from child to carer, romantic partner to sole provider; this change is also culturally relative, dependent on context and expectations. This renegotiation is exemplified most notably within Chinese American families, many of whom live in multi-generational households and view many of the symptoms associated with ADRD (memory loss, states of confusion) with "normal" aging (Barg et al. 2014; Cohen 2000; Hashmi 2009). In addition, Korean beliefs regarding care throughout the lifespan are shaped by the prominent cultural values of filial obligation and cyclical reciprocity (Barg et al. 2014; Chee and Levkoff 2001). Additionally, Hong Kong's cultural shift over the last two decades (specifically in the case of young women), who have undergone significant changing societal roles, daughters are not solely expected to lead successful careers but do so while caring for their parents, their husbands, and their children. This phenomenon is reflected among Korean-American women who work as caregivers, as they are reported to experience the highest levels of caregiver burden compared to other groups (Barg et al. 2014; Chee and Levkoff 2001).

The stigma surrounding ADRD and "senility," unfortunately, is not unique to cultural contexts. One reason possibly attributed to older Chinese-Americans with ADRD being undiagnosed for extended periods is not only cultural perceptions of the role of older adults and aging but stigma surrounding mental health and shielding older adults from public view (Hinton and Levkoff 1999; Mahoney et al. 2005; Sun et al. 2012). In Japan, the withdrawal from public life and reduced participation in social activities, considered vital for maintaining mental acuity among individuals with ADRD by the larger community, are often perceived as personal moral shortcomings (Honda et al. 2013). This societal perspective frames individuals with ADRD as burdens on the broader community (Barg et al. 2014; Honda et al. 2013). Additionally, some studies indicate that Latino families see ADRD as a result of sadness, loss, or trauma, believing that negative emotions are an important underlying cause for the onset of Dementia (Hinton and Levkoff 1999; Mahoney et al. 2005; Neary and Mahoney 2005). These perspectives inherently carry with them cultural practices and societal beliefs of associating 'senility' with personal responsibility of safeguarding one's own mental wellbeing. It should then come as no surprise that among the motivations of formal advocacy groups for the

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in psychology (Dunkin and Anderson-Hanley 1998)). When considering the comparison of caregiver burden between white North American caregivers and Latinx caregivers, it is important to acknowledge that while in some cases, there may be little material difference in burden, statistically Latinx families often experience greater levels of social inequality compared to their white counterparts (citing a broadly held understanding being that social inequality increases caregiver burden). That being said, white Americans may have a higher perceived burden, stemming directly from internalized individuation and social expectations.

medicalization of A.D. was the hope that through A.D.'s recognition, the stigma associated with senility would be eradicated.

By exploring cultures in the context of Alzheimer's and Dementia, the elaborate interplay between societal values, cultural norms, and diagnosis can be illuminated. Albeit a brief exploration of a truly impressive body of scholarly work on cultural perspective and ADRD, this section sought to unveil the multifaceted nature of the ADRD diagnosis and cultural constructions surrounding it, laying the groundwork for understanding the role of the caregiver. By recognizing the influence of Western individualism and the perception of the body on caregiver burden, the following section is informed in light of the broader sociocultural factors that shape caregivers' experiences and the role of Caregiving.

2.3 Caregiving, Cultures, and Burden

Within the realm of Caregiving, the complexities extend far beyond the immediate caregiver-care recipient dyad. Caregiving practices are intricately intertwined with the fabric of contemporary society, institutions, structures, cultural beliefs, interpretation, and meaning-making. The dynamics of Caregiving cannot be fully understood without considering the broader sociocultural context that shapes and influences this phenomenon. This section delves into the multifaceted dimensions of Caregiving, exploring its interaction with contemporary society, the institutional landscape, structural factors, and the intricate processes of interpretation and meaning-making. Through this exploration, it is possible to develop a comprehensive understanding of factors that shape and inform caregivers' experiences within the larger social frameworks.

2.3.1 Caregiving

Caregiving and caregiving practices are themselves culturally varied. Some contexts hold strong values on nurture, extending throughout the lifecycle, whereas, in others, these forms of relationships are primarily situational, formal, and spread outside of kin networks. Regardless, When illness or the effects of aging require family members to receive care, in almost all cultures and contexts, families provide it for dependent members. John G. Bruhn provides a pithy and useful definition of what a caregiver is, framed for sociological analysis: "a person who provides paid or unpaid assistance and support to another person who, for reasons of illness, disability, and/or age, cannot independently perform the usual activities of daily living." (Bruhn and Rebach 2014:5). Caregiving is further understood as "a life span experience associated with aging and the roles of spouses and adult children." (Bruhn and Rebach 2014:x)

This work is concerned solely with informal caregivers: e.g., non-professionals. The extent to which caregivers identify themselves as "caregivers" mainly depends on the psychological and economic burden, with estimates of 75% of family caregivers in the United States providing personal care not identifying as a caregiver (Bruhn and Rebach 2014). Caretaker identity theory posits that the role of Caregiving arises within established relationships, often within the family. As the needs of the care recipient evolve, the nature of care adjusts in terms of quantity and intensity, influenced by the expectations of both the family and the care recipients (Montgomery et al. 2007). Montgomery and Kosloki (2000) divide caregiving identity into five general phases:

> Phase I: period of role onset. In most cases, caregivers do not identify as caregivers. It entails performing tasks that are not usually an aspect of familial relationships (Montgomery et al. 2007:441).
>
> Phase II: period of self-identification. During this period, caregivers acknowledge their roles and that their activities are beyond the initial familial role (Montgomery et al. 2007:441).
>
> Phase III: period of increased needs. In this phase, caregivers' assistance falls well beyond the familial role. In this period, caregivers are torn between maintaining their primary identity, familial role, and that of caregiver as their primary identity.
>
> Phase IV: period of conflict. In this stage, caregivers consider whether to move the care recipient into a formal structure. This period is when caregiving identity has superseded familial roles, and caregiving responsibilities are increasingly intensified.
>
> Phase V: period of relocation. This is the stage where the care recipient is moved to a formal setting where the caregiver is relieved of their responsibilities as a caregiver. In this phase, the caregiver can shift their role back to the initial familial role.

These periods vary vastly across time and the needs of the care recipient. At times, caregivers jump between phases (particularly Phase II directly to Phase V) depending on many cultural and economic factors (Bruhn and Rebach 2014).[2] Transition between these phases, however, across cultural boundaries, is notably distressing, creating a sense of burden and added tension. This transition is complex, the duties and tasks associated with the phases listed above vary, and the experiences felt by caregivers and families are not all the same.

As mentioned in the previous section, the burden felt by female caregivers in Korea is especially acute. This intensity is also shared by Korean-American women working

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[2] One such example can be found in studies of caregivers based in the United States where middle-class white caregivers were found to relocate their dependants to care facilities at a significantly higher rate and much sooner than other social groups (Neary and Mahoney 2005).

as caregivers. Feminist perspectives regarding the gendered nature of care work paint a bleak picture of women embodying the role of caregiver. Care work, more broadly in economic terms, is consistently devalued in broader society. This type of labor refers to face-to-face service jobs (child care, teaching, therapy, nursing) (England and Folbre 1999). Some theorists argue that this segregation and devaluation stem from emotional labor (e.g., invisible, uncompensated labor) (Guy and Newman 2004). Others take a more explicit historical materialist perspective, arguing that care work's devaluation is part and parcel of capitalist modes of exploitation (Aruzza 2014; Bhattacharya 2017; Fraser 2017). Within the familial relationship, however, women bear the brunt of caregiving duties (Hayes, Boylstein, and Zimmerman 2007).

Additionally, women comprise most caregivers, not just in the United States (NAC and AARP 2020) but globally (Swinkels et al. 2019). It is clear that something doesn't add up: while ADRD affects women more predominantly (partially due to extended life expectancy and the relationship between ADRD and old age), women make up the majority of caregivers, irrespective of cultural context or geography. However, the intensity of that labor, the tasks involved, and the internalization of caregiving roles are culturally shaped and relational (Cipriani and Borin 2015; Funk 2010). Anthropology then offers the tools to explore how caregiver experience is shaped by meaning, culture, and interpretation.

2.3.2 Burden and Burnout

A voluminous body of literature explores the cultural variation in caregiving experience. Caregiving across cultures is just as diverse as ADRD is perceived and understood, as referenced earlier with ethnic minority American caregivers (Chee and Levkoff 2001; Cipriani and Borin 2015; Mahoney et al. 2005), caregiver "burden" is experienced differently, depending on social determinants of health (Lindt, van Berkel, and Mulder 2020), and cultural practices.

Burden is an inseparable term from Caregiving, aging, and ADRD research. Having gone through countless iterations since its coining in the 1960s by Grad and Sainsbury's (1963) hypothesis of being any cost to a family (Grad and Sainsbury 1963; Hoffmann and Mitchell 1998), Hoffmann and Mitchell (1998) define burden in terms of balances; when there is a deficit in the number of resources available within a family unit or community, and the physical and mental resources caregivers have to provide care to their dependents. Burden is further divided into two subcategories: subjective (e.g., mental) and objective (material resources and their availability) (Bachmann and Hruska 2022; Beach et al. 2022; Chiao, Wu, and Hsiao 2015). Burden is further contrasted with the term 'burnout,' referring to a tridimensional syndrome in response to chronic stress, which had primarily been used to refer to wellbeing in the workplace (Gérain and Zech 2019:2). In psychology, burnout has three defining characteristics, describing the emotional reaction to excessive stress: Depersonalization (e.g., detachment in relationships), Emotional exhaustion (feeling of being overwhelmed), and Loss of personal accomplishments (reduced sense of any possible feelings of fulfillment in Caregiving) all of which represent the 'dimensions' of burnout syndrome (Cross, Garip, and Sheffield 2018; Gérain and Zech 2019; Truzzi et al. 2008). When a caregiver is perceived to be experiencing burnout, the medical professionals and network of intervention specialists that caregiver is in contact with try to remedy the symptoms by providing respite care (McConnell, Haggar, and Hernández 2022).There are specific sets of protocols addressing caregiver burnout for healthcare professionals, among them maintaining physical wellbeing and ending "negative health behaviors"; by communicating effectively with healthcare professionals, taking breaks, seeking counseling, and developing a routine (Krishnan et al. 2017). Within this framing, burnout is itself a medicalized term, embodying elements of a social system.

Borrowing from Giddens (1984), human agency and human actions produce situated reflections and revisions of social order. In other words, Giddens highlights an eminent tension between people's actions and the composition of institutional systems, whereby the context behind social life is both transformed and transformative of that same system (Giddens 1984). Berger and Luckmann (1967) led this understanding of institutional theory:

> shared meanings and actions (typifications) which become objectified, taken-for-granted, and construed as real, become the social structures which then constrain future actions, understandings and typifications. The more institutionalized the cognitive categories and belief systems, the more human actions are defined by a widening sphere of taken-for-granted routines (Berger and Luckmann 1966:57)

To that end, we broadly carry expectations and perceptions for caregiving experience: burden, exhaustion, fulfillment, and, most importantly, burnout. Western societies at large reinforce (and are reinforced by) a collective understanding of 'burnout,' an understanding circumscribed by medical paradigms, medicalized language, and institutionalized care practices.

Within the field of caregiving, the term 'burnout' is used to describe crisis. In line with identity transformation theory, caregivers navigate a complex web of shifting conceptualization of selfhood. As previously mentioned, the transition between caregiver identity frequently manifests in a "crisis" for the caregiver. That being said, caregiver "crisis" (e.g., lexically, 'burnout') is not without its own sets of issues in pathology; how much burden is too much burden, how much burden is 'burnout' and can universalizing language be used describe such a contextualized and relational phenomenon? Burnout also implies that caregiving duties and responsibilities are going poorly; the caregiver is not embodying an ideal type of caregiving. What then is 'deviant' caregiver behavior, when does caregiving psychology and burden manifest in ineffective care provision for their dependents, and can we, as social scientists, pinpoint a precise moment of crisis?

Foucault's concept of the "body politic" offers an increasingly fine-tuned lens for examining the pathology of caregiver "burnout" and its normalized counterpart, burden. By applying Lupton's (2012) reading of Foucault's (1979) work, the medicalization of burnout as a term reflects a specific understanding and management of the caregiving experience, encompassing control over caregivers' subjectivities and bodies within broader social and political context. This inherently involves framing burnout as an individual problem that necessitates medical intervention or personal coping strategies, by which the onus for addressing it is placed on the caregiver rather than the underlying social, economic, and political determinants (Lindt et al. 2020). Within the body politic framework, burnout can be interpreted as a mechanism of control and normalization, functioning as a disciplinary mechanism that regulates the caregiving experience by pathologizing the fatigue, emotional exhaustion, and decreased personal fulfillment often associated with Caregiving, and placing its root causes at the feet of the caregiver, reinforcing societal expectations and upholding the existing social order.

Given the nature of burden and burnout, caregiver experience, and cultural practices inherent in ADRD's diagnosis, an unconsidered issue of boundaries appears. In the face of apparent burdens individuals endure, the true scope and probability of their "burnout" often eludes our grasp, leaving us inadequate in its precise delineation. Nevertheless, when we venture into defining it, we do so with clutched pearls and indignation, fervently proclaiming the significance of 'self-care.' Consequently, another question is raised, one eluded to in the first section of this chapter: how can self-care be practiced when selfhood no longer exists, or perhaps never truly existed? As we observe suffering and pain in caregivers, we encounter growing challenges in pathologizing their experiences. In the intricate caregiving landscape, we may struggle to define the boundaries of suffering ontologically. However, it is caregivers themselves that have the power to delineate the vibrant contours of a caregiving journey enriched with well-being, offering a tangible path forward for research.

2.4 Expertise, Empowerment, and Flourishing

In order to elaborate on caregiving success, three concepts arise from literature to pinpoint its genesis. The first being lay expertise, referring to the knowledge people with no formal professional training in a specific domain but have acquired practical, experiential, or self-learned expertise through their personal experiences and engagements in a particular area of interest or concern. The second is the interlinked concept of empowerment, or the multidimensional process of enhancing individual capabilities, resources, and ability to exert control. Empowerment expands beyond individual cognitive processes but also their ability to exert control within their social and political contexts. Finally, a bridging and manifestation of effective and wholistic integration of empowerment and lay-expertise can be found in the theoretical concept of “flourishing,” an effective way to operationalize caregiving “success.”

2.4.1 Lay-Expertise

Lay-Expertise finds its theoretical grounding in sociological literature on lay knowledge, Durkheimian theories on conscience collective, and interpretivist frameworks found in medical anthropology (Byron 1994). As described by Gareth H. Williams (2013), lay knowledge refers to “the ideas and perspectives employed by social actors to interpret their experiences of health and illness in everyday life” (Williams 2013:119). Work throughout the 20th century on lay knowledge paid close attention to potential patient-doctor conflicts that could arise from preexistent notions of health and pathology, at times manifesting in ‘non-compliant’ behavior. Herzlich (1973), however, took this concept further, positing that, while lay knowledge may reflect in ideas on pathology and medical procedure, lay knowledge is a unique cultural artifact, representing the cultural agency in individuals and wider societal ideas on health and illness (Herzlich 1973; Williams 2013). In this regard, lay knowledge is no longer viewed as residuals of a primitive time but as an essential tenet to understanding culture and society. Lay knowledge carries an empirical approach to making sense of an individual’s health and illness, along with communities at-large – specifically when illnesses are frightening – inserting personal experiences in complex relational, moral, and political matrixes (Williams 2013). Lay knowledge is inherently relational in that it relies heavily on broader societal perceptions of illness.

Existing within a web of expert systems, lay-expertise is inherently reflexive. As an assemblage of social practices, which are inherently reformed in light of a constant barrage of information, lay-expertise evolves as its character is constitutively altered in line with Giddens’s conceptualization of the modern self as a reflexive project of development (Giddens 1996).

The ever-evolving nature of selfhood and the reciprocal changes in expert systems lead to conflicting epistemologies vying for dominance within the public sphere. One such epistemology is lay-knowledge, challenging traditional notions of expertise and presenting a reflexive “work-in-progress” understanding of selfhood. Giddens’ approach emphasizes the reciprocal relationship between agency and structure, which is relevant to understanding lay knowledge in health phenomena. Rather than prioritizing one over the other, his framework recognizes their interdependence (Hughes 2015). This challenges conventional approaches focusing solely on individual agency or structural determinants. Examining the dual role of lay knowledge as both a product and an active agent in encounters with healthcare professionals and caregiving practices highlights its contextual relevance and interconnectedness.

Considering Friedson's (1970) professional dominance paradigm, Prior (2003) argues that at the turn of the century, the state of patient involvement and patient-centered care initiatives implies shared decision-making, therein reducing the effectiveness of the prevailing professional dominance paradigm. This trend in moving the patient towards the center of the conversation acts as an adapt to "democratize" the once anti-democratic nature of expert culture, as per Habermas's (1987) analysis of the hierarchical dimensions of expert systems. According to, Prior (2003), this process has produced two dominant perspectives in medical sociology:

> The first [...] an increased interest in what lay people have to offer by way of knowledge of health and illness. The second has been a tendency to argue that lay knowledge can be every bit as valuable as professional knowledge. The two trends often come together in discussion of that 1990s hybrid, the lay expert (Prior 2003:43)

As early as the 1980s, medical sociologists dealt with the term 'lay-expert' or 'expertness.' Unpacking the concept of lay-expertise meant that patients could be viewed as experts on their own health matters, thereby blurring some of the boundaries of expert systems and lay systems of knowledge. That being said, there is a definitive difference between lay-expertise and expert knowledge.

Conducting fieldwork on the complexity of ADRD diagnosis in people with Down's syndrome, Prior (2003) makes a clear distinction between the lay-experts and professional experts. The instrument used at the time to diagnose people with Dementia was strikingly misleading when used with people with Down's syndrome, leading to frequent overdiagnosis. Deb et al. (2007) worked with carers to design a new model for diagnosis, focusing instead on change or intensification of symptoms. Their work highlighted the importance of lay-expertise in care's daily workings, not the medical practices behind them. That being said, the relationship between medical knowledge and lay-expertise does, while not 'blurring' the boundary of the two, at least may complement and accentuate each other, albeit in convoluted ways.

As previously mentioned, lay-knowledge can appear in the cultural sediments of context. While problematic, in Japan, shared beliefs on how people living with Dementia must remain active and in contact with the larger community to keep their minds alert is in line with most medical treatment regimens of care. Inadvertently, the shame caregivers feel if their dependent is isolated from the broader community is a form of sanctioning. This means that, while the stigma surrounding people with Dementia who have isolated themselves from the general public is a form of surveillance and external coercion (potentially increasing caregiver stress/burden), it does touch on an aspect of cultural practice surrounding illness, therein exemplifying lay-knowledge in practice (e.g., lay-expertise).

The centering of lay-knowledge has also become an aspect of state government initiatives in informal caregiver support. In health services literature, the figure of the caregiver is identified by its adverse effects on health outcomes; caring as a cause of morbidity. In response, governments have proposed intervention training for caregivers for individuals with long-term conditions, stressing the need to build up experiential knowledge and (their words) "expert carers." For the Department of Health (2008) of the United Kingdom, this entails acquiring "knowledge and skills related to coping, balancing different roles and an ability to look after one's health and wellbeing" (Health 2008). Per Sadler and McKevitt (2013), these forms of policies create normative models of Caregiving, where carers are technical authorities, and as Twigg (1989) would refer to as co-workers with state agencies (Twigg 1989). An alternative and perhaps more critical interpretation posits that state-imposed caregiving guidelines subject caregiving behaviors to the scrutiny of medical authority, intensifying surveillance beyond existing community norms and expectations.

Inadvertently, this grants state intervention services the authority to dictate the parameters of "good caregiving." for the U.K. Department of Health, this means attending expert carer workshops, learning the practical techniques of care, and meditating in the face of suffering. Such discourse not only reflects neoliberal tendencies by burdening individuals with the responsibility for wellbeing, but it also raises a pressing question that would surely give Foucault heart palpitations: How does the State prescribe the standards for "good caregiving" amidst its inherent cultural fluidity, and can such a concept be meaningfully defined and enforced within the confines of rigid governance? In this critical perspective, the lay-expert embodies experiential learning shaped by lived experiences and influenced by encounters with medical knowledge systems. The concept of the lay-expert and 'the good caregiver' emerges as a multifaceted construct, integrating practical know-how, community knowledge, and medical systems knowledge. However, the existing literature on lay-expertise often overlooks a crucial prerequisite for effective caregiving: agency.

2.4.2 Empowerment and Flourishing

The lay-expert risks becoming an assemblage of a "democratized" (not truly) system of medical authority while simultaneously circumscribed to rulesets by medical institutions and the community at large. Underlying the lay-expert is the idea of empowerment, whereby lay-knowledge and lay-expertise are grounded on agency in decision-making in medical encounters and agency in the body politic. That being said, the concept of empowerment is not without its own set of concerns. The idea of the empowered patient is today a central theme in medical sociology, with research centering empowerment as an analytical tool to describe patterns in data and as an object of study in its own right (Andreassen and Trondsen 2010:282). The issue then is that 'new public health' policies tend to place responsibility onto smaller institutions and individuals themselves – with much of this responsibility manifesting in state prevention initiatives and adopting risk-averse behavior (Petersen and Lupton 2000). As mentioned earlier, this perspective highlights a shift where the responsibility for wellbeing is placed on the individual rather than healthcare systems (Fox, Ward, and O'Rourke 2005; Greener 2008). In other words, the 'expert patient' concept may reflect a sense of medical dominance rather than true empowerment in decision-making processes (Foucault 1973; Fox et al. 2005). Moreover, the increased accountability can exacerbate burden, considering that numerous patients do not actually want to assume responsibility for their own healthcare (Andreassen and Trondsen 2010). Gaining autonomy in managing one's well-being involves a crucial distinction between being compelled to assume full responsibility and being equipped with the necessary resources to do so.

Regarding knowledge and agency, Paulo Freire offers critical pedagogy as a possible point of inspiration. In line with the principles of critical pedagogy and the acquisition of lay-expertise, the work of Paulo Freire can contribute to understanding the connection between empowerment and caregiver well-being (Freire [1970] 2000; Magagnin and Heidemann 2020). Freire emphasizes the importance of conscientization, which involves raising critical consciousness and developing a sense of agency among marginalized individuals. Applying this to caregiving, empowering caregivers through critical pedagogy through the acquisition of lay-expertise allows them to challenge oppressive systems, recognize their own expertise, and actively participate in shaping their experiences, and truly give them the tools to be active agents in their own lives, as opposed to transferring responsibility onto themselves. This process not only enhances caregiver well-being but also promotes a more equitable and inclusive caregiving environment. Accordingly, for lay-expertise to be empowered, caregivers cannot only be seen as vessels; experts of medical procedures stemming from medical encounters; nor the effective practitioners of 'self-care,' nor caregivers without burden or burnout, but instead reflexive individuals, knowledgeable about their present state of being, their future, their past within and beyond their respective roles as 'caregivers.' For caregiving to be considered 'good' and for caregivers to be effectively empowered, their success depends on their ability to flourish.

The final concept that can be considered the manifestation of the empowered lay-expert is Flourishing. Beach et al. (2022) consistently refer to the idea of designing policy to enable caregivers to "flourish" within and beyond their respective roles as caregivers. Rather than referring to knowledge of pathology or cultural interpretations and knowledge therein, this work proposes expanding the concept of 'expertise' further to encompass the political realm of caregiving experience and subjective wellbeing. To flourish as a term descends from psychology and represents an operationalized understanding of subjective happiness. Flourishing is interconnected with life satisfaction and wellbeing, yet, as a broader concept also encompasses a form of stasis; for flourishing to be realized, it also requires a perception of stability, namely financial and material stability. Additionally, flourishing also incorporates dynamic processes of sense-of-purpose, fulfillment, and personal growth (e.g., virtue). As VanderWeele (2017) explains:

> i) happiness and life satisfaction; (ii) health, both mental and physical; (iii) meaning and purpose; (iv) character and virtue; and (v) close social relationships. All are arguably at least a part of what we mean by flourishing. Each of these domains arguably also satisfies the following two criteria: (i) Each domain is generally viewed as an end in itself, and (ii) each domain is nearly universally desired. (VanderWeele 2017:8149)

While these practices are connected to physical health and wellbeing, they also, as Vanderweele (2017) describes, are qualities with their own ends, independent of health outcomes. Flourishing caregivers means that caregivers are inherently engaging with some of the cited positive aspects of caregiving and are "empowered" in the absence of being burdened with additional responsibility. In this particular scenario, expert caregivers possess a range of technical capabilities, including:

1) adeptness in navigating healthcare systems and accessing government services,
2) practical knowledge for effective communication and interaction with loved ones,
3) proficiency in understanding the pathology of ADRD (Alzheimer's Disease and Related Dementias), and
4) mental health literacy and the ability to navigate identity changes, coping strategies, and evolving roles. Furthermore, these caregivers are empowered through:
5) the freedom and resources to make autonomous decisions beyond caregiving, without being burdened by additional responsibilities,
6) achieving financial stability,
7) finding a sense of purpose, and
8) having the necessary political tools to support these endeavors (Beach et al. 2022). In essence – for a caregiver to be a lay-expert, they must be empowered. If flourishing is absent in this experience, then they are not truly empowered. Flourishing accounts for qualities that extend beyond medical paradigms and the state – focusing on interpretivist structures of meaning in caregiver experiences, while distancing empowerment from the pitfalls of blaming individuals for poor health outcomes.

2.5 Conclusion

This chapter has explored the interplay between Alzheimer's Disease and Related Dementias (ADRD), cultural dimensions, diagnosis methods, and caregiver experiences. The ethical complexities arising from early ADRD detection methods and the medicalization of risk have been highlighted (Lock 2013). Cultural variations significantly influence the recognition and diagnosis of ADRD, as well as the transformation of caregiving roles and familial responsibilities (Barg et al. 2014; Chee and Levkoff 2001; Hinton and Levkoff 1999; Lock 2013; Mahoney et al. 2005; Sun et al. 2012).

The next section expanded on informal caregivers, particularly non-professionals, emphasizing the values and practices associated with caregiving across diverse cultural contexts. The identification of oneself as a caregiver is influenced by psychological and economic burden, leading to a significant portion of family caregivers not recognizing themselves as such (Bruhn and Rebach 2014). Caregiving roles evolve within established relationships and adjust in response to the changing needs of care recipients, shaped by family and societal expectations (Montgomery et al. 2007). These transitions and burdens experienced by caregivers vary across cultures and economic factors.

Caregiver burden, encompassing subjective and objective components, is a significant determinant of the caregiving experience and has been frequently cited to lead to "burnout". However, burnout should be understood as a response to chronic stress rather than a pathologized and universal syndrome given its symptoms are imbued with cultural practices and determinant on large social mechanisms (Chee and Levkoff 2001; Cipriani and Borin 2015; Lindt et al. 2020). Rather than pathologizing burnout as a result of poor self-care, and placing blame on individuals, research is best served by delineating 'success' in caregiving, as 'failure' or poor caregiving are not as easily identifiable given their relationality. Success, however, depends on how caregivers perceive themselves, in this way, recognizing the agency of caregivers and their ability to shape their caregiving journey and promote well-being is crucial for understanding empowerment through lay-expertise.

As a form of knowledge in health, lay-expertise has the potential to complement professional expertise, particularly in complex diagnoses. It encompasses the knowledge and perspectives individuals use to interpret health and illness in everyday life, challenging traditional notions of expertise (Byron 1994; Herzlich 1973; Prior 2003). Lay-expertise is influenced by cultural and societal perceptions of illness and is shaped through reflexive practices (Giddens 1984; Greener 2008; Meyerson 1994). It is a valuable and evolving form of knowledge that requires consideration of agency in caregiving practices, since, lay-expertise is itself considered a liberatory experience, by giving lay-persons the knowledge necessary to exercise control over their lives. However, there is a fine line between empowering caregivers through knowledge and burdening them via reading material and added responsibilities.

Empowerment, a critical component of lay-expertise, emerges as a pivotal factor grounded in individual agency (Freire [1970] 2000; Magagnin and Heidemann 2020). Paulo Freire's critical pedagogy provides valuable insights into empowerment and caregiver well-being, emphasizing conscientization and the dismantling of oppressive systems. Caregivers' empowerment hinges upon their reflective understanding of well-being that extends beyond health outcomes, encompassing stasis and dynamic aspects of social life, financial stability, purpose, and personal growth (Beach et al. 2022; VanderWeele 2017). However, their empowerment extends beyond mere expertise, encompassing autonomy, financial stability, purpose, and the formidable force of political support. Additionally, the role of the state in ensuring caregiver well-being is not necessarily a novel idea (*see* Giovanna Vicarelli and Bronzini (2009)), that is, the priniciple that the state itself should bear some form of responsibility in maintaining and implementing programs that encourage "flourishing" has been readily suggested. The essence of lay-expertise thrives within this flourishing state, transcending conventional medical paradigms. As a transformative phenomenon, lay-expertise can only be practiced by an empowered person; and a person is not truly empowered if they are not 'flourishing'.

To recognize what qualifies as "good" caregiving, it is essential for caregivers to experience liberation, free from insecurities, protected against adverse health outcomes, and maintain a state of mental well-being. The lay-expert in this context refers to individuals who actively engage in or have successfully laid the foundation for achieving these objectives. They are empowered, practicing agency and independence in decision-making. Ultimately, they find success in various aspects of their lives that contribute to their own well-being, enabling them to provide exemplary caregiving, thereby embodying a state of "flourishing". It is within this state, lay-expertise and the qualities of 'good' caregiving are to be identified in the following chapter.

Chapter 3

Caregiving as Process: the Social Ecology of Support and Burden

3.1 Introduction

When I first embarked on this study of caregiving as a sociological phenomenon, I was concerned with three specific things. First, how to effectively enter and engage with a community that, in the realm of medical sociology, might not appear to be formally organized. These caregiving communities, though not recognized traditionally, form around shared experiences and needs related to Alzheimer's care and support. Second, I aimed to understand how these communities interact with and influence broader societal structures—a complex interplay often overlooked in traditional studies. This inquiry is deeply rooted in the theoretical frameworks laid out in the first and second chapters, drawing from both classical and contemporary sociological theories.

It was obvious to me at the beginning that the way these communities operate is not dissimilar to others in that personal identification is the first necessary element to being accepted into it. People spend their lives going about their business, at one point a person in their family requires constant care and supervision, and they step in to do "their part". For the most part, there is not a cold calculation of checks and balances, weighing pros and cons, that comes later. As one participant in my study said, "It's all crisis-driven". That is not to say that caregivers do not base their decisions on logic; quite the contrary. Caregivers' decisions are contextually bounded, wrapped in familial roles and obligations, financial constraints, and influenced by their personal history. Understanding how caregivers adapt and transmit knowledge within these fluid contexts presents as much of a challenge as the logistical aspects of finding time to sit down with them.

To encapsulate the multifaceted reality of caregiving, my methodology evolved to reflect the dynamism and complexity of the field. The unpredictable nature of life events, including pandemics and natural disasters, necessitated a methodological approach that could capture a “dynamic snapshot” of ongoing processes rather than a static picture. While Wittgenstein would argue that a fuzzy photo is a photo nonetheless, I was unsatisfied with a single fuzzy photo. To grasp the subject I chose to incorporate a larger tapestry of longitudinal data. As a cross-national comparison of caregiving, the necessity to adopt a flexible lens became apparent. Since this study is essentially looking at three moving targets *1) Caregiving Identity*, *2) Knowledge and Community*, and *3) The landscape in which all these things are constructed and deconstructed*, methodology needed to be just as adept at analyzing all the key points as these points were varied.

This study is anchored in narrative accounts from caregivers in Italy and the United States, providing rich, biographical insights into their lived experiences. These narratives reveal the personal and often painful journeys of caregivers, enriched by their interactions at support centers and online platforms such as AlzConnected and Reddit. While traditional support structures offer tangible spaces for interaction, digital platforms extend these spaces, serving as vital forums for knowledge exchange and community support. This integration of netnographic research underscores my methodological recognition of digital spaces not as separate but as extensions of physical interactions, challenging the ontological distinction some theorists make.

“So, an ethnography?” Yes, but not strictly so. While simplifying my research into a single methodological category might have been easier, the cross-cultural and interdisciplinary nature of this work demanded a more robust approach. By leveraging both descriptive statistics and in-depth qualitative data, this research bridges the gap between narrative richness and empirical rigor. Instruments related to caregiver self-efficacy and burden, drawn from studies like the National Study on Caregiving and the European SHARE study, were meticulously analyzed in RStudio, highlighting the practical implications of theoretical insights, while only the results of NSOC are presented in this work.

The decision to conduct this work in this way was not an act of convoluted mental gymnastics - while I would like to think that I am the first to do such a thing, alas, I am not. Plenty of smarter and sociologically grounded scholars have undertaken similar work. Inspired by seminal works in sociology, I sought to create something that inhabited a similar methodological space to the sociological work that inspired me - in short, I wanted narrative and numbers to have a conversation, albeit a short one.

3.2 Methodology: Theories and Practices

In order to comprehensively understand the intricacies of caregiving within the context of Alzheimer's and related dementias, this study employs a multifaceted methodological approach. The following sections will detail the various methodologies utilized, each offering distinct yet complementary insights into the caregiving experience. It is essential to take a step back and examine the procedural aspects of these research methodologies. Understanding the theoretical underpinnings and practical applications of each method is crucial for ensuring the rigor and validity of the study. This examination allows for a transparent and systematic approach to data collection and analysis, highlighting how different methodologies can intersect and complement each other. By scrutinizing the procedures involved, the strengths and limitations of each method can be better appreciated, ultimately leading to a more nuanced and comprehensive understanding of the caregiving landscape. This reflective practice also underscores the importance of methodological coherence, ensuring that the research findings are robust, credible, and relevant to both academic and practical contexts.

3.2.1 *Ethnography*

An ethnography is a loose term. It can encompass a mass of varying forms of inquiry: it can be mixed-methods, it can be discursive, it can be autobiographic. Regardless of the assorted taxonomy of terms, ethnography carries some concise guiding principles. Ethnographic studies are carried out in everyday settings. Its problematic origins set the Western gaze on non-Western cultures to explore small sample sizes and to provide a "legitimate" account of practices and beliefs (Savage 2000). The early view that the ethnographer's account is the sole valid account of that being studied, or that their report emerges from a place of neutrality has since been long abandoned. Ethnographers have since turned inward, turning their fixtures to the artifacts and practices of everyday life, oftentimes engaging with the practices of their background (Kendall and Thangaraj 2013), a recentering that entailed an attunement of epistemology. Focus now, instead of focusing solely on either the 'self' or the 'other', entails the interaction, the discursive elements of that encounter; as Tedlock (1991) explains "participant observation to the observation of participation." To that end, ethnography seeks to understand "emic" patterns of social life.

It is reflexive, that is, *contextualized* in its search for meaning, and fluid. Turning our lens inward to reflect on our work, our place in that social world and, as academics and social actors our production of knowledge. Reflexivity can therein be divided into two distinct camps, one epistemological, concerning sociologists and social theorists alike, grappling with issues of bias as they relate to greater social schema or epistemological underpinning (more on that in the sections to come).[1] The other is personal, reassessing the research question and examining a researcher's point of departure (e.g., *positionality*). Perhaps in search to distance itself from its colonial past, ethnographic work is consistently revised, issues revisited, and personal beliefs interrogated. In a sense, reflexivity means acknowledging your impact as a researcher on the field and participant behavior. Reflexivity implies the recognition of the researcher in the process of research; that as writers, thinkers, and scientists we are not tasked with simply mirroring reality but that we are creating it through its inscription.

As it is contextually grounded, culture acts as a guiding point of study (Savage 2000). Geertz (1973a) offers a clear and succinct understanding of how culture works within ethnographic study: "Believing, with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning." (Geertz 1973b:6).

In essence, culture is both contexts, embodied as behavior. Our gestures speak volumes to greater structures at work, and ethnographers are essentially tasked with effective unweaving of tangled strands of meaning, and performing *thick description* - "culture is not a power, something to which social events, behaviors, institutions, or processes can be causally attributed; it is a context, something within which they can be intelligibly-that is, thickly-described." (Geertz 1973a:15). And to thickly describe, to interact with deeply and meaningfully, Geertz prescribes "deep hanging out". This means participation, observation, interrogation, and self-reflection; that is the bread and butter of ethnographic work: regardless of the procedural steps undertaken to observe specific phenomena, these defining pillars are what set ethnographic inquiry apart from other forms of qualitative research. A broad consensus among ethnographers is that they write. As do all social scientists yet ethnographers place a heavy importance on written text. This comes in the form of field notes and observations. The denotation of that writing however is where researchers diverge. Geertz argues that ethnography implies *inscribing* social discourse, Clifford (1990) posits that a more apt term for writing what is studied is transcription as it examines preexistent constructions of social life - others posit that ethnographers are *translating* the language and customs of one culture to make it discernible to another (Emerson, Fretz, and Shaw 2011). Sociologists instead posit that the core to ethnographic writing is "narrating", where Clifford and

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[1] Reflexivity has concerned social theorists far more profilic and patient than myself for the latter part of the 20th century. Anthony Giddens who I have cited consistently in the first two chapters expands on the their critique of modernity, arguing that the exploration of both structure agents can produce methodologically sound research and Bourdieu's work calling researchers to simply acknowledge their positionality in their production of knowledge - literature is abundant on the issue of reflexivity, so much so that I will only be engaging with the selected writings that are relevant to the procedural aspects of social research.

Marcus (2010) refers to *textualization* as the process of ethnographer "translating experience into the text" (Emerson et al. 2011:45). Emerson et al. (2011)'s work which at this point has become required reading for any aspiring ethnographer, places these exchanges on the crafting of fieldnotes and observations to their final output being a published text -

> In a fundamental sense, they [fieldnotes] constitute a way of life through the very writing choices that the ethnographer makes and the stories that she tells; for through her writing, she conveys her understandings and insights to future readers unacquainted with these lives, people, and events. In writing a fieldnote, then, the ethnographer does not simply put happenings into words. Rather, such writing is an interpretive process: It is the very first act of textualizing. Indeed, this often "invisible" work - *writing ethnographic fieldnotes* - is the primordial textualization that creates a world on the page and, ultimately, shapes the final ethnographic, published text (Emerson et al. 2011:46)

Ethnographers are recalling observed scenes, interactions, dialogue and movement, spatial relations, moods, tone, and details - the act of notetaking as *jottings* is episodic - not everything will be interesting, not everything will be illuminating - and ethnographers must be attuned to what will make up the substance of a full fieldnote. That is, after rushing to your desk to write up the events of the day in full form, what was pertinent to the study, and how can these jottings construct a coherent sequence of scene and character (Emerson et al. 2011:83). Ethnography has given rise to numerous methodological practices in qualitative research. What sets ethnography apart is its focus on culture, the importance of reflexivity in data collection, and a structured approach to observational data. Ethnography provides an immersive, detailed sketch of social life. For this project, ethnography serves as a comprehensive methodological toolbox to analyze and theorize varied data sets collected through diverse methods.

Transitioning to grounded theory, this ethnographic approach complements the project's aim to understand caregiver experiences and knowledge transfer. Grounded theory provides the procedural rigor needed to elevate the concepts drawn from ethnographic data, ensuring that the analysis remains rooted in participants' perspectives. This combined approach allows for a thorough exploration of how caregiving identities, community knowledge, and the broader landscape are constructed and deconstructed.

3.2.2 *Grounded-Theory*

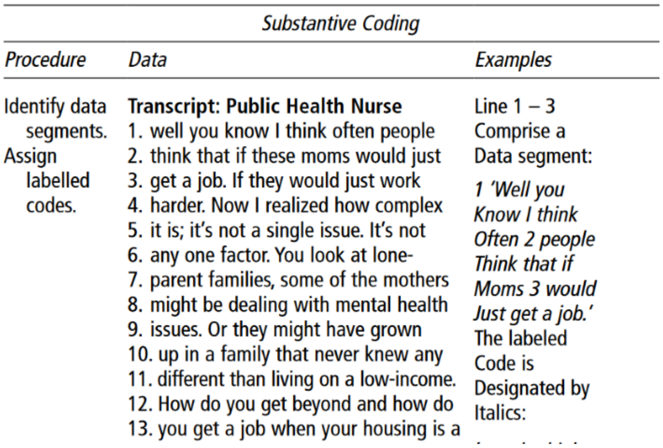
If ethnography is the vehicle then grounded theory can be the engine. What grounded theory best offers are procedural guidelines. Departing from the most positivist conceptualization of grounded theory as a method dating to Glaser and

Strauss (1971), Charmaz (2006a) harkens to Glaser and Strauss's (1967) original invitation to employ grounded theory in flexible ways. That being said, while the tenets of grounded theory remain the same, *how* a researcher adopts and adapts these guidelines is not. A prevailing aspect of grounded theory is that of induction, that is, concepts are lifted from the data through a cyclical process of comparison, notetaking, and reassessment. GTM, as Belgrave and Seide (2019) argues in their reading of Bryant and Charmaz "GTM [grounded theory method] can be seen as a somewhat turbulent family of methods, with a variety of interpretations, modifications, and conflicting claims regarding validity, authenticity, and varying views of key features" (Belgrave and Seide 2019:167). In other words, GTM has become so ubiquitous, notably in empirical sociology, that it is an extremely common practice undertaken in most qualitative research endeavors and an operandi sub silentio when those endeavors involve interviewing. Just as scholars conflate ethnography with conducting semi-structured interviews, and GTM with writing notes and tagging transcripts, they each have their guidelines and rulebooks. At its most basic principles, grounded theory involves memo-writing, coding, categorizing, and concept generation.

Grounded Theory's most appealing quality is that its procedural components are quite straightforward. A key feature of GTM is generating *memos*, or "slices of data", in the form of extracts, observations or more theoretically/big picture oriented *jottings* as ethnographers might refer to (Bryant 2013:110). Codes are then created through the process of data collection and represent relationships between data. These can be interview segments, statements, observations, or document sections (Bryant 2013:110). Once created, researchers seek to generate patterns between them via coding. Coding therein is the process by which codes speak to or reflect broader abstractions from the data; it describes what the data is about. Researchers give labels to parts of the data that show what these sections are speaking on. How these sections or concepts interact is the basis for identifying the patterns between codes. Once sets of memos are coded, and their patterns/relationships identified, they can be segmented into broader categories. These categories' interactions in turn are studied via their relationships, whereby the ephemeral and most abstracted element of data can be drawn forth as a concept. The concept-indicator model is at heart the outcome and the intended purpose of grounded theory (at least from the classical iteration). It is produced by the cyclical interrogation of memos, coding, and categorization; these processes are undertaken in tandem with one another as data is collected, codified, and analyzed. The concept is the product of a researcher's construction of relationships between categories - as Charmaz (2006a) explains it is the very idea that each concept generated through the grounded theory methodology rests on 'empirical indications' (Bryant 2013). Therefore, that is the aspect of 'grounding' the concepts. At least, in its early stages, this is what grounded theory had been conceived as.

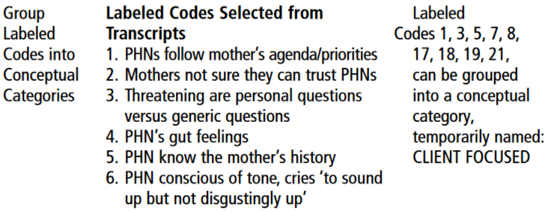
Taken at face value, this process is quite straightforward - we have our interviews, we transcribe them, and we then slap labels or ideas consisting of sentences or words or paragraphs giving them meaning; unfortunately as with anything worth doing, it is not quite so simple. In practice, these processes are cyclical or undertaken simultaneously and the *memo - codes - coding - category - concept* pathway is not necessarily a linear one. Firstly, different methods of coding stem from the epistemological framing of one's study. Belgrave and Seide (2019) delineates between Glaser & Strauss, Glaser, Strauss & Corbin, Charmaz/Bryant, and finally, Clarke. These approaches to coding data are defined by their Objectivist/Realist, Positivist, Intepretivist, Constructivist, Interpretive Situationist/Constructionist paradigms. While these "ists" written in list form create a word soup of epistemological jargon, they are important to understanding the underlying lens used when coding data, and the process by which concepts or theories are generated in the end because a researcher's explanatory paradigm not only determines data analysis and interpretation but also where value is found in data.

For Objectivists, the more traditional approach to GTM in Glaser & Strauss' original work, In their later work, Glaser (1978) introduces several coding families for theoretical coding, most importantly The Six Cs; "causes, contexts, contingencies, consequences, covariates and conditions" (Belgrave and Seide 2019:206). The initial coding process (referred to as *substantive* coding) is done line-by-line, the researcher seeks to code as many things as possible. *Selective coding* follows, where the researcher narrows down the focus, concentrating on a main variable and its related variables that are crucial for the emerging theory. *theoretical coding* then tries to knit a frayed narrative back together to generate a formal theory. An example is shown below. *Figure 1* shows the procedure of coding line by line - for Glaserian Grounded Theorists, each step of the data coding process is an act of abstraction. *Figure 2* illustrates how these codes are then grouped into conceptual categories. This is in turn followed by theoretical coding as shown in *Figure 3.*



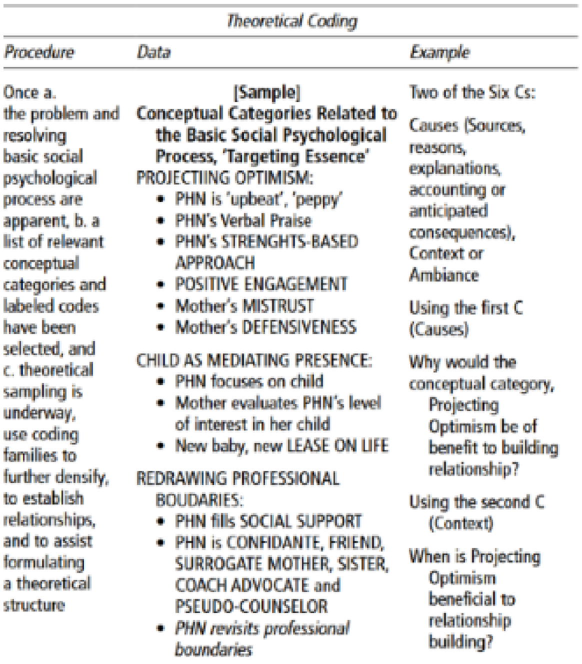
Substantive Coding		
Procedure	*Data*	*Examples*
Identify data segments. Assign labelled codes.	**Transcript: Public Health Nurse** 1. well you know I think often people 2. think that if these moms would just 3. get a job. If they would just work 4. harder. Now I realized how complex 5. it is; it's not a single issue. It's not 6. any one factor. You look at lone- 7. parent families, some of the mothers 8. might be dealing with mental health 9. issues. Or they might have grown 10. up in a family that never knew any 11. different than living on a low-income. 12. How do you get beyond and how do 13. you get a job when your housing is a	Line 1 – 3 Comprise a Data segment: *1 'Well you Know I think Often 2 people Think that if Moms 3 would Just get a job.'* The labeled Code is Designated by Italics:

Figure 3.1: Substantive Coding (Belgrave and Seide 2019:172; Porr 2009)



Group Labeled Codes into Conceptual Categories	**Labeled Codes Selected from Transcripts** 1. PHNs follow mother's agenda/priorities 2. Mothers not sure they can trust PHNs 3. Threatening are personal questions versus generic questions 4. PHN's gut feelings 5. PHN know the mother's history 6. PHN conscious of tone, cries 'to sound up but not disgustingly up'	Labeled Codes 1, 3, 5, 7, 8, 17, 18, 19, 21, can be grouped into a conceptual category, temporarily named: CLIENT FOCUSED

Figure 3.2: Conceptual Categories (Belgrave and Seide 2019:173)



Theoretical Coding

Procedure	*Data*	*Example*
Once a. the problem and resolving basic social psychological process are apparent, b. a list of relevant conceptual categories and labeled codes have been selected, and c. theoretical sampling is underway, use coding families to further densify, to establish relationships, and to assist formulating a theoretical structure	**[Sample]** **Conceptual Categories Related to the Basic Social Psychological Process, 'Targeting Essence'** PROJECTIING OPTIMISM: • PHN is 'upbeat', 'peppy' • PHN's Verbal Praise • PHN's STRENGHTS-BASED APPROACH • POSITIVE ENGAGEMENT • Mother's MISTRUST • Mother's DEFENSIVENESS CHILD AS MEDIATING PRESENCE: • PHN focuses on child • Mother evaluates PHN's level of interest in her child • New baby, new LEASE ON LIFE REDRAWING PROFESSIONAL BOUDARIES: • PHN fills SOCIAL SUPPORT • PHN is CONFIDANTE, FRIEND, SURROGATE MOTHER, SISTER, COACH ADVOCATE and PSEUDO-COUNSELOR • *PHN revisits professional boundaries*	Two of the Six Cs: Causes (Sources, reasons, explanations, accounting or anticipated consequences), Context or Ambiance Using the first C (Causes) Why would the conceptual category, Projecting Optimism be of benefit to building relationship? Using the second C (Context) When is Projecting Optimism beneficial to relationship building?

Figure 3.3: Theoretical Coding (Belgrave and Seide 2019:173)

What can be noted in both Glaser's work and the examples from Porr (2009)'s dissertation is that the coding families used do not include, what for more constructivist researchers, would consider extremely important families - power, agency, narrative, empowerment - it is through this lens that coding procedures already reflect the paradigms of the researcher.

Taking a markedly analytical approach to GTM, Strauss and Corbin (2003) illustrates that broadening the schematic structure of coding allows concepts to be interrogated cyclically. Strauss and Corbin advocate for a versatile strategy to open coding, allowing researchers to code by paragraphs, lines, phrases, or key individual words (micro-analysis) (Belgrave and Seide 2019). Additionally, they introduce inter-coder validity into research design; that is when two researchers are exposed to the same data set with the same question and come to the same coding results. Their most significant contribution is adding axial coding to GTM, where collections of codes are grouped into categories, and the *interaction* between them is labeled as a subcategory. Strauss and Corbin use specific scientific terms to clarify the connections between categories: The circumstances or situations that establish the framework of the studied phenomena (*Conditions*), The participants' routine or strategic responses to issues, events, or problems (*Actions/Interactions*), and the results or outcomes of these actions/interactions (*Consequences*)(Charmaz 2006b).

Conditions can also further be delineated into subcategories *Causal*, *Context*, and *Intervening* (Belgrave and Seide 2019; Corbin and Strauss 2015; Williams and Moser 2014) and give way to selective coding as the next step of abstraction. All these elements surround a phenomenon; with causal conditions answering the *Why* - they are the reason something happens; context conditions describe the situation around the main issue, they are the *Where*; and intervening conditions are the extra factors influencing the phenomena the *how* answering under what circumstances context and causal conditions may change.

Here's a very simple example of my cat (Lumi) and her laziness analyzed through Axial Coding.

Table 3.1: Axial Coding Procedure

Category	**Element**	**Description**
Causal Conditions	Lack of Stimulation	Absence of new toys or activities.
	Comfortable Environment	Cozy and warm spots for napping.
Context Conditions	Home Environment	Overall atmosphere of the home, including noise levels and space.
	Lumi's Health	Physical health and energy levels.
Intervening Conditions	Lumi's Age	Older age can lead to decreased activity levels.
	Interaction with Owner	Amount and type of interaction Lumi has with you.
Interaction Strategies/Actions	Providing Restful Spots	Ensuring Lumi has comfortable places to rest.
	Engaging in Light Play	Encouraging gentle activities when possible.
Consequences	Increased Rest	Lumi gets more rest and relaxation.

Usually axial coding involves the creation of a sort of flowchart - or code mapping as shown below.

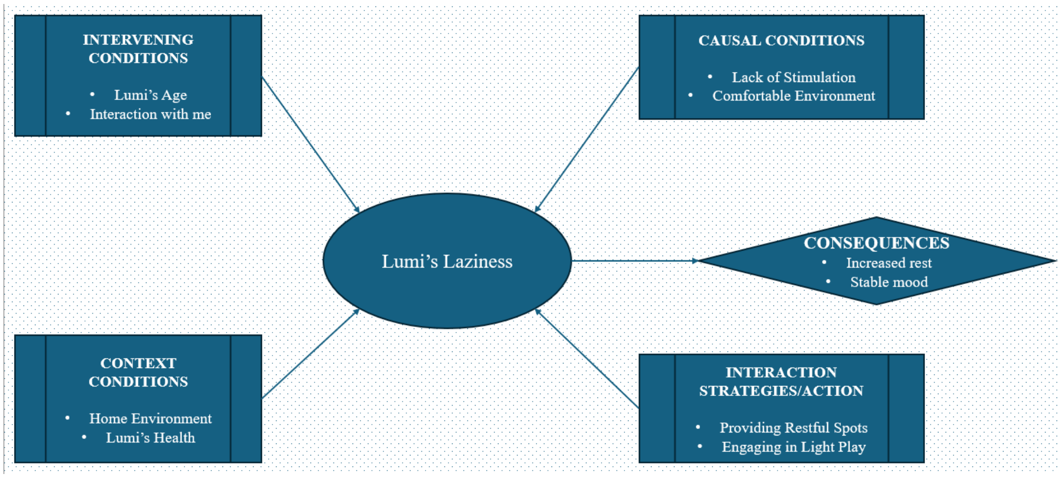


Figure 3.4: Axial Coding Chart

While it may seem trivial, the additional labels or *codified* forms of subcategories are an incredibly useful tool for transcription, allowing researchers to glean additional information, permitting richer descriptions of phenomena and an enhanced form of abstraction. It is through operationalizing the interaction that the “theoretical promise” of grounded theory can be realized (Acock et al. 2009; Williams and Moser 2014). Charmaz (2006b) takes an explicitly constructivist stance on coding procedure; it is the researcher who creates the codes, defines what is significant, and describes what they think is happening in participants' experiences. Both Bryant (2013) and Charmaz (2006b); Charmaz and Bryant (2019) employ line-by-line initial coding, remaining open to various theoretical directions by initially querying; *What is the _data indicating, “Pronouncing”, And from whose perspective?*. This then takes a step back to explore what* processes* at issue; their definition; development and implications (Charmaz 2014). This meticulous approach to data analysis, with the ability to explain processual dynamics of phenomena is foundational in Situational Analysis, an extension of Grounded Theory developed by Adele Clarke (Belgrave and Seide 2019).

Situational Analysis incorporates the procedural rigor of axial coding but expands it by including mapping strategies such as situational maps, social worlds/arenas maps, and positional maps. These maps enable researchers to visually represent the complexities and relationalities in the data, incorporating broader social, cultural, and institutional contexts. Thus, the structured approach of axial coding in identifying and linking conditions is pivotal in Situational Analysis, where it forms the basis for a more comprehensive and holistic examination of the data's situational elements. In addition to seeing where a given phenomenon is *situated* in the research process or social world in which it operates, Situational Analysis overtly adds ethnographic elements to grounded theory, focusing on reflexivity -

instead of exploring action-centered social processes, understanding the ecology of relations is its prime goal. There is special attention paid to the interpretivist traditions of Herbert Blumer and Everett Hughes.[2]

For Adele Clarke, Situational Analysis adds an important *situational* component to GTM that previously had been absent. It is significant to stress the difference in situation vs context, as Corbin and Strauss (2015) introduced contextual factors through conditional matrices, (e.g., axial coding), Clarke (2003) adds situational mapping to explore non-human, discursive, and collective actors or elements that can be found in a given *situation* and explores the relationships between them. For Clarke (2003); Clarke et al. (2022), the interactions between elements on a broad mapping of dynamic forces are constitutive of each other e.g., positions taken and not taken, working at multiple levels of inquiry. An enduring promise of situational analysis is to theorize "long-term politico-economic and related change" (Belgrave and Seide 2019; Clarke et al. 2016). Figures 5, 6, and 7 are examples of the situational map process, starting with an Abstract Messy Situational Map, an Abstract Relational map, followed by an Abstract Social Worlds/Arenas Map that illustrates these principles in action using the example of my cat's laziness again.

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[2] Interestingly, schools of thought in sociology still find themselves in lockstep with their philosophical or theoretical lineage; with Glaser being trained by Robert K. Merton and Lazarsfeld at Columbia and Strauss by Blumer and Hughes at the University of Chicago. Unsurprisingly these two camps of GTM - Glaserian vs Strauss (ie. Charmaz, Bryant, Seide, Clarke) are aligned epistemologically with their academic lineage. While she was taught by both Strauss and Glaser, Charmaz followed the interpretive interactionist sociology of Strauss (Clarke, Washburn, and Friese 2022). Adele Clarke's expansive academic career - a pioneer in STS, History of STM and gender studies aligns herself greatly with the interpretive traditions.

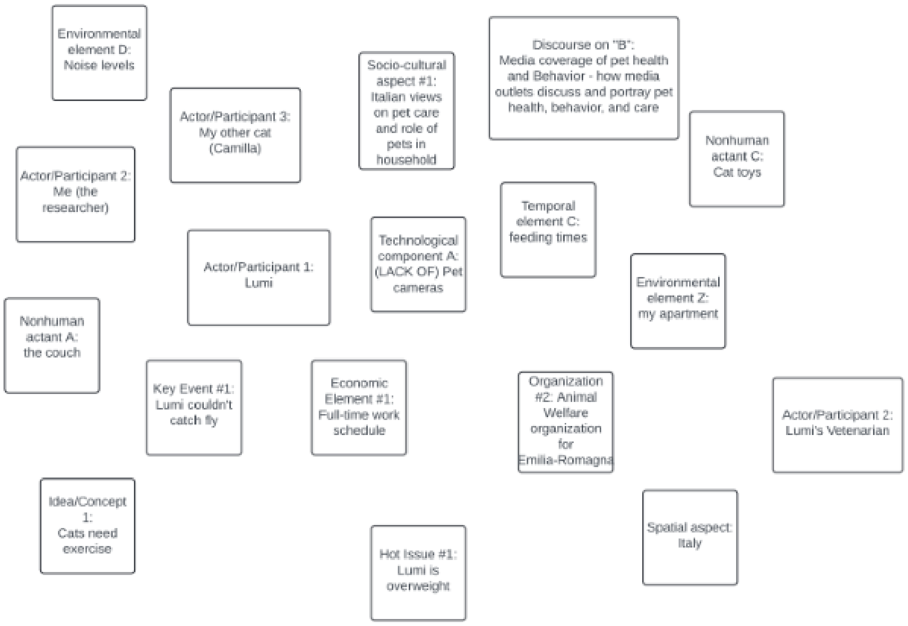

Figure 3.5: Messy Abstract Mapping

Now once that has been structured in a bit more of a digestible fashion, the researcher can apply relational flows between the most interestingly related elements on the map (Clarke et al. 2022:13). For continuity, the following reuses my cat's laziness to demonstrate situational mapping. After having created the structured situational map, I've discovered that the most intriguing element is that my cat is "overweight" and how media outlets portray overweight cats/healthy pet behaviors.

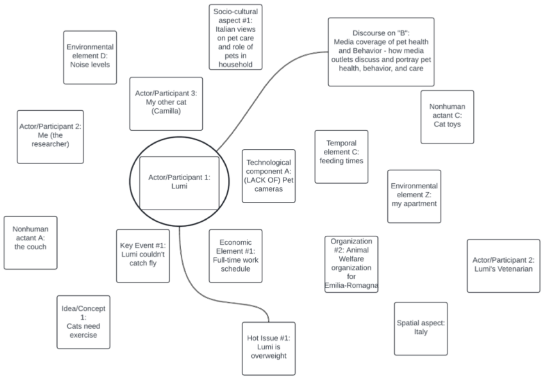

Figure 3.6: Abstract Relational Mapping

Where this and other relationships between elements and data take place is not in a vacuum however, and Clarke (2003) (*See also* (Clarke et al. 2016, 2022) posit a further step in GTM abstraction, where *action* is occurring in social worlds which Clarke refers to as arenas. Adele Clarke's expansion on grounded theory looks to examine the social world through an unspoken 'processualist' framework. From this thinking, of social ecologies of interaction and interpretation, Clarke adds a crucial element to grounded theory being *Social Arena Mapping.* For brevity and continuity, for this example, we will use my cat's laziness again.

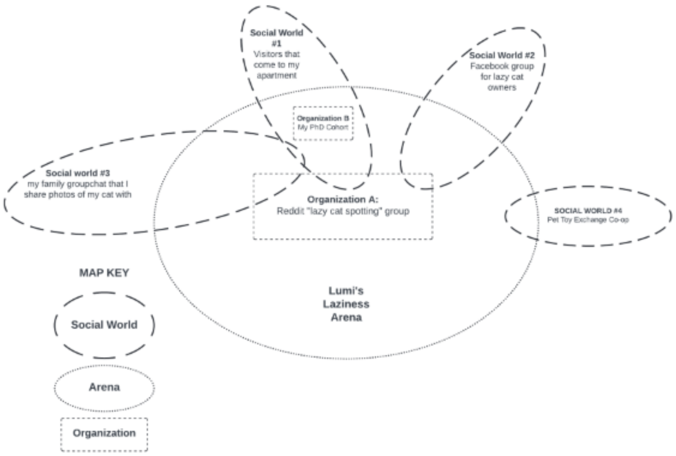

Figure 3.7: Social Arena Mapping

In the final example, we can see the interaction of social worlds surrounding a specific phenomenon. Situational analysis encourages studying *how* these social worlds operate, how they create themselves, and how they construct others (Clarke 2003, 2019; Clarke et al. 2022). Through Social Arena mapping, discourses (narrative, historical) are constitutive of the phenomena being studied (Clarke et al. 2022). The reason for these porous lines around social worlds and organizations implies fluidity and negotiation; as they are constitutive of social ecology, and GTM is the guiding principle of inquiry, the Social Arena explores the negotiations on a multitude of fronts in a visually operationalized way. Moreover, expanding on discourses found in a given situation, the subsequent procedure of positional mapping examines disarticulated discourses from their sites of production.

Figure 3.8: Positional Mapping Example from (Clarke et al. 2022:16)

Harkening back to chapter 2 where Giddens's work on structuration is mentioned briefly, highlighting the eminent tension between individual action and the composition of institutional systems, situational analysis presents an alternative to Giddens's argument of context behind social life as both transformed and transformative of that same system (Giddens 1984, 1994). Inasmuch as Giddens's work aids in accounting for micro-meso-macro discrepancies in interpretation, situational analysis can be used to effectively explore social arenas and their co-constitutive elements and *processual* change where they occur in a constantly rearranging and dynamic asynchronicity. In short, while situational analysis does not overtly deal with the historicality of individual or human elements, it does provide an ecological perspective to explore qualitative data that has been generated in varied forms. Presenting a promising methodological procedure for a project like my own, wherein the varied relationships between elements of processes (the process of *becoming a lay expert in ADRD caregiving*) can be delineated through a cross-cultural comparison of caregiving experiences. What was once the *cultural milieu of context*, through SA is rendered observable and digestible. For example, when caregivers assume their respective roles, aspects of identity or self intimately shape their decisions. In addition, their own perception of the disease, its trajectory, and past experiences with caring for others mediate this appraisal. Previous studies of ADRD caregiving explore how identity is reformulated in accordance with 'structural' constraints (Au et al. 2009; Greenwood et al. 2019; Varik, Medar, and Saks 2019). Yet, limitations from such perspectives arrive when researchers seek to connect this relationships as direct top-bottom hierarchical dichotomies. Instead, to fill these gaps that fail to take into account 1) nonlinear temporal considerations in identity reformulation (Barken 2014), 2) the interwoven contingencies associated with identity and 'situation' (McIntosh et al. 2012), and the non-human elements that are co-constitutive of these experiences, and finally 3) the diversity of production settings. Through a processual analysis of caregiving experiences, the relationship between narrative, situation, and time can begin to be understood.

It is no surprise then that Clarke's work was massively influential in the field of STM and STS, as the vital introduction of non-human actants and inclusion of discursive elements means that a composite of social ecologies surrounding phenomena is given breath in study. Adele Clarke's development of Situational Analysis has significantly expanded the scope of grounded theory by incorporating mapping strategies that visualize the complexities and relationalities within social worlds and arenas. This method emphasizes the importance of context and fluidity through the interactions between human and non-human elements, providing a robust framework for understanding the ecology of relations in qualitative research. Moving to the next section on Nethnography, it is important to recognize how Situational Analysis lays the groundwork for exploring digital spaces. Netnography, an adaptation of ethnographic methods to study online communities and cultures, similarly values the rich, contextual insights gained from observing and interacting with participants in their natural environments.

3.2.3 *Netnography*

Drawing on ethnographic principles, Netnography provides a systematic approach to studying virtual communities, while Grounded Theory offers a rigorous framework for generating theory based on empirical data (Addeo et al. 2019; Kozinets, Dolbec, and Earley 2014; Kozinets and Gambetti 2021; Markham 2013). By immersing themselves in data; pinpointing that which is relevant, and that which warrants "thick descriptions", digital spaces are inherently their separate forms of community (Kozinets and Gambetti 2021; Markham 2013).Likewise, digital ethnographic studies into the health sphere, specifically those conducted in the context of Italy, are not without precedent (Piras and Miele 2019). However, digital spaces present unique challenges for qualitative comparative analysis. It is therefore important to acknowledge the uniqueness of "digital" and what, specifically that means for qualitative research. As Markham (2013) explains:

> Certainly, digital technologies influence the shape and practice of what we call culture [but] Our research can and will shape the ethics of our future social structures and practices. We play a critical role in defining what counts as human experience, how it is accounted for, whose stories are told, and how people are represented in these tellings. Whether or not we intend or seek this political function, our decisions about how to frame and enact our small research projects matter (Markham 2013:1151).

Online ‘places’ carry their histories, etiquette, and ways of speaking, issues which researchers can find exceptionally complex when faced with the sheer data overload present online (Addeo et al. 2019; Kozinets et al. 2014; Kozinets and Gambetti 2021; Murthy 2008). An all-too-common issue in ethnographic and qualitative research more broadly, is finding data everywhere and nowhere; collecting mountains with data providing superficial descriptions and unintegrated categories (Charmaz 2006b:23). Grounded theory ethnography directs observers’ gaze and provides systematic guidelines for conducting the cyclical process fieldnote review. As grounded theory seeks to elevate concepts from data, it is nevertheless important to recognize the findings of individual qualitative studies, to highlight shared and congruent trends. Unless individual studies are synthesized with more established methodologies and conceptual frameworks, they run the risk of becoming what Glaser & Strauss (1971) refer to as “little islands of knowledge” (Cross et al. 2018:3; Glaser and Strauss 1971:181).

Social media then enters into this social arena as another space of interaction. To encapsulate the social ecology of a phenomena, a methodology finding its footing in urban studies, multifaceted data sets and analysis take place in varied locales. For situational analysis to be effective, it first must be comprehensive; “the conditions *of* a situation are *in* the situation. There is no theory, and lifting concepts from conditional elements of the situation need to be specified in the analysis of the situation itself as *they are constitutive of it*, not merely surrounding it framing it or contributing to it; they *are* it” (Clarke et al. 2022:101). In line with pragmatist paradigms, notably that of early Chicago School sociologists and thinkers (Dewey 1938; Mead 1934; *see also* Abbott 1997), Clarke (2003) argues that situational analysis is interested in the relational empiricalities; that it is actant, actor, human, and non-human are co-constitutive of each other - and that the relationship between these ‘situational’ elements *is* the unit of analysis. Moreover, situational analysis is the glue holding this procedure together; it is through this empirically grounded interactionist framing, which takes into account post-modern sensibilities (Friese, Clarke, and Washburn 2022), that grounded theory is launched into novelty.

So far, the points of this chapter have focused on a procedural overview of conducting qualitative research - a brief sketch of how three sets of qualitative methods work in practice and in tandem. The next sections take a step back to highlight theoretical components that inform method and qualitative inquiry. In the second chapter, there was a clear focus on the lens with which a phenomenon is studied - the preceding sections instead focus on how that framing can be effectively applied through an integrative paradigm. As an exploration of social ecology, how actors construct narratives and create meaning to their experiences represents a salient form of ‘discursive field’ as per Foucault (1977). What is being recounted through interviews is, in the end, a story when comprehensively studied - that story can be picked apart and put back together as would be the procedure in more traditional streams of GTM, yet through the 'interpretivist' turn in sociology, the personal and innately human act of constructing a narrative adds a disparate (discursive) - element to the social arena.

To that end, caregivers' words in this project serve twofold - one is creating meaning through codifying responses, adopting the procedural rigor of grounded theory, lifting concepts from the data - the second is how these words construct a cohesive, albeit messy, narrative in their entirety. The task then is to determine where these narratives find themselves mapped out in the social arena (*e.g., the social ecology*). For example, narratives on pain, loss, and identity specifically unique to the context of rural U.S. are informed and constitutive of what elements (human and non-human) surround them. The same is true for familial ties and sense of responsibility in Italy - *where* narratives are located through situational mapping, and *how* transcripts are analyzed and codified permits an inclusive interpretation of the dynamics and complexities within familial relationships.

3.2.4 ***Narrative***

Narrative has a rich history in social science and medicine. Brought into the fore by Arthur Kleinman through his seminal *The Illness Narratives: Suffering, Healing, and The Human Condition*, Kleinman (1988), elevated the importance of story telling as it relates to the body, self, illness and identity. For Kleinman, a practicing psychiatrist and anthropologist, how his patients formulated and interpreted their experiences with illness was at the center of patient-centered care. Kleinman's work has been immensely influential, charting a course for the 'interpretative' turn in health-related social sciences (Bury and Monaghan 2013). Following the *Illness Narratives*, qualitative research adopting narrative perspectives while simultaneously employing diverse toolsets of methodologies expanded. Employed in tandem with various forms of qualitative inquiry - narrative is in essence the providing of space to patients to produce accounts of their experiences, whether they are elicited from the researcher through support groups or testimonies, or through recorded open-ended interviews. A biography of illness is then constructed through participants' own words. It can be then broken down and built back up, explored holistically as would be the case in more traditional forms of ethnography, and in both of these cases can be explored through processual lens -e.g., *social ecologies* and semantic/performative functions of language.[3]

In most cases, at least in opening discussion with participants, researchers are confronted with symptoms and their subsequent interpretation. In the first sequence of illness narratives, cultural practices and performance can be gleaned from initial

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[3] For further reading on how semology and illness, specifically the *Disease, Illness, Sickness* triad explored briefly in the second chapter, Maturo (2007) presents a compelling arguement for an expansion of the DIS combinatorial to include institutional sickness, imagery of sickness, and the *semantics* of illness. *See also* Moretti (2019).

interactions as they tend to focus on participants' disease or their bodies and well-being. Kleinman situates culture at the fore.

Another component that appears in illness narratives is a relational ontology - through this rupturing of personal biography and the potential loss of self-hood that it implies, juggling contingency on '*why me?*' can be a restorative process of identity reconstruction. Additionally, narratives form around moral estimations of society and self; choices are reevaluated, interactions with the medical systems and participants' surroundings. These in turn can shed light on the interaction between individual actors and non-human actants/elements. Finally, Illness narratives can explore both organizational narratives and individual, united by biological or medical similarities in experience. Illness narratives in turn follow a similar pattern in construction and form, with researchers focusing on perceptions, interpretations, and course of life orbiting disease. As such, as individuals represent actors with their own personal biographies (or as Abbott (2016) would refer to as *historicality*) narratives are then considered iterative references between "body, self, and society" configured in time.

Throughout the 2000s, a notable critique levied against narrative/biographical forms of data collection in health research was that they lacked analytical rigor (Atkinson 2009; Atkinson and Delamont 2006). That is, narratives were celebrated as "privileged means of access to informants' personal experiences" existing within a vacuum of "internal validity" (Atkinson and Delamont 2006). While this was obviously not the intention of the narrative turn in health social sciences, it did represent a common pitfall which researchers found themselves in - that in narrative research, the speaking subject is "Individualised and personalized, but devoid of social identity or cultural resources, the narrating speaker is celebrated as an atomised subject" (Atkinson 2009:200). To that end, this work consciously sidesteps the critiques outlined by Atkinson by embedding narrative approaches within a comprehensive processual sociology framework. This approach interlinks individual caregiver stories with the social structures and cultural dynamics that inform and shape these experiences. By doing so, it ensures that narratives are not viewed as mere personal accounts but as dynamic interactions within broader social processes. This methodical integration highlights the relationship between individual experiences and the evolving social processes in that they are situated; thereby addressing the critique of narratives as isolated or devoid of social identity. The processes in the social arena, expand to the historicality of the individual as well. As netnography enhances our understanding of interpretative situations which caregivers find themselves, narrative bolsters identity and the "historicality" of individuals - to pinpoint a process, a multi-layered approach to data collection and analysis calls for, lack of a better word, mountains of data. This data, for it to be meaningful, for it to challenge an emergent theme in qualitative research which follows an all-too-familiar pattern; *make an interview guide, find some folks* *to talk to, transcribe, label excerpts, theorize over them, publish findings*, it needs to integrate multiple interwoven threads of social worlds.

3.2.5 *Multisited Narratives and Populations*

Caregiving ontologically stems from a socio-cultural necessity. While not universalizing its complex manifestations across cultures, it can be said that caregiving is a practice that has existed alongside human social formations in some form. It is an inherent aspect of life courses, that caring for those that came before and those that will come after is an unspoken rule of *human-ness*. While this work focuses on caregiving and lay expertise for people living with ADRD, it is evident that the subject resonates deeply, extending to a more profound understanding of the human condition and social formations. For that reason, caregiving as a phenomena touches on multiple fields and subdisciplines - demography and population studies, palliative care and professional knowledge, social gerontology, cultural practices and aging studies; all fields studying caregiving from their own disciplinary paradigm to explore actors, social mechanisms, and processual contingencies..s previously mentioned, paraphrasing Glaser, for fear of this work becoming its own atoll of insight, engaging with research coming from our colleagues across disciplines was a vital necessity. Then, having an understanding of literature around caregiving, dementia, aging, and demography has shown what this work can offer: a sociologically informed analysis armed with a diverse toolset ready to explore actor, social mechanism, and processual contigencies.

Social demography, as a critical subfield of sociology, provides a robust framework for examining the statistical study of populations, particularly size, structure, and distribution, and how these parameters change over time. This discipline analyzes the interactions between social, economic, and cultural factors and population trends, offering insights into demographic patterns and their implications. In aging studies, social demography seeks to illustrate the societal implications of demographic trends (e.g., increased life expectancy and declining fertility rates) within a population. Social demography also has the power to tell stories on a large scale, through statistical instruments and broad data sets. Since this work is a comparative analysis of caregiver lay expertise, the demographic landscape represents a vital element of the social ecology of caregiving experience.

Italy can be seen as a snapshot of what many wealthy OECD countries will face in the coming decades. Only three other countries have a similar demographic landscape - Monaco and Japan. 24% of Italy's population is 65 years or older, meaning that almost a quarter of the population is outside of working age (OECD 2019). By 2030, 1 in 5 will be over the age of 65 in the United States; by 2060, 1 in 4 (Carr 2023). The United States is inching towards Italy's population age - but so are the rest of wealthy OECD countries, if they are not already. Globally, median age continues to rise because of advances in health and medicine. As populations age, so too do diseases and illnesses associated with it, namely Alzheimer's and related dementias (ADRD). Much of the prognosis of ADRD rests on informal networks of care; kin, in-home intervention services, and friends bearing the brunt of support (Lindt et al. 2020).

This demographic reality drastically changes the landscape of a country, from economic strain on households (Meijer et al. 2022), to reduced working hours (Socci et al. 2021), to the numerous health issues posed by taking on the extensive tasks of caregiving (Kaddour and Kishita 2020; Schulz et al. 2020; Schulz and Beach 1999; Vitaliano, Zhang, and Scanlan 2003). Demographic transformation presents significant challenges for social support systems, informal caregiving networks, healthcare provision, and economic policies. Through detailed statistical analyses and projections, social demography highlights the intricate relationships between aging populations and social institutions. However, emergent survey sets studying social connection, stress, perceived isolation, and the health outcomes therein add a rich stratum for inquiry; specifically with regards to caregiving.

In my research, I use social demography to add a temporal quality to the project, enabling the tracking and prediction of changes over time. This temporal perspective is crucial for identifying trajectories of burden, burnout, and stressors that caregivers experience. By analyzing secondary cross-sectional survey data, trends and needs can be identified, enhancing understanding of the challenges and opportunities presented by an aging population and the increasing demands on informal caregivers. Moreover, social demography helps identify the social mechanisms related to these trajectories and, in the context of this work, aid in situating them within a co-constitutive mapping of elements. This approach allows for examination of how social, economic, and cultural factors interact and impact caregiving experiences at a large-scale level, shedding light on the socioeconomic status and living conditions of older adults, regional disparities in caregiving resources, and the impact of aging on family structures and intergenerational relationships.

3.3 Methodological Framework

An overarching theme in this project is to identify streams where caregivers gather information on ADRD pathology, acquire new skills in symptom management, and mediate preceived burden. Essentially, the goal of inquiry is to discover 1) what strategies caregivers use to insulate themselves from stress 2) what qualities of caregivers mediate perceived stress/burden 3) what are the relationships between lay expertise and the multitude of elements surrounding caregiving experience and trajectories. To that end, the netnographic study undertaken (perhaps digital observation is more appropriate verbiage) explores how caregivers communicate with each other in their own digital spaces; what forms of content they share, and how knowledge is passed from one person to the next. Previous work on discursive themes in Italy and U.S.-based Facebook groups showed promising signs for thematic analysis (Beckett and Castellaccio 2023). Work on these platforms illustrated clear thematic distinctions between forms of discourse types. However, given increased privacy concerns surrounding Facebook groups since the Cambridge Analytica scandal and the 2016 election, data collection (e.g., *scraping*) has been rendered unfeasible given the timeframe and resources allocated. Instead, what was gleaned from the initial content analysis of these Facebook groups served to inform larger data collection efforts on the caregiver forum Alzconnected. Threads (and comments) scraped from Alzconnected were codified based on the three discursive themes identified in previous research: Informational, Engagement, and Venting/Support. While not a large part of this dissertation, this separate project has already proven a fruitful avenue for caregiver research.[4]

3.3.1 ***Synthesis***

Intimately connected with narrative forms of data collection, the more empirical aspect of this work sought to identify mediating effects on caregiver burden/perceived stress on a broad scale. An abundance of work on perception and social support pointed out this work to explore perceived social support and perceived burden in caregiver experiences (Cornwell and Waite 2009; Waite, Iveniuk, and Laumann 2014). By way of exploring the relationships between social isolation, caregiver burden, efficacy, and well-being among informal caregivers of individuals with Alzheimer's and related dementias, the social health and support frameworks can be used in an elastic and supportive way. By exploring aspects such as age, gender, socioeconomic status, and social networks, the study delves into how perceived isolation—a subjective sense of inadequate social resources (Santini et al. 2020)—and caregiver burden, defined through self-perception and multifaceted strain (Liu, Heffernan, and Tan 2020), affect caregivers' health outcomes. This framework helps highlight the variability in caregivers' experiences and stress levels. Additionally, the concept of efficacy, both social and self-efficacy, is examined to understand its impact on caregivers' ability to manage their roles effectively (Au et al. 2009; Bandura 2010; Cacioppo and Hawkley 2009; Steffen et al. 2002). Finally, by integrating the notion of flourishing and well-being as per VanderWeele (2017), previously mentioned in chapter two, the research highlights the necessity of supportive policies that enhance caregivers' quality of life,

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[4] In its most basic form, the procedure for thematic analysis and big data involves hand coding roughly 20% of data - that means combing through 20% of all comments or threads and assigning them a defined value. Once coded, this 20% is used to train a language learning model that can analyze the remaining data, with 10% fed to the model, the remaining 10% of hand-coded data is used to test the codes and the language model to see if it arrives at the same conclusions. This initial coding procedure allows for thematic analysis to explore network size, elasticity, and composition of group members. This also allows this project to explore directly how information is transferred from one caregiver to another. A separate project of thematic analysis of data gathered from Alzconnectd is currently being undertaken.

underscoring the importance of targeted interventions and support mechanisms As these concepts are effectively operationalized through survey design and secondary sources, they are analyzed and interrogated through narrative and grounded theory methodologies. As previously illustrated, the interpretative qualities in grounded theory methodology in tandem with the cultural sensitivities and nuances in illness narratives allow for participants' data to be explored twofold. On the one hand, caregiver narratives serve as a whole to illustrate biographical rupturing and identity reformations. These same interviews can be then explored from a more iconoclastic perspective through grounded theory; where transcripts are cyclically slashed and rebuilt around conceptual formation.

Between these empirical findings and the broader theoretical discussions, there exists a vital interlinkage that enriches our understanding of caregiving dynamics. This study positions itself at the intersection where quantitative measures of social support and burden meet qualitative insights into caregiver experiences, thereby enriching the narrative dimension with robust empirical data. The juxtaposition of detailed personal stories with systematic data analysis enhances our ability to discern patterns and build theories that are not only grounded in personal realities but also resonate with broader societal structures. Thus, by interweaving these methodological approaches, the research not only captures the immediate impacts of caregiving but also situates these experiences within a larger framework that considers cultural, social, and policy-related implications. This comprehensive approach underscores the complexity of caregiving and highlights the necessity of integrating diverse methodological perspectives to capture the multifaceted nature of this social phenomenon.

Silverstone (2007) contends that our moral challenge is to get better at seeing the way our research interweaves in larger structures of meaning. In that sense, an informed grounded theorist lens engages with micro-interactions and the collective imaginary of concepts in the spaces being navigated. To that end, exploring the concepts that surround caregiver empowerment and flourishing, seeing caregiving as an evolving process involving the dismantling and reconstruction of identity, permits cultural practices and in-group collective imaginaries to be disentangled. Numerous studies on the conceptual contours of caregiving highlight important methodological procedures to follow to study specific and practical outcomes. Qualitative studies on the topic of caregiving intervention services, however extensive, are lacking in a formal integrated theoretical grounding, existing independently from one other, all observing the same phenomenon finding, not dissimilar results, but using an extremely variable vocabulary (Cottagiri and Sykes 2019; Dixe et al. 2019; Gallagher-Thompson et al. 2020). As one of the most prodigious writers on Grounded Theory, Kathy Charmaz (2006) states that there is an exceptionally close relationship between grounded theory and ethnographic study in the field. As this project is uniquely situated to explore narrative through interviews and community observation through fieldwork, what became apparent early on is that, in the end, this work is a study of an emergent 'process' constitutive of both human and non-human elements, operating in interwoven social worlds. Methodology, in the end, has sought to bridge the exhaustive qualitative work done by social scientists over the last decade on the phenomenon of caregiving and explore that for which it is – not a thing- not a 'what,' but a process.

Building on the foundation laid by Silverstone (2007) and the insights of Kathy Charmaz, this project's methodological approach bridges the theoretical with the practical. It underscores the interconnectedness of narrative, ethnography, and grounded theory to dissect the dynamic processes shaping caregiving practices. This interwoven approach facilitates a comprehensive exploration of caregiving as a process, moving beyond the confines of static observational studies. By employing a consistent methodological framework across varied cultural settings, the study ensures that the narratives captured are not merely reflective of isolated experiences but are indicative of broader, systemic patterns and interactions. This methodological consistency allows for the deep exploration of themes such as resources, burden, burnout, and expertise, enriching the analysis of how caregivers navigate their roles across different social contexts. Thus, the research not only charts the micro-interactions within caregiver communities but also maps these interactions onto larger cultural and structural paradigms, offering a nuanced understanding of caregiving as a dynamic and socially embedded process.

3.3.2 *Narrative and "Context"*

While literature on comparative ethnography, with varying units of analysis, the procedural components are not completely fleshed out (Saint Arnault and Sinko 2021). Some key components accompanying the comparative nature of this study is analytical similarity. Saint Arnault and Sinko (2021) explains that data that is collected must be fundamentally similar for comparison (p. 6). The instruments used in collection must be the same, guided by the same research questions/aims. Moreover, narratives gathered from multiple sites, conducted with the same instruments, and with caregivers bound by the same relational homogeneity, allow for effective cultural analysis. Methodology therein seeks to highlight cultural differences and relational contingencies surrounding four main themes (e.g., *resources*, *burden*, *burnout*, and *expertise*), the interview guide which is included in the final appendix of the results steered conversation around these concepts. However, while interviews were conducted with a guide, and followed the "semi-structured" format of interviewing, questions posed gave ample space for *Narrative* to flow from participants who were seldom interrupted. This permitted for open interpretation of the progression of the interview, an additional discursive element to the grounded theory procedure that followed. This research endeavors to further embed these qualitative insights within the structured analytical framework of grounded theory. The pivot from discussing narratives and their cultural resonances to a grounded theory approach underscores the methodological synthesis at the core of this project. Grounded theory, with its rigorous coding and systematic analysis, provides the tools to distill broader theoretical insights from the rich descriptive accounts collected through narrative methods. This transition not only bridges individual experiences with theoretical constructs but also enriches the understanding of caregiving dynamics through a more formalized inquiry. Thus, while narratives provide depth and temporality, grounded theory offers a pathway to elevate these insights, ensuring that the findings contribute to a cohesive and actionable body of knowledge that spans both the particularities of personal experiences and of social processes.

3.3.3 *Situated Narrative and Process*

The overlap between ethnographic research, narrative, and grounded theory is apparent, not only in this project but across qualitative healthcare research. Most recently, Mroz et al. (2023) conducted grounded theory analysis on family caregiver preparedness for persons living with dementia (PLWD) at a larger scale than this work. Their findings also stress the importance of caregiving confidence (which throughout this work has been referred to as perceived self-efficacy, closely related to the caregiver *flourishing* concept previously illustrated in Chapter two). Similarly, an analysis of the challenging aspects of caregiver experiences related to activities of daily living (ADLs), instrumental activities of daily living IADLs, and needed support interventions has been thoroughly explored through grounded theory recent publications (Kokorelias et al. 2022; Mroz et al. 2023). Additionally, this procedure has been applied in exclusively in digital spaces and used the same grounded theory framework to code and categorize responses (Bachmann and Hruska 2022). The inclusion of situational analysis to grounded theory in caregiving research is also not without precedent. Previous literature expands on geographic components to palliative care (McIntosh et al. 2012), intergenerational and caregiving and Covid-19(Rayanpour et al. 2022), interpretivist analysis of personhood and identity (Brennan et al. 2023). The most recent example explores caregiving preparedness for dementia from an institutional perspective in South Africa (Jacobs et al. 2024), and another similar example conducted in Vietnam (Dang et al. 2021). Situational analysis has found an audience in more empirical business studies and SWOT analyses on program implementation. While beneficial towards meeting study aims of appraising project milestones, there is a general disconnect with the theoretical components that guide it. Through the humanistic approaches inherent in narrative and cultural comparison, grounded theory firmly positions itself within Sociology's purview; emphasizing the examination of social factors and providing a detailed understanding of the social ecology caregivers act in. In doing so, situational analysis connects individual experiences with broader cultural patterns. In that way, discursive patterns are gleaned from many sources, one of which is digital arenas.

A number of studies either in print or preprint have explored inter-group relationships and thematic analysis on Alzconnected and other digital platforms.(Yin et al. 2023; Yin et al. 2024). These studies explored specific thematic issues surrounding ADRD care. From medication management (Liu et al. 2024), to peer to peer teaching in unmoderated forums (Yin et al. 2023), to sense of community and support (Ni et al. 2022). These studies have stressed the importance of digital spaces informing caregiver experiences. Since the sampling procedure of this work has granted access to caregivers who are involved predominantly in in person support groups or intervention services, the findings would inevitably be too limited to generate meaningful contributions. For that reason, within the nexus of caregiving experiences and narratives are those divulged online. These spaces represent self-directed interaction, deviating from the other observational work that had been conducted in person.

3.4 Data Collection and Procedure

3.4.1 *Sampling*

Participants were selected via snowball sampling through fieldwork conducted, taking into account the scarcity of publicly available channels for contacting caregivers. Throughout the Fall and Winter of 2022-23 and again in the Winter and Spring of 2024, I engaged in extensive volunteer work with a local organization, La Rete Magica, based in Forlì. This involvement included participation in numerous support groups and performing various tasks that helped in building a relationship of trust with both the organization and its participants.

My participation in these settings was not passive; I was actively involved in facilitating group activities and discussions, which allowed me to observe the dynamics of caregiver interactions first-hand. During my time with La Rete Magica, I took comprehensive field notes focusing on group dynamics, individual behaviors, gestures, symbols, and the characteristics of interactions between actors. This was particularly intense during the sessions of the Gruppo ABC, a course designed to enhance communication strategies for managing individuals with Alzheimer's and related dementias (ADRD). Having tracked several iterations of the Gruppo ABC course throughout the 2022-23 academic year, I had the unique opportunity to engage with caregivers who had completed the course a year earlier, providing a longitudinal perspective on their learning and application of communication strategies. However, an unforeseen natural disaster, a severe flood in the spring of 2023, significantly disrupted my planned follow-up interviews by rendering many areas inaccessible and affecting the local community deeply.

Simultaneously, my research extended to the United States where I connected with

LifeStream Services, a rural outreach program in central Indiana. After participating in a lunch meeting that served as an informal gathering for local caregivers, the program director facilitated introductions to several caregivers participating in their network. Beyond these connections, I utilized word-of-mouth referrals to recruit four additional participants unaffiliated with established caregiver support resources. This method proved essential in understanding the diverse environments and support systems—or lack thereof—that shape caregiver experiences.

Each participant, regardless of their geographic or organizational affiliation, was asked a uniform set of 20 questions designed to delve deep into their caregiving experiences. These questions were open-ended to allow for extensive narrative responses and were followed by probing questions that varied depending on the responses given. This approach aimed to uncover detailed personal narratives and allowed for the exploration of specific themes related to caregiving dynamics, stress management, and community support mechanisms.

These dual threads of my research—one in Italy and one in the United States—offered a comparative insight into the caregiving experience across different cultural and social contexts. The varied methodologies employed, from participant observation to structured interviews, were instrumental in providing a comprehensive understanding of the caregiving landscape, highlighting the universal challenges and unique adaptations of caregivers in distinct environments

3.4.2 *Analysis*

Each interview began with a thorough initial listening session, during which I made extensive notes and marked critical timestamps for future reference. This meticulous process was instrumental in familiarizing myself with the nuances of each discussion before proceeding to transcription. I utilized turboscribe.ai, which employs WhisperAI for language structuring, offering one of the most direct and refined transcription services available. Despite its near-perfection, the transcription output required careful editing to correct minor inaccuracies. This process is illustrated in Figures 9 through 12 in the appendix.

After a second review of the audio to ensure accuracy, the cleaned transcripts were converted into .txt files for coding. This was done using MAXQDA, a sophisticated qualitative analysis software that supports graphic visualizations and advanced coding and memoing capabilities, facilitating an organized and detailed analysis process. A detailed visualization of the initial coding process is shown in the following chapter.

The initial coding of the transcripts was comprehensive, employing Grounded Theory Methodology (GTM) as outlined earlier. This involved segmenting the text into discrete passages and assigning contextual tags, accompanied by margin notes that captured emergent themes and observations. This process was first applied to all English-language transcripts. The Italian transcripts required a dual-layered approach: they were initially coded in their original language to preserve nuance and then re-coded after translation to English to ensure consistency and comprehensiveness in thematic analysis.

Following the initial coding phase, I engaged in substantive coding, which involved refining and merging tags to distill core themes and eliminate redundancies. This iterative process of analysis was crucial for developing a nuanced understanding of the data.

The next stage involved constructing situational maps—Messy, Ordered, Social Arena, Positional—to visually represent the relationships and dynamics within the data. This method, derived from situational analysis, helps illustrate the complex interplay of social, cultural, and personal factors influencing caregiver experiences.

In parallel with the primary data analysis, I explored themes of self-efficacy and social support using secondary sources. The National Social Health and Aging Project (NSHAP) and the National Study on Caregiving (NSOC) provided valuable insights into the U.S. context, while the Survey of Health, Ageing, and Retirement in Europe (SHARE) offered comparative data from Italy. Although these datasets vary in scope, they are pivotal in understanding the broader social and demographic contexts that frame caregiver experiences. However, given the time-frame allotted for completion of this work, the preliminary analysis of NSOC is presented.

This dual approach of primary qualitative analysis and secondary data exploration allowed for a comprehensive, cross-cultural comparative study of caregiving. It also underscored the theoretical underpinnings of the project, particularly the role of historicality in situational analysis. By integrating these diverse methodologies, I was able to capture the multifaceted nature of caregiving experiences, highlighting issues of burden, burnout, support, and resilience in a way that bridges individual narratives with broader social processes.

3.5 Conclusion

In concluding this chapter, we've delineated a methodological tapestry that integrates the layered approaches of narrative, ethnography, grounded theory, and netnography to explore the complex ecology of caregiving within Alzheimer's and related dementias contexts. Each method contributes a unique perspective and analytical strength, enriching our understanding of both the personal and collective dimensions of caregiving.

Firstly, our narrative approach, heavily influenced by Arthur Kleinman's insights, delves deep into the personal stories of caregivers, exploring the emotive and psychological terrains they navigate. This method privileges the personal narratives of caregivers, offering insights into the emotive underpinnings and existential reconfigurations brought about by their caregiving roles. It seeks to articulate the emotional and experiential aspects of caregiving, often overshadowed by the functional aspects of care.

Secondly, the ethnographic lens, drawing from the reflexive and immersive principles advocated by scholars such as Clifford Geertz, situates these personal narratives within their broader cultural and social contexts. This approach enriches our understanding of the social dynamics and cultural norms that shape caregiving practices, offering a backdrop against which the personal experiences of caregivers can be contextualized and more fully understood. The incorporation of grounded theory, particularly through the contributions of Kathy Charmaz and Adele Clarke, introduces a rigorous analytical framework for distilling key themes and patterns from the narratives. This methodology systematically transforms raw data into a structured exploration of caregiving as a dynamic social process. It ensures the study not only captures rich personal narratives but also constructs a coherent theoretical framework that reveals the underlying mechanisms at play.

Finally, netnography acknowledges the evolving digital landscapes that increasingly characterize social life, highlighting the relevance of online communities in caregiving. Inspired by the work of Robert Kozinets and Annette Markham, this approach explores how digital interactions complement and enhance traditional support networks, providing new avenues for community building and knowledge exchange among caregivers. It recognizes digital platforms as integral spaces for support, extending the geographical and emotional reach of caregiver networks.

Collectively, these methodological strands weave a comprehensive narrative that is both rich in qualitative depth and expansive in its analytical scope. They facilitate a nuanced examination of how caregiving experiences, practices, and identities are articulated, enacted, and transformed across diverse settings. This chapter sets the stage for analysis that aims to significantly enhance our understanding of caregiving, highlighting the reciprocity of individual narratives, social processes, and the mechanisms that bind them. The research is poised to offer critical insights into policy implications and support mechanisms that could profoundly impact caregivers' quality of life and effectiveness, marking a significant contribution to the fields of medical sociology and caregiving research.

Chapter 4

Data Collection and Procedure

4.1 Introduction

The primary focus of this dissertation is to explore the development of lay expertise among caregivers for individuals with Alzheimer's Disease and Related Dementias (ADRD), and how this growth can be fostered and encouraged. Additionally, the study examines the role of flourishing and self-efficacy and their mediating effects on burden, stress, and burnout—concepts extensively discussed in the preceding chapters. A shared component among these themes is the transference of knowledge and experiential learning, which is crucial in the caregiving journey.

Embarking on this research presented unique challenges. As an immigrant and non-native Italian speaker delving into a new field, I faced dual hurdles of cultural adaptation and professional unfamiliarity. Italy in 2022 was still grappling with the aftermath of the COVID-19 pandemic, with restrictions in place, particularly in clinical settings. These limitations posed ethical dilemmas related to personal privacy, mobility, and defining essential contact. At the outset, there was a lack of familiarity with the field and connections with key stakeholders—an obstacle that required immediate attention.

To navigate these challenges, active outreach to professionals in the field became essential. Psychologists, non-profit organizations, nurses, and primary care physicians were contacted to establish a network. Given that this is primarily a qualitative project focused on narrative exploration, experience, and grounded theory—with significant emphasis on observation and field notes—close interaction was crucial. However, in 2022, establishing direct contact with caregivers and medical professionals involved with people living with ADRD posed significant risks that many were unwilling to take. Despite the sympathy and interest expressed during initial outreach efforts, it became evident that COVID-19 restrictions would prevent many stakeholders from meeting in person.

Ironically, a comprehensive study on lay expertise was made possible largely through the goodwill of medical professionals who acted as intermediaries, connecting with caregivers. This dynamic was also applied to fieldwork conducted in the United States, which will be detailed in subsequent sections. A turning point occurred when the local health department eased some restrictions concerning volunteers, and the organization Rete Magica graciously allowed participation in their efforts. In April 2022, meetings were held with its founding members and full-time staff. Initially, there was some hesitation among the team regarding the role—a reaction entirely understandable given the number of ongoing studies at Rete Magica at the time. The organization was involved in several concurrent projects, including master's theses by psychologists, internships for nurses, and research on Parkinson's and clinical practices. Adding a sociologist conducting a dissertation may have contributed to a sense of "survey fatigue."

Nevertheless, the staff found the proposal intriguing, and within a few months, participation in arranging courses alongside volunteers became possible. Sharing this experience is not intended to lament the obstacles encountered but to illustrate the protective measures that institutions involved in caring for caregivers take. These institutions, mainly non-profits, carefully ensure their members are safe—both physically (by avoiding unnecessary exposure to COVID-19) and in terms of safeguarding their stories. They strive to protect caregivers from being overwhelmed by fruitless surveys or coerced into sharing their experiences with unvetted outsiders. This apprehension is telling; caregivers entrust these organizations with their loved ones[1], their own experiences, worries, and woes. It instills a deep sense of obligation to "do right" by these places, these people, and their histories.

Considering that the main focus of this project is the cultivation of lay expertise—with its genesis stemming from flourishing and empowerment—the journey from layperson to expert is shaped by various encounters. Along this path, caregivers acquire skills, receive information, and subsequently share knowledge with others. Understanding how caregivers learn to excel in their role highlights the formative impact of support services. These services provide opportunities for peer-to-peer teaching and vicarious learning, essential components in developing expertise.

The significance of support and the caregiving journey emerged as one of the most challenging aspects of this dissertation. The complex dynamics of how caregivers navigate their roles, the burdens they face, and the ways in which they develop expertise will be explored in the subsequent chapters. By examining both the

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[1] The term *Loved Ones* is used throughout this chapter and is the wording that is frequently used in online spaces and in support group settings. Throughout this dissertation there are a number of terms used to describe the individual that caregivers care for. The clinical verbage; PLWD - Person Living With Dementia, is for the most part absent beyond medical or clinical settings.

obstacles and the strategies employed to overcome them, this research aims to shed light on how lay expertise in caregiving can be nurtured and supported, ultimately enhancing the well-being of both caregivers and care recipients.

4.2 Procedure

As this project employed multiple forms of data collection, it made sense to structure this chapter into succinct sections on *how* these data collection methods were applied. The first subsection, titled *Field Work* details how data was generated from content analysis of Italian and U.S.-based Facebook groups, titled Netnography. Following the netnography section, the procedure and site description for fieldwork conducted with the Rete Magica between the fall of 2022 and the Spring of 2023 is illustrated.

Following site descriptions, the grounded theory procedure is outlined to demonstrate how interview data and transcripts were analyzed and coded. The procedure section concludes with a description of the NSOC data set and how variables were interpreted in relation to the substance of this work (e.g., Lay Expertise, Flourishing, and Self-Efficacy).

4.3 Fieldwork

4.3.1 Netnography (digital *ethnography*)

Following the COVID-19 crisis, many in-person support groups for individuals working as informal caregivers closed indefinitely (Bernabeu-Wittel et al. 2020). The closure of these support groups and care centers spurred the growth of online peer-support communities. These virtual spaces were defined as "self-care" or "self-management" regimes, addressing needs that were often unmet in formal medical settings, ranging from psycho-social support to practical caregiving techniques (Lawless et al. 2022). Social media's role in mitigating caregiver isolation and providing an outlet for frustration became a growing area of interest. Virtual spaces as intervention tools were not limited to user-generated content—they included virtual conferencing, telehealth, and internet-based videoconferences (Armstrong and Alliance 2019; Piras and Miele 2019). Caregivers find these services, often used in conjunction with medical practitioners and treatment regimes, to be overwhelmingly beneficial (Adelman et al. 2014; Chien et al. 2011; Dam et al. 2016; Varik, Medar, and Saks 2021). Studies on the efficacy and feasibility of private Facebook groups as intervention services showed promise in empowering caregivers with access to information and community-based education (Bateman et al. 2017; Johnson et al. 2022; Ruggiano et al. 2021). For researchers and healthcare professionals, these groups offered a means to identify caregiving challenges (Bachmann and Hruska 2022) and served as tools for professional education (Chan and Leung 2020). Completely virtual and user-generated support groups, however, were less frequently analyzed. When they were, they were primarily considered secondary forms of intervention, similar to in-person support groups. Netnographic approaches emphasized the importance of studying digital communities as distinct spaces with their own symbols, rules (e.g., collective imaginary), and perceptions of collective selfhood (Kozinets and Gambetti 2021; Lüders, Dinkelberg, and Quayle 2022).

Netnography was employed to gather naturally occurring data from two Facebook caregiver support groups—one English-speaking and one Italian-speaking. Participants were observed based on their participation in two public Facebook groups, each with over 5,000 members. Observational data collection began in March 2023, tracking group comment threads to identify themes of interest. The focus was on the role of virtual spaces in sharing lay expertise, the peer-to-peer transmission of caregiving knowledge, and self-care practices.In this digital ethnographic analysis, private Facebook groups were examined with permission from group administrators, and the observer functioned as a non-participatory "lurker," avoiding direct engagement with members. All personal or identifiable information was anonymized, and guidelines from the Association of Internet Researchers (AOIR), as well as institutional ethics requirements, were followed. Both the total number of posts (N=140) and the corresponding percentages were included to ensure clarity and accuracy in reporting quantitative data.

The observations centered on the spontaneous, naturalistic conversations within the groups, aiming to understand how caregivers share experiences and support one another. By following the interactions in real-time, recurring themes and patterns related to caregiving, isolation, and self-management were identified and categorized. This approach allowed for a detailed analysis of the online community dynamics and the caregiving practices discussed within the groups.

The U.S.-based Facebook group, founded by Ann Knopp Miscoi in July 2014, provides a supportive environment for caregivers to share suggestions, stress-relief techniques, and updates on dementia care. The group functions as an open forum with minimal moderation (two moderators and one administrator), allowing for free interaction among its members. It provides not only caregiving advice but also serves as a space to reduce isolation and offer emotional support through humor, shared frustrations, and encouragement. This group effectively functions as an informal intervention service, helping caregivers feel less alone in their roles.

In contrast, the Italian Facebook group, created by clinical psychologist Milena Barone, places a stronger emphasis on reflections, emotions, and practical caregiving challenges. With more active moderation by professionals and caregivers, this group encourages discussions around well-being and safety for both caregivers and those with dementia. The Italian group, though smaller and more closely monitored, fosters a broad range of conversations, from emotional support to professional advice.

It is more focused on the exchange of knowledge and caregiving techniques, serving as a medium for sharing both professional and personal caregiving insights.

4.3.2 Support Groups

In conducting this research, a multi-sited fieldwork approach was employed, encompassing both online and in-person environments across the United States and Italy. This methodology allowed for a comprehensive exploration of the caregiving experience in diverse contexts. Online platforms, particularly caregiver support groups on social media, provided invaluable insights into the digital spaces where caregivers seek advice, share experiences, and find community. These virtual environments offered a unique vantage point to observe the informal exchange of knowledge and the cultivation of lay expertise in settings unbounded by geography.

Simultaneously, in-person fieldwork was conducted through observations of support groups and direct interactions with caregivers and professionals. Engaging with organizations like Rete Magica facilitated immersion into the daily realities of caregiving. This dual approach enriched the research by capturing both the immediacy of online interactions and the depth of face-to-face engagements. It highlighted how caregivers navigate and integrate multiple support systems, both digital and physical, in their journey toward developing expertise and coping with the challenges of caregiving.

4.4 Facilities and Caregiving

Caregiving facilities play a crucial role in providing intervention services aimed at supporting informal caregivers who are responsible for individuals with chronic conditions, such as Alzheimer's disease and dementia. These services can be offered by various entities, including non-profit organizations, for-profit agencies, and state-funded programs, depending on the structure and funding mechanisms in place. Intervention services for caregivers are generally classified into two primary categories: Clinic-Based and Community and Home-Based services (Elliott 2011). Each category serves different functions and may offer varying benefits. Clinic-based services typically focus on psychoeducation and structured training for managing caregiving routines, while Community and Home-Based services emphasize practical, at-home caregiving support with personalized strategies tailored to individual needs.

Research suggests that Community and Home-Based services may be more effective in helping caregivers develop applicable skills and cope with daily caregiving responsibilities. These services often include at-home courses, direct interventions, and tailored support plans designed to meet the specific needs of both the caregiver and the care recipient. On the other hand, Clinic-Based services offer more formalized programs, such as stress management workshops, psychoeducation sessions, and therapeutic interventions aimed at addressing the emotional and psychological toll of caregiving. Facilities offering these services frequently incorporate support groups, respite care, and practical skills-building workshops to enhance caregivers' capacity to provide quality care.

A common challenge cited across the caregiving literature is the difficulty caregivers face in navigating healthcare systems and managing the bureaucratic processes involved in accessing services and support (Bruening et al. 2020). This complexity is compounded by the wide variability in service availability across different regions and countries in Europe. The level of service provision often depends on the funding mechanisms at the national and regional levels, with some regions offering more robust support structures than others (Courtin, Jemiai, and Mossialos 2014) .

In Italy, caregiving services are particularly stratified by region. In the Emilia-Romagna region, for instance, the funding for caregiving facilities is largely regional, with organizations like Rete Magica relying on government support as part of the local healthcare network, as well as charitable donations through the 5x1,000 tax program. In addition to public funding, participants in certain courses and services are required to cover additional costs. Rete Magica offers its primary caregiving courses twice a year, with enrollment periods in late August and January. The courses typically run from October to December and from February to March. During the months from March to July, the organization shifts its focus to providing respite care services and hosting special events, while maintaining a continuous helpline to offer ongoing support to caregivers.

The Rete Magica

Rete Magica is a caregiving facility located in the Emilia-Romagna region of Italy, dedicated to providing support services for caregivers of individuals with Alzheimer's disease, dementia, and other related conditions. Established as part of the regional healthcare network, Rete Magica offers a wide range of intervention services designed to meet the diverse needs of informal caregivers. These services aim to provide both practical assistance and emotional support, helping caregivers manage the often overwhelming responsibilities associated with long-term care for loved ones with neurodegenerative diseases.

As a hybrid organization, Rete Magica receives funding from multiple sources, including the regional government, through its inclusion in the regional healthcare system, and charitable donations, primarily from the 5x1,000 tax deduction scheme. This funding model allows Rete Magica to offer a variety of services at low cost, although some services, such as specialized courses, require participants to cover part of the expenses. The facility operates on a biannual schedule, with courses and programs available during two main enrollment periods: one beginning in late August, with courses running from October to December, and another starting in

January, with courses running from February to March. From March to July, Rete Magica shifts its focus to respite care services and special events, while maintaining a year-round helpline to provide continuous support to caregivers.

The intervention services at Rete Magica are divided into two broad categories: Clinic-Based and Community and Home-Based services. The Clinic-Based services include psychoeducation programs, which focus on educating caregivers about the psychological and emotional aspects of caregiving, as well as practical skills related to managing care routines. These programs are typically facilitated by trained professionals such as clinical psychologists, who guide caregivers through stress management techniques, coping strategies, and ways to handle the emotional challenges of caring for someone with Alzheimer's or dementia.

In contrast, the Community and Home-Based services focus on more personalized, hands-on support, often delivered through home visits or small group sessions. These services are designed to help caregivers develop practical caregiving skills that can be applied directly in their home environments. The Rete Magica offers courses on effective communication with care recipients, behavioral management, and strategies for reducing caregiver burnout. This category of services is particularly focused on addressing the day-to-day challenges caregivers face, providing them with tools and strategies that can immediately improve their caregiving routines.

Throughout its history, Rete Magica has been known for its adaptability to the evolving needs of caregivers. The organization has a dedicated team of full-time staff members, including clinical psychologists, social workers, and administrative personnel, as well as volunteers who assist in running the facility's programs. In April 2022, the organization welcomed the participation of external researchers and volunteers, after some Covid-19 restrictions were lifted by the local health department. Prior to this, the pandemic had imposed significant limitations on direct interaction between caregivers and medical professionals, and the facility had to adapt by relying more heavily on virtual support and remote services.

In addition to the courses offered, Rete Magica serves as a hub for various support groups, allowing caregivers to connect with one another and share their experiences. These groups include Spazio ai Caregivers, Gruppo ABC, and Mutuo Aiuto Caregivers, each designed to target different aspects of the caregiving experience and provide tailored support to participants. The facility's support groups are facilitated by professionals with backgrounds in psychology, sociology, and caregiving, ensuring that participants receive expert guidance alongside peer support.

One of Rete Magica's hallmark features is its flexibility in addressing both the psychological and practical needs of caregivers. Recognizing that caregiving is not just a matter of managing tasks but also a deeply emotional experience, the facility offers a range of services that address the mental health and well-being of caregivers. The courses and support groups often incorporate mindfulness exercises, stress management techniques, and relaxation practices such as guided meditation and controlled breathing. These interventions help caregivers mitigate the physical and emotional tolls associated with long-term care, reducing the risk of burnout and promoting resilience.

Beyond its core programs, Rete Magica also plays a role in broader community outreach and advocacy for caregivers. The organization regularly organizes events aimed at raising awareness about Alzheimer's and dementia and the challenges faced by caregivers. These events include public seminars, workshops, and awareness campaigns designed to educate the general public and healthcare professionals about the needs of caregivers. By engaging with a wider audience, Rete Magica contributes to a more informed and supportive community environment for caregivers and their loved ones.

Moreover, Rete Magica collaborates with local healthcare providers, non-profit organizations, and academic institutions to conduct research on caregiver needs and intervention effectiveness. This research aims to improve the understanding of caregiving challenges and inform the development of more effective support services. For instance, the facility has been involved in studies examining the role of "lay expertise" in caregiving, exploring how informal caregivers develop practical knowledge and coping mechanisms through their lived experiences. These collaborations have positioned Rete Magica as a leader in caregiver support and innovation within the region.

As part of its commitment to continuous improvement, Rete Magica regularly solicits feedback from course participants and caregivers to refine its services and ensure they meet the evolving needs of the community. The facility also engages in regular staff training and development, ensuring that its team remains at the forefront of caregiving best practices. This dedication to high-quality service delivery has earned Rete Magica a strong reputation among both caregivers and healthcare professionals in the region.

Rete Magica provides a comprehensive and multifaceted approach to caregiver support, offering a wide range of intervention services that address both the practical and emotional needs of caregivers. Through its Clinic-Based and Community Home-Based services, support groups, and continuous advocacy and research efforts, the organization plays a pivotal role in improving the lives of caregivers in Emilia-Romagna.

4.5 Grounded Theory

In total, interview transcripts numbered 20 full-length interviews, 8 in English and 12 in Italian, and 10 hours of audio fieldnotes and recordings from courses attended throughout 2022 - 2023. Locations for interviews ranged from three public cafes, a dedicated room in the Rete Magica, and in caregiver's homes, alongside two extended telephone interviews and one virtual meeting. Some participants were known prior to conducting interviews from courses or events, others were not. Interview lengths ranged from 53:23 minutes and 2:16:41 hours. Transcription was conducted using Turboscribe which incorporates Whisper AI for extremely sophisticated transcripts with minimal cleaning.

Initial coding of the first 12 transcripts (Kaya, Ted, Cindy, Katie, Sue, Jack, Maria, Silvia, Patrizia, Sally, Marco, and Manuel) identified 1221 initial codes. These codes were then grouped and cleaned through axial coding procedures. All codes were initially generated "in vivo" that is, extracted lines of data, quoted verbatim. Codes were then reformatted to create full gerund sentences as per (Charmaz and Bryant 2019; Clarke 2019) grounded theory procedures. For example, what initially was one single line of text - *"But she always took her medications without any problems. She had her pill boxes, she knew when to take them and which ones to take." (Maria-ENG, Pos. 76)"* would then be in vivo coded as *But she always took her medications without any problems.* Following initial in vivo coding, substantive (open) codes were created *helping with medications*; this was followed by selective coding, where initial codes were grouped by selective coding. Once grouped, selective codes were then reassessed and reintegrated through axial coding. This process allowed for the generation of the following maps of what would become essential categories.

The first round of selective coding surrounding learning about disease and illness is represented visually in the figure learning disease illness. Following this coding system, a second coding system surrounding stress as understood through pathology was identified and shown in figure 4.2.

As further interviews were transcribed and coded, coding systems were modified iteratively as codes were integrated and merged. The following coding system map shows how coding for Learning about Disease and Illness as shown in figure 4.1 became renamed to reflect new data, from *Learning about Disease and Illness* to *Learning Pathology Management* shown in figure 4.3. This also was later repeated for Stressors Through Pathology in figure 4.4. Finally, following the creation of two more selective coding systems, Axial Coding (shown in figure 4.5) permitted an additional step of data abstraction. This finally gave way to the following substantive coding system and two main core categories (*building lay expertise*, and *constellation of burdens*) to which categories and subcategories were grouped alongside their codes. The following table illustrates the final coding structure that was formally applied to the last three transcripts when coded.

4.5.1 Ground Theory Coding Matrixes

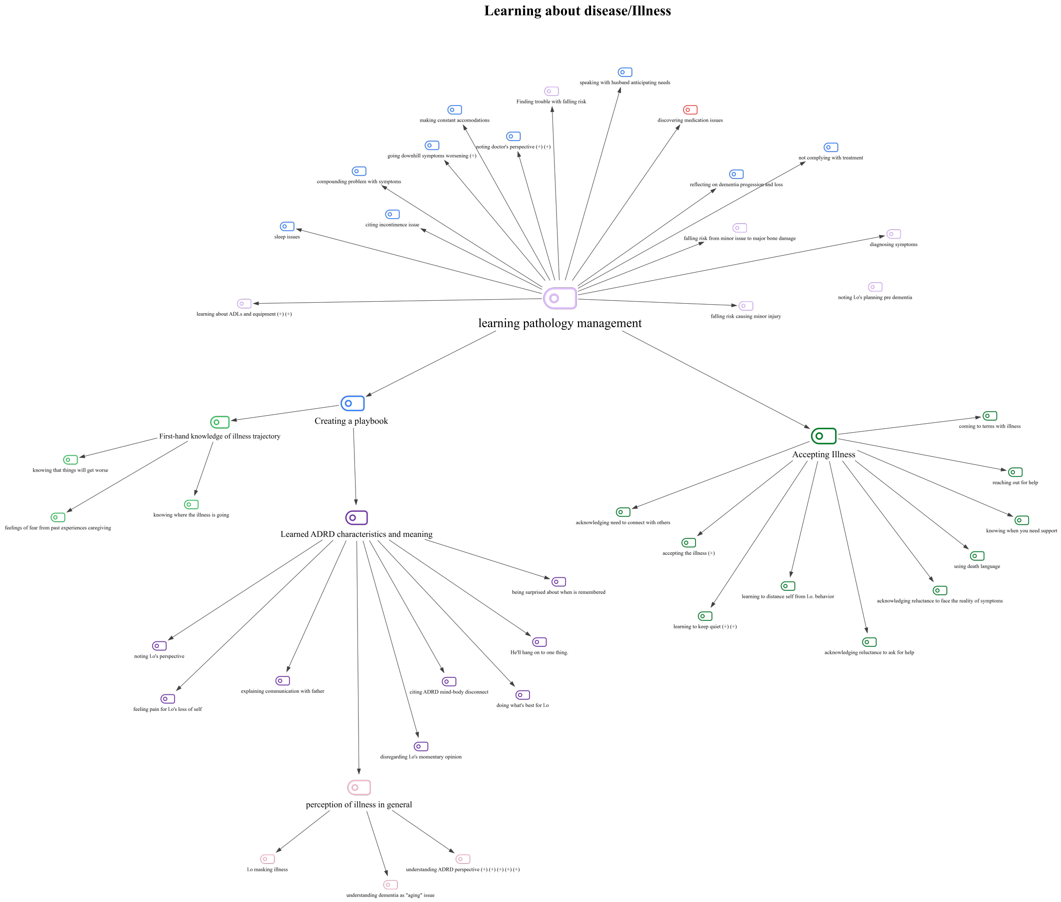

Figure 4.1: Learning About Disease and Illness

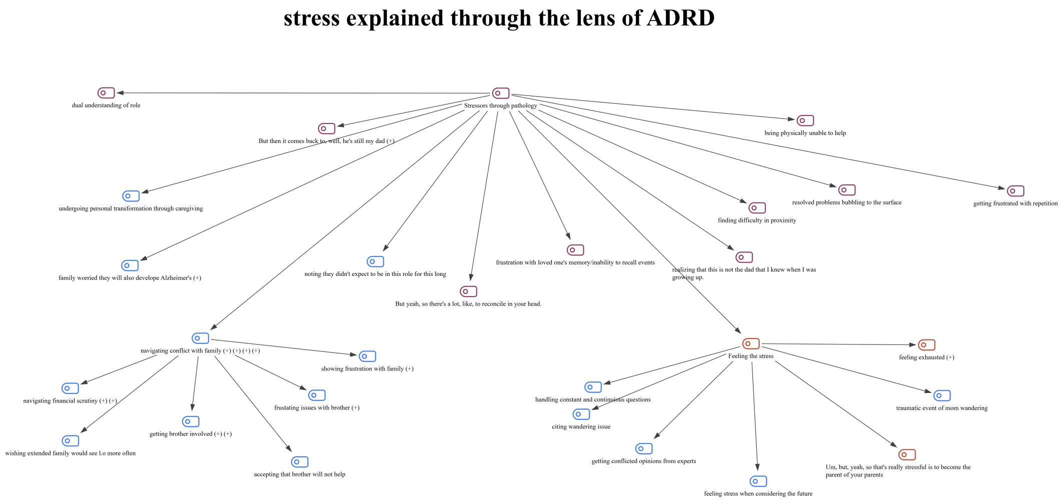

Figure 4.2: Stressors Through Pathology Preliminary

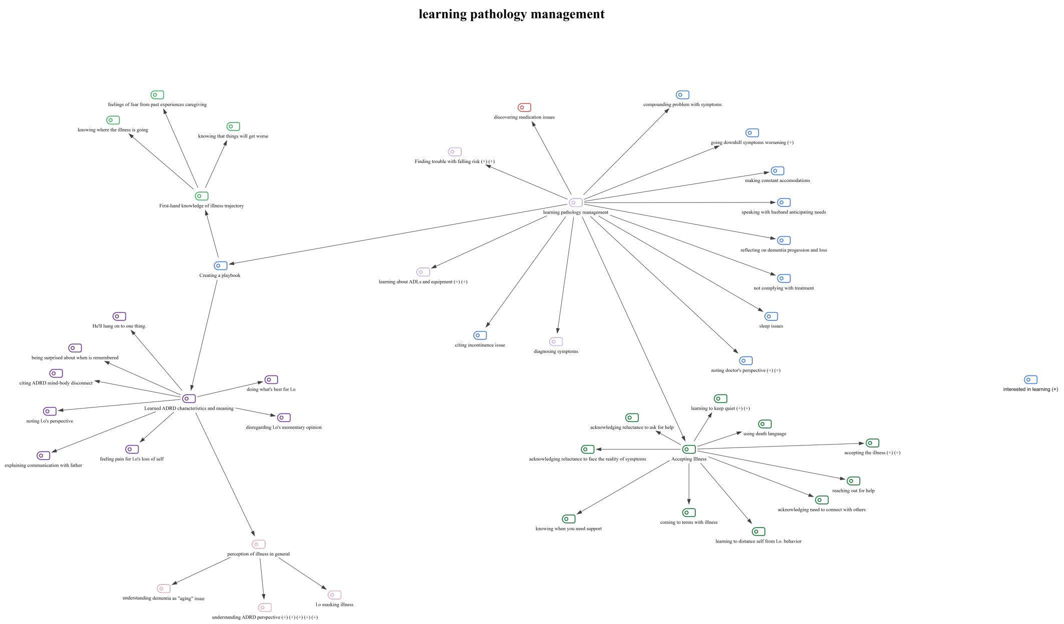

Figure 4.3: Learning Pathology Management

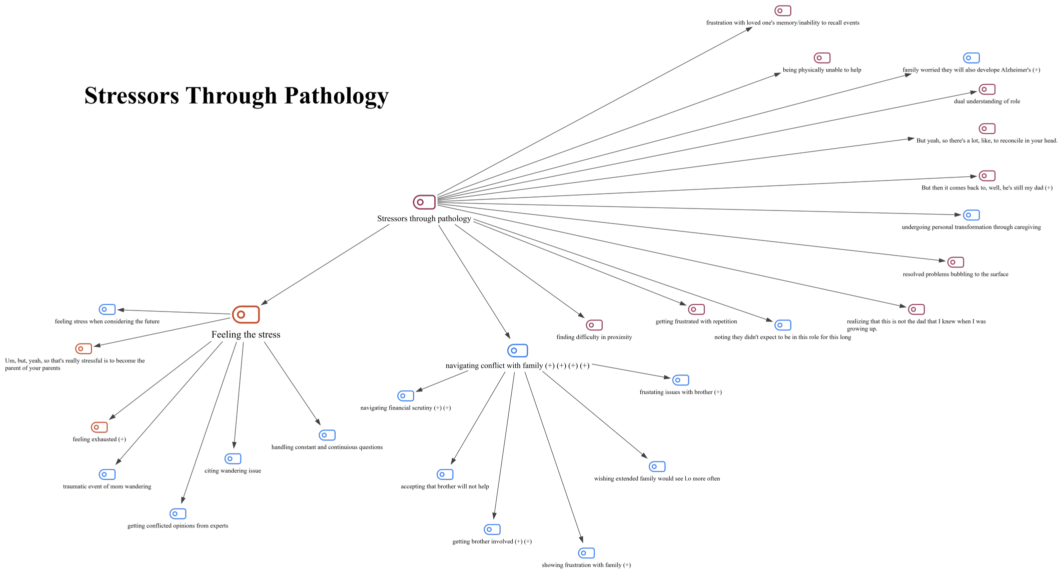

Figure 4.4: Stressors Through Pathology Substantive

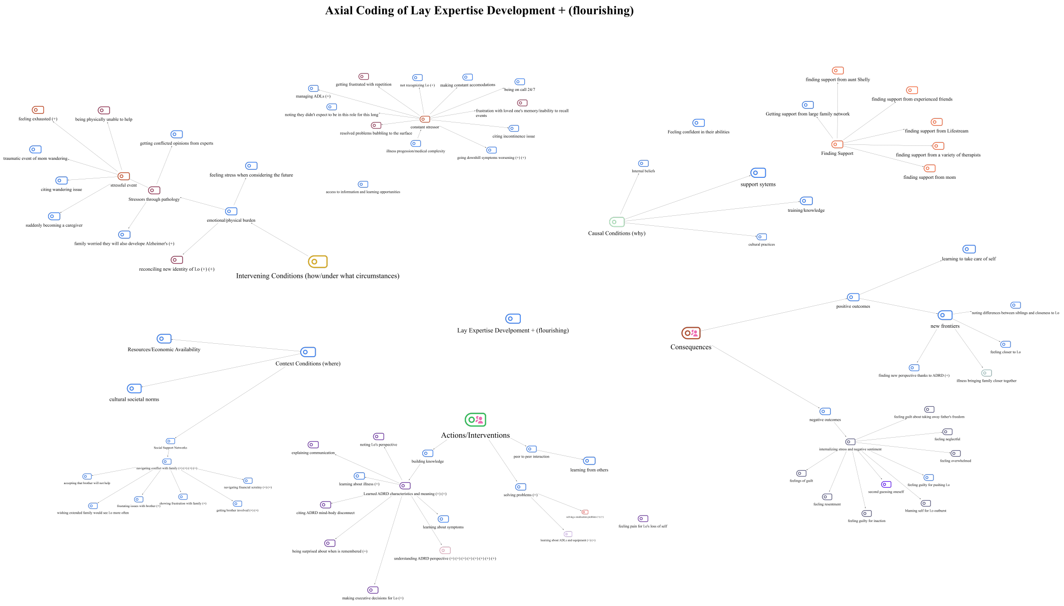

Figure 4.5: Axial Coding

4.6 Caregiving and Perceived Self-Efficacy in Data Sets

Caregiving outcomes, particularly in relation to stress and burden, are heavily shaped by perception. Perceived isolation, or the feeling of being socially disconnected, plays a key role in determining negative health outcomes for caregivers. The concept of burden, whether it is emotional (subjective) or related to caregiving tasks (objective), depends largely on how caregivers internalize their responsibilities. Research shows that caregivers' self-reflection, the length of time they've been in the role, and the compounded health and social strains all influence how they experience burden. This underscores the importance of subjective experience when examining the broader impact of caregiving on health and well-being (Cornwell and Waite 2009; Santini et al. 2020). Efficacy, or the belief in one's ability to manage tasks and relationships, is equally critical in caregiving. Both social efficacy—the confidence to maintain relationships—and self-efficacy—the belief in handling caregiving tasks—are vital in navigating stress. Caregivers who feel more effective in their role are better equipped to manage stress and seek help when needed, allowing them to maintain better mental health outcomes. As I move into the next section, the focus shifts to how these perceptions of burden and efficacy manifest in caregiver narratives, revealing key insights into their lived experiences across different caregiving contexts.

4.6.1 The National Study on Caregiving

The study began with a secondary analysis of the National Study on Caregiving (NSOC), a sub-study administered by the National Health and Aging Trends Study(NHATS).[2] The NSOC is designed to represent caregivers of individuals that took part in the NHATS study who take care of a person with limitations in daily activities. By merging NHATS and NSOC files by sample person ID (SPID, NHATS respondant) and an Other Person Id (OPID), researchers can focus on specific types of pathology or illness that an NHATS participant reported. To follow previous studies, I elected to focus only on primary caregivers There is both a longitudinal sample and a cross-sectional sample (Sullivan et al. 2022). Using a two-stage eligibility process, with one for care recipients and one for caregivers that help with any activity.

Prior to the merging process, filters were applied to the NHATS dataset to exclude rows based on specified conditions related to the cp12dad8dem and hc12disescn9 variables. Variable cp12dad8dem indicates whether dementia was reported in prior AD8, possible values were -1 inapplicable or 1, dementia response to any AD8 items

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[2] interestingly, while modifying codes, the substantive code defined as "learning pathology management" with the subcodes of "personal reflection", "role negotiation", and "ADL/IADL management" later became the final core category of *building lay expertise*, with subcodes being modified to form substantive codes changing form.

in prior rounds. The established criteria was based off of NHATS responses to two Alzheimer's and Related dementias variables. Rows where cp12dad8dem equaled -1 were excluded. Variable hc12disescn9 identifies whether NHATS respondent has ever had dementia or Alzheimer's. Rows with responses labelled 1 for Yes, or 7 for previously reported were included. This filtering criterion was adjusted to ensure that these conditions were applied independently, permitting the inclusion of rows that satisfied either condition, rather than necessitating both. NHATS and NSOC Datasets were merged following the filtering of the NHATS dataset based on the two ADRD measures. A one-to-many merge with the NSOC dataset was executed using the left_join function from the dplyr package, predicated on a common key variable (spid). This operation resulted in the amalgamation of the datasets into a singular, comprehensive dataset, with rows aligned based on the spid value and $N = 335$.

A number of variables addressed issues that touch on perceived social support and burden through the *Aspects of Caregiving* instruments. Those include the level of family disagreement (cac12fmlydisa), caregiver perception of share of caregiving workload (cac12careamt), level of physical exhaustion (cac12exhaustd), feelings of being overwhelmed with caregiving duties (cac12toomuch), and having no time for ones self (cac12notime).

This chapter has outlined the rigorous methods of data collection and procedural approaches that underpin this exploration into the development of lay expertise among caregivers. Through a combination of in-depth interviews, grounded theory coding, and secondary data analysis from sources like the NSOC, I have constructed a detailed framework to capture the dynamic and multifaceted nature of caregiving. This research delves into how caregivers acquire and adapt their knowledge within diverse settings—ranging from online support networks to in-person interactions—while addressing the nuanced factors that shape their perceived efficacy and sense of burden. In the following chapter, we explore the emergent themes, experiences, and insights shared by caregivers themselves, providing a closer look at the realities of caregiving as a transformative, and often deeply personal, journey. Here, the narratives and patterns derived from the collected data will illuminate how caregivers navigate their roles, reflect on their evolving expertise, and contend with the intertwined challenges of responsibility.

Chapter 5

Development of Lay Expertise in Caregiving

Findings derived from fieldwork in digital spaces are shared first, illustrating the defining characteristics of content generated by group users and transitioning to findings from observational fieldwork conducted at the Rete Magica after following three key groups (*spazio ai caregiver*, *Gruppo ABC*, and *Mutuo Aiuto Caregivers*).

Following fieldwork findings are the results of data analysis conducted on the NSOC survey, exploring the relationships between the variables previous mentioned (feelings of being overwhelmed with caregiving duties, family disagreement on care, levels of physical exhaustion, and having no time for ones self.).

Subsequently, findings from grounded theory analysis with interview data are shared, alongside an exploration of two key themes that emerged through data collection - the Constellation of Burdens and Building Lay Expertise. Categories and codes are elaborated under their respective theme.

5.1 Fieldwork

The fieldwork conducted at Rete Magica provided invaluable insights into the lived experiences of caregivers navigating the challenges of Alzheimer's and related dementias (ADRD). By combining traditional ethnographic methods with the netnographic analysis of digital caregiving spaces, I was able to explore both face-to-face and online support networks. Findings from Rete Magica highlight how in-person interactions facilitated deeper emotional connection and sustained support, while netnographic results revealed distinct patterns of online engagement, including the use of informational, engagement, and cathartic posts. Together, these observations illustrate the complex interplay between digital and physical caregiving communities, emphasizing the strengths and limitations of each in addressing caregivers' needs.

5.1.1 Netnography

The netnographic analysis of caregiving-focused Facebook groups provided a comprehensive view of how caregivers engage with digital platforms to seek support, share experiences, and access practical advice. Through a systematic examination of online interactions, three primary categories emerged: informational, engagement, and cathartic posts. Each category served distinct purposes within the community, with informational posts focusing on practical caregiving strategies, engagement posts fostering brief social interactions, and cathartic posts offering a space for emotional expression. While the frequency and nature of posts varied, the analysis revealed the diverse ways caregivers utilize online spaces to navigate the complexities of caregiving, with notable differences in the depth and continuity of engagement across post types. The following sections provide a detailed breakdown of these findings, beginning with informational posts, which formed the largest category.

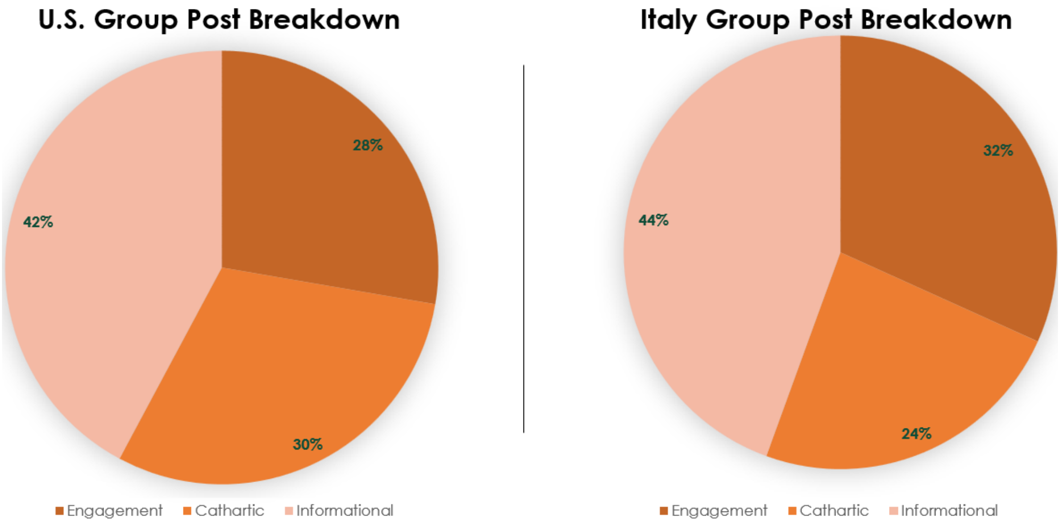


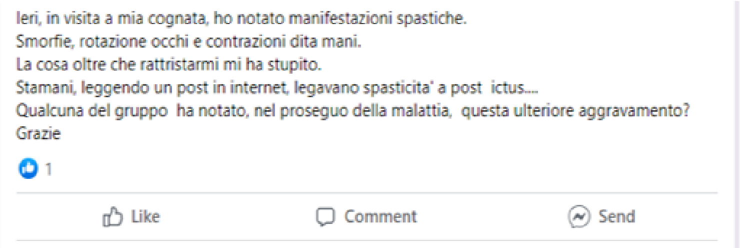
Figure 5.1: Post Breakdown

5.1.1.1 *Informational*

Informational posts formed the largest category, with an average of 35 posts per week, though they garnered relatively low community engagement, averaging only two comments per post. These posts served a utilitarian purpose, sharing specific details that were largely practical in nature. Three key themes emerged in this

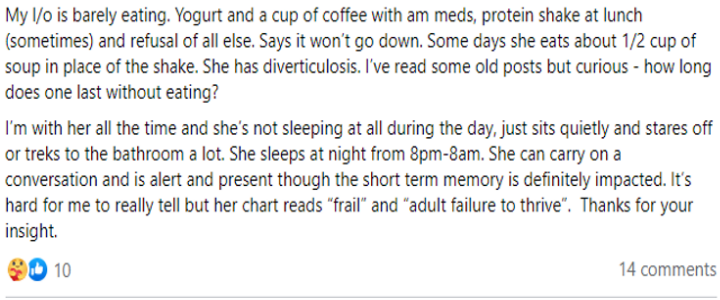
category: Disease, Destress, and Resources/Centers.
- *Keywords* used to identify Informational posts: help, suggestions, please, tips, advice, assistance, how, resources, anyone, does, ever, suggestions

- *Disease posts* were particularly prominent, often utilizing medicalized language (e.g., blood pressure, dementia stages, diet, medications). These posts typically detailed the general trajectories of diseases like Alzheimer's and related dementias (ADRD). By focusing on the biological and clinical aspects of caregiving, disease-related posts provided valuable insights into managing the medical conditions of care recipients.



Ieri, in visita a mia cognata, ho notato manifestazioni spastiche.
Smorfie, rotazione occhi e contrazioni dita mani.
La cosa oltre che rattristarmi mi ha stupito.
Stamani, leggendo un post in internet, legavano spasticita' a post ictus....
Qualcuna del gruppo ha notato, nel proseguo della malattia, questa ulteriore aggravamento?
Grazie

Figure 5.2: Informational Disease Posts One



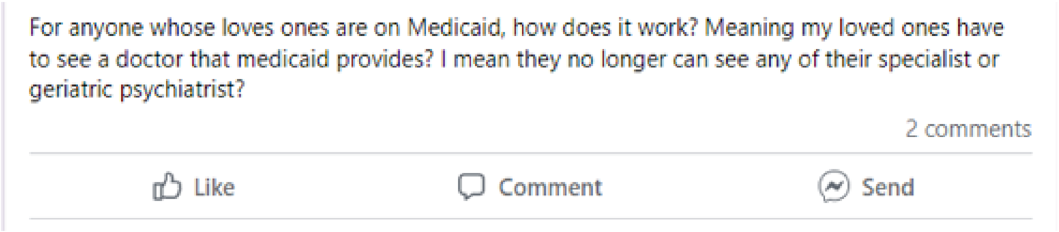
My l/o is barely eating. Yogurt and a cup of coffee with am meds, protein shake at lunch (sometimes) and refusal of all else. Says it won't go down. Some days she eats about 1/2 cup of soup in place of the shake. She has diverticulosis. I've read some old posts but curious - how long does one last without eating?

I'm with her all the time and she's not sleeping at all during the day, just sits quietly and stares off or treks to the bathroom a lot. She sleeps at night from 8pm-8am. She can carry on a conversation and is alert and present though the short term memory is definitely impacted. It's hard for me to really tell but her chart reads "frail" and "adult failure to thrive". Thanks for your insight.

Figure 5.3: Informational Disease Posts Two

- *De-stress posts*, although less frequent, focused on the mental health needs of caregivers, emphasizing relaxation techniques, meditation, and respite care. These posts often fell under "self-care" guidance, offering strategies to alleviate stress through moments of rest or temporary caregiving relief. However, these posts had the smallest level of community engagement.

- *Resource posts* were concerned with sharing practical tools or services available to caregivers. These posts touched on three main areas: home resources such as nanny cams or medical devices (e.g., canes, walkers), bureaucratic services like Medicaid and Medicare, and legal resources such as power-of-attorney information. Engagement was limited here, often due to regional variations in available services, as discussions frequently highlighted state-specific differences in healthcare access and legal frameworks.



For anyone whose loves ones are on Medicaid, how does it work? Meaning my loved ones have to see a doctor that medicaid provides? I mean they no longer can see any of their specialist or geriatric psychiatrist?

Figure 5.4: Informational Resource Posts

5.1.1.2 ***Engagement***

Engagement posts were the second most common category, with an average of 23 posts per week. These posts attracted a higher level of community interaction, averaging five comments per post. However, despite the increase in comments, sustained conversations or repeat engagement were limited. Two main types of posts define this category: Humor and material.
- *Keywords* associated with Engagement posts: interesting, must-read, surprising, food for thought, strange, haha, (emojis: *shrug*, *cry-laugh*)

- *Humor posts* aimed to lighten the mood and foster interaction within the group, often featuring content like YouTube videos, memes, or gifs. Uplifting stories or jokes provided a form of emotional release and encouraged brief moments of connection among users. While these posts had a relatively high level of engagement, they did not result in extended discussions, functioning more as a temporary reprieve from caregiving responsibilities.

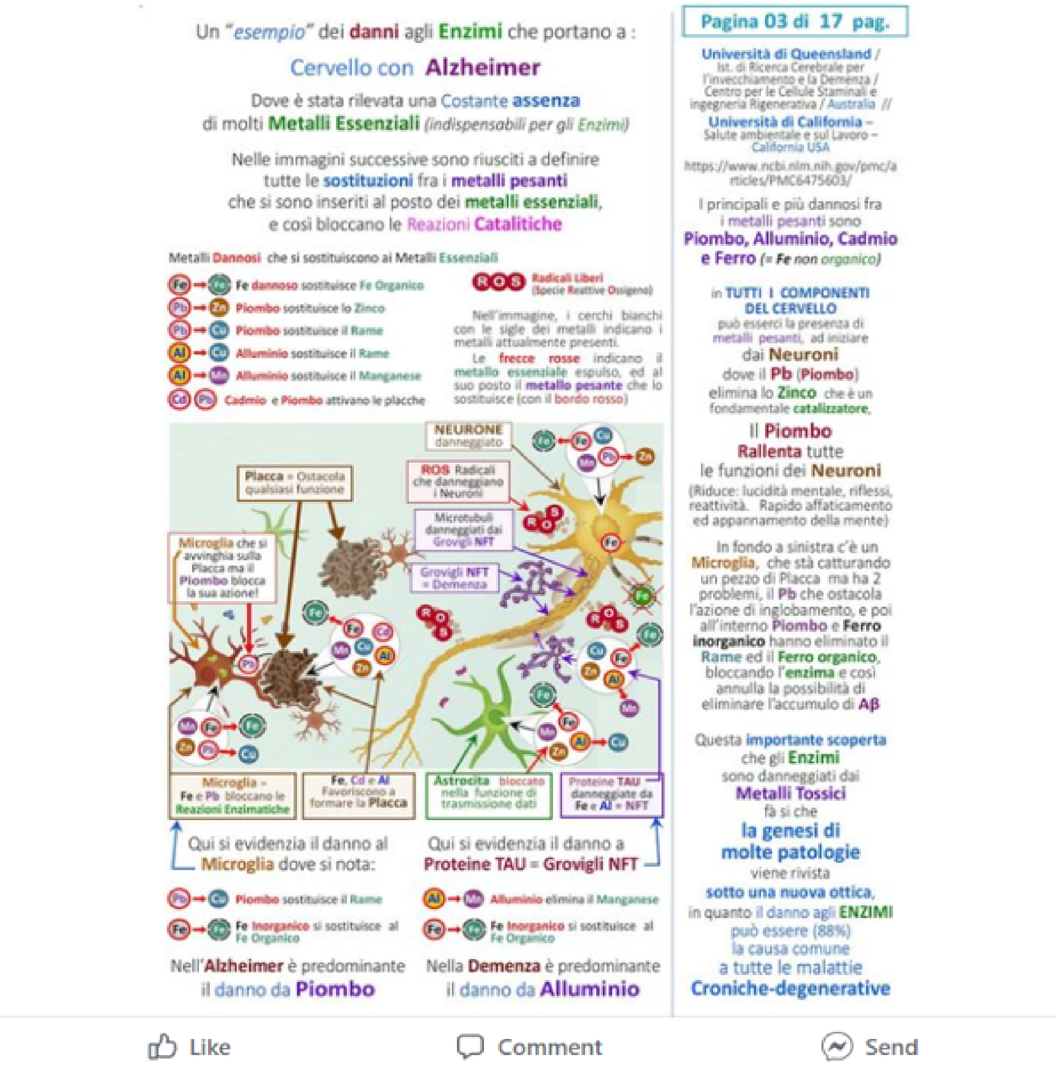
Kind of like this. 🤷‍♀️

When you realize that no help is coming, you're an adult, and have to motivate yourself to move forward

[redacted]

Figure 5.5: Engagement Post Humor

- *Material posts* dealt with general information about ADRD, aging, and caregiving but were largely non-specific in nature. Unlike Informational posts, they did not directly address pressing caregiving needs or practical advice. Instead, these posts often promoted books, articles, or other reading material that was of tangential interest. Unsurprisingly, these posts garnered the lowest levels of engagement, likely due to their broader and less immediately applicable content.


Un "*esempio*" dei **danni** agli **Enzimi** che portano a :

Cervello con **Alzheimer**

Dove è stata rilevata una Costante **assenza**
di molti **Metalli Essenziali** *(indispensabili per gli Enzimi)*

Nelle immagini successive sono riusciti a definire
tutte le **sostituzioni** fra i **metalli pesanti**
che si sono inseriti al posto dei **metalli essenziali**,
e così bloccano le Reazioni **Catalitiche**

Metalli Dannosi che si sostituiscono ai Metalli Essenziali

- Fe → Fe **Fe dannoso** sostituisce Fe Organico
- Pb → Zn **Piombo** sostituisce lo Zinco
- Pb → Cu **Piombo** sostituisce il Rame
- Al → Cu **Alluminio** sostituisce il Rame
- Al → Mn **Alluminio** sostituisce il Manganese
- Cd Pb **Cadmio** e **Piombo** attivano le placche

ROS Radicali Liberi (Specie Reattive Ossigeno)

Nell'immagine, i cerchi bianchi con le sigle dei metalli indicano i metalli attualmente presenti.

Le **frecce rosse** indicano il **metallo essenziale** espulso, ed al suo posto il **metallo pesante** che lo sostituisce (con il bordo rosso)

Qui si evidenzia il danno al **Microglia** dove si nota:

- Pb → Cu **Piombo** sostituisce il Rame
- Fe → Fe Fe **Inorganico** si sostituisce al Fe Organico

Nell'**Alzheimer** è predominante
il danno da **Piombo**

Qui si evidenzia il danno a **Proteine TAU = Grovigli NFT**

- Al → Mn **Alluminio** elimina il Manganese
- Fe → Fe Fe **Inorganico** si sostituisce al Fe Organico

Nella **Demenza** è predominante
il danno da **Alluminio**

Pagina 03 di 17 pag.

Università di Queensland / Ist. di Ricerca Cerebrale per l'invecchiamento e la Demenza / Centro per le Cellule Staminali e ingegneria Rigenerativa / Australia //
Università di California – Salute ambientale e sul Lavoro – California USA

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6475603/

I principali e più dannosi fra i metalli pesanti sono
Piombo, Alluminio, Cadmio e Ferro *(= Fe non organico)*

in **TUTTI I COMPONENTI DEL CERVELLO** può esserci la presenza di metalli pesanti, ad iniziare dai **Neuroni** dove il **Pb** (**Piombo**) elimina lo **Zinco** che è un fondamentale **catalizzatore**,

Il **Piombo**
Rallenta tutte
le funzioni dei **Neuroni**
(Riduce: lucidità mentale, riflessi, reattività. Rapido affaticamento ed appannamento della mente)

In fondo a sinistra c'è un **Microglia**, che stà catturando un pezzo di Placca ma ha 2 problemi, il **Pb** che ostacola l'azione di inglobamento, e poi all'interno **Piombo** e **Ferro inorganico** hanno eliminato il **Rame** ed il **Ferro organico**, bloccando l'**enzima** e così annulla la possibilità di eliminare l'accumulo di **Aβ**

Questa **importante scoperta**
che gli **Enzimi**
sono danneggiati dai
Metalli Tossici
fà si che
la genesi di
molte patologie
viene rivista
sotto una nuova ottica,
in quanto il danno agli **ENZIMI**
può essere (88%)
la causa comune
a tutte le malattie
Croniche-degenerative

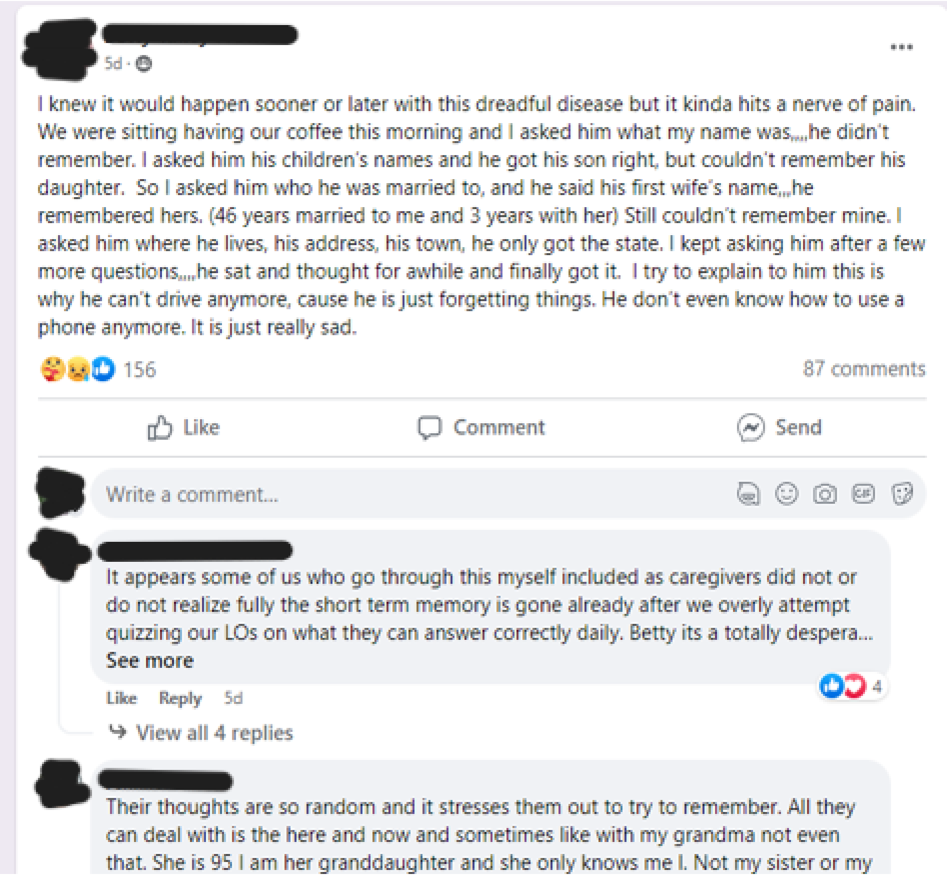
Figure 5.6: Engagement Post Material

5.1.1.3 *Cathartic*

Cathartic posts were the second most common type, with an average of 25 posts per week, and they garnered the highest level of community engagement, with an average of 8 comments per post. These posts played an essential role in providing emotional support, as caregivers shared their personal experiences, frustrations, and grief. Three subcategories emerged: Reassurance, Condolences, and Venting.

- *Keywords* commonly found in Cathartic posts: vent, lost, exhausted, angry, guilty, prayers, help, advice, suggestions, goodbye

- *Reassurance posts* provided emotional comfort to users by emphasizing shared experiences and mutual understanding. Rather than seeking clinical or technical advice, these posts focused on offering support through the sharing of personal caregiving journeys. Users frequently detailed disease trajectories and shared their expectations, hoping to connect with others who had similar experiences. This peer-to-peer reassurance was often highly engaged as users sought validation and empathy for their unique but relatable situations.



[redacted]

5d ·

I knew it would happen sooner or later with this dreadful disease but it kinda hits a nerve of pain. We were sitting having our coffee this morning and I asked him what my name was,,,,he didn't remember. I asked him his children's names and he got his son right, but couldn't remember his daughter. So I asked him who he was married to, and he said his first wife's name,,,he remembered hers. (46 years married to me and 3 years with her) Still couldn't remember mine. I asked him where he lives, his address, his town, he only got the state. I kept asking him after a few more questions,,,,he sat and thought for awhile and finally got it. I try to explain to him this is why he can't drive anymore, cause he is just forgetting things. He don't even know how to use a phone anymore. It is just really sad.

[redacted]

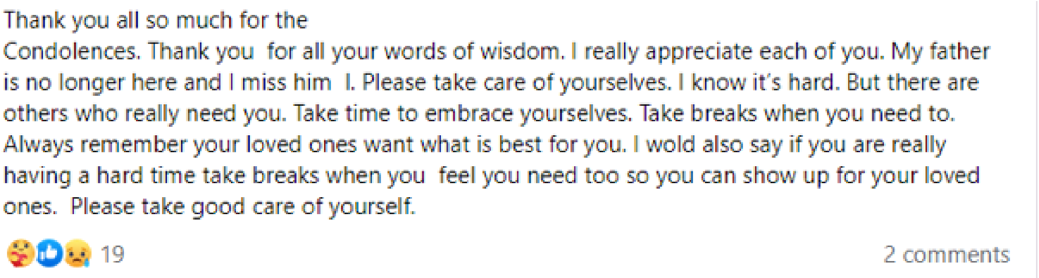
It appears some of us who go through this myself included as caregivers did not or do not realize fully the short term memory is gone already after we overly attempt quizzing our LOs on what they can answer correctly daily. Betty its a totally despera...

[redacted]

Their thoughts are so random and it stresses them out to try to remember. All they can deal with is the here and now and sometimes like with my grandma not even that. She is 95 I am her granddaughter and she only knows me I. Not my sister or my

Figure 5.7: Catharsis Post Reassurance

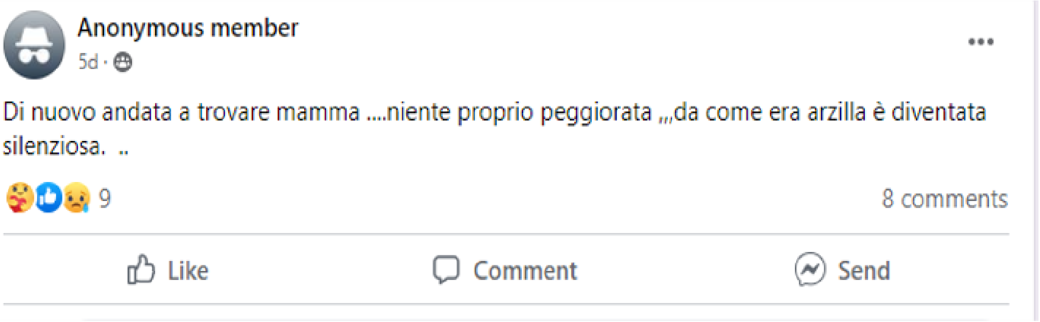
- *Condolence posts* were typically centered on loss, grief, and mourning, often following the death of a care recipient. These posts offered a space for community members to express their condolences and emotional support. Religious elements were also common, with some posts requesting prayers or sharing faith-based messages of comfort. These posts saw an outpouring of empathy from other users, often marking significant life transitions for caregivers who had lost their loved ones.



Thank you all so much for the
Condolences. Thank you for all your words of wisdom. I really appreciate each of you. My father is no longer here and I miss him I. Please take care of yourselves. I know it's hard. But there are others who really need you. Take time to embrace yourselves. Take breaks when you need to. Always remember your loved ones want what is best for you. I wold also say if you are really having a hard time take breaks when you feel you need too so you can show up for your loved ones. Please take good care of yourself.

Figure 5.8: Catharsis Post Two

- *Venting posts* represented the most common subcategory of Cathartic posts and were also the most engaged overall. These posts provided caregivers with a safe space to express feelings of frustration, anger, and burnout. Often brutally honest, these posts revealed the emotional toll of caregiving, with users confessing resentment, exhaustion, and a sense of helplessness. The raw emotional content in these posts resonated with many other caregivers, fostering a strong sense of community through shared hardship.



Anonymous member

Di nuovo andata a trovare mamma ....niente proprio peggiorata ,,,da come era arzilla è diventata silenziosa. ..

Figure 5.9: Catharsis Italian Post One

Hi, it is normal to feel no affectionate towards your LO. My mother law had mid stage dementia when i got married and never knew who i was. In the beginning i use to spend so much and take her abuse and beating. But overtime I couldn't bcoz she become manipulative and would do more because she know i would tolerate it. Now i would prepare her meals, get her meds and do everything but i dont want to hug her or show any affection. I dont know when it happened. I have a kid now and currently pregnant maybe thats why. I dint mind doing things for her but i can no longer be lovely dovy i feel maybe its resentment bcoz she has taken over my lifr. I had no married life and then stressful pregnancy and now having a child around her worrying if she will harm him. Please guide... i feel bad but i don't understand what i can do to change this!

Figure 5.10: Catharsis Italian Post Two

The content analysis of U.S. and Italian caregiver Facebook groups reveals distinct patterns of engagement, each serving different functions for those providing care to individuals with Alzheimer's and related dementias (ADRD). Informational posts are primarily focused on practical caregiving strategies, covering topics such as disease management, respite care, and available resources. However, these posts often receive low engagement, reflecting their more transactional nature. On the other hand, engagement posts, such as those containing humor, facilitate brief social interactions, while cathartic posts provide a space for caregivers to share personal struggles, frustrations, and grief. While these digital spaces offer critical peer-to-peer support, the exchanges tend to be fleeting and lack the depth seen in other forms of communication.

Although virtual support networks provide quick access to advice and emotional validation, the nature of these interactions often limits the opportunity for caregivers to fully express the complexity of their experiences. Cathartic posts, for example, reveal significant emotional burdens, yet the fragmented responses and the anonymity of the digital space can prevent deeper connections. The sense of community found in these groups is valuable, but it can also feel insufficient for caregivers seeking more in-depth discussion or sustained emotional support. Thus, while digital platforms meet an important need for connection, they rarely allow for the more profound reflection and guidance caregivers may require.

In contrast, the interview data offers a richer, more comprehensive view of caregiving experiences. Through in-depth conversations, caregivers in both the U.S. and Italy articulated their emotional burdens, caregiving strategies, and the development of lay expertise in ways that went beyond what could be captured in short online exchanges. These interviews provide a space for caregivers to explore their journeys more fully, offering insight into the challenges and resilience required in their roles. The following section will delve into these interview findings, drawing out themes related to caregiving burden, self-efficacy, and the social and cultural factors influencing caregiving practices across different contexts.

5.1.2 Support Groups

The fieldwork for the Support Groups section was conducted through in-depth observation and participation in three caregiver support programs facilitated by Rete Magica. These groups provided distinct settings for caregivers to come together, share experiences, and receive guidance tailored to their emotional and practical needs. Each group, ranging from informal discussions to structured psychoeducational sessions, offered a space for caregivers to explore coping strategies, communication techniques, and self-care practices while building a sense of community. This section introduces the diverse methods and experiences documented through these support networks, illustrating the essential role they play in caregiver well-being.

5.1.2.1 Spazio ai Caregivers

Spazio ai Caregivers began its weekly sessions in early October 2022 and continued through December 2022, providing a structured support environment for caregivers managing the care of individuals with Alzheimer's and dementia. The group consisted of five participants, ranging in age from 40 to 76 years, and included one male participant and four female participants. The participants varied in their caregiving experience, with durations ranging from one to seven years. Three participants were caring for their spouses, while two were adult children of care recipients. The group met every Tuesday afternoon at the Rete Magica facility, with each session lasting approximately 90 minutes.

Moderated by a clinical psychologist, each session focused on psychoeducational techniques and stress management strategies, tailored to address the challenges specific to caregivers. The overall aim was to equip participants with practical skills to manage the emotional and physical demands of caregiving. The content of the sessions emphasized self-care, managing negative emotions, and coping with the progressive nature of Alzheimer's and dementia care.

During the first session, held on October 4th, 2022, participants were introduced to the concept of psychoeducation and the goals of the course. Initial discussions revolved around personal introductions and an overview of each participant's caregiving journey. Over the subsequent weeks, the group explored various stress management techniques, including mindfulness exercises and breathing techniques designed to reduce caregiver burnout. In the third session, held in mid-October 2022, participants were guided through discussions on "over-caring" — a term used to describe the tendency of caregivers to become overly involved in their loved one's day-to-day tasks, which can lead to physical and emotional exhaustion. Two participants, both daughters caring for their mothers, shared that they had begun to let go of certain meticulous tasks, such as constant cleaning and monitoring, to alleviate some of their caregiving burdens.

In the fourth session, held on October 25th, 2022, religion emerged as a prominent theme. During a values-alignment exercise, participants were encouraged to reflect on how their personal values and beliefs were represented in their daily caregiving routines. Three out of the five participants cited religion as a significant, yet somewhat neglected, part of their lives. One participant, who had worked as a formal caregiver before retiring, noted that her husband had been diagnosed with dementia shortly after her retirement. She shared that her strong religious beliefs had been a source of inner conflict since the diagnosis, as she struggled to reconcile her faith with the challenges of caregiving. Another participant mentioned feeling a renewed interest in her religious practices as a way to cope with the emotional burden of caregiving, expressing a desire to reconnect with her faith community.

Throughout the sessions, Spazio ai Caregivers consistently revisited the importance of recognizing personal limits and creating emotional distance in caregiving. By November 2022, the discussions had shifted toward self-care strategies, including how to set boundaries with loved ones, acquaintances, and others to avoid emotionally draining situations. Several participants shared personal examples of how they had begun to implement these strategies in their lives. For instance, two participants reported that they had started reducing their involvement in daily caregiving tasks that were not essential, allowing them to focus on their own well-being.

In addition to discussions on self-care, the group also examined the evolving relationships between caregivers and their care recipients. As dementia progresses, the caregiver's role often shifts from a traditional family relationship (e.g., spouse or child) to that of an informal caregiver. During the sessions in late November, this theme was addressed by exploring how participants could adapt to these changes and how this shift in roles could affect their emotional well-being. The discussions included coping strategies for handling difficult emotions, such as guilt and frustration, that often accompany this role transformation.

The final sessions of Spazio ai Caregivers, held in early December 2022, focused on the consolidation of the coping techniques learned throughout the course. Participants shared their progress in applying stress management techniques and discussed the impact of the group on their caregiving routines. A recurring theme in these discussions was the importance of community support, with participants emphasizing the value of having a space to share experiences and receive guidance. The course concluded with participants reflecting on the lessons learned and the ongoing need for emotional and practical support in their caregiving journeys.

Overall, Spazio ai Caregivers provided participants with a structured and supportive environment in which they could share their experiences, learn practical coping strategies, and receive professional guidance on managing the complex demands of caregiving.

5.1.2.2 Gruppo ABC

Gruppo ABC began its first cycle of sessions on October 20th, 2022, and continued through early December 2022. The group met once a week on Thursday afternoons, with each session lasting approximately 90 minutes. The group consisted of a mix of six participants, including professional caregivers and informal family caregivers. This mix allowed for a diversity of perspectives, as professional caregivers brought their expertise and structured approaches, while family caregivers shared personal experiences. The group was facilitated by a clinical psychologist with a background in sociology, ensuring that both emotional and practical aspects of caregiving were addressed.

The focus of Gruppo ABC was on improving communication skills between caregivers and care recipients, particularly in challenging situations. The group used structured techniques such as “conversation trees” to explore how caregivers could respond to specific caregiving challenges. The primary goal was to enhance caregivers’ ability to engage in constructive and empathetic communication, improving the caregiving experience for both the caregiver and the care recipient.

In the first session, held on October 20th, 2022, participants were introduced to the concept of conversation trees, which involve mapping out potential responses to caregiving challenges and analyzing the emotional impact of each response. The session began with introductions, during which each participant shared their background and caregiving experience. The facilitator then guided the group through a discussion on a common caregiving scenario: convincing a care recipient to take a bath. One participant, a home care professional in her mid-40s, presented a situation in which a patient refused to bathe, claiming they had already done so. The group collectively brainstormed possible responses, ranging from direct confrontation (“It’s time to bathe”) to humor (“Are you sure? You don’t smell like you’ve bathed”), to logical appeals (“Bathing is relaxing, it’s good for you”). Each response was then analyzed in terms of how it might affect the care recipient’s emotions and cooperation.

In subsequent sessions, the group continued to practice using conversation trees to navigate other caregiving challenges, such as defiance from care recipients and power dynamics within family caregiving relationships. By the second session, held on October 27th, 2022, the tone of the group had shifted to a more light-hearted approach, particularly among the professional caregivers. One participant, a caregiving professional who also cared for her father at home, shared experiences of power struggles with her mother, specifically over controlling the television volume. The group discussed how defiance and confrontation often arise in parent-child caregiving relationships, with several participants noting similar experiences. The only male participant in the group, a middle-aged man caring for his parents, discussed his difficulties managing his father's resistance to caregiving while simultaneously dealing with his mother's more advanced cognitive decline.

During the third session in early November 2022, the group focused on the emotional implications of caregiving, particularly the feelings of frustration, helplessness, and confusion that caregivers often experience. The facilitator led the group in analyzing how different communication strategies could either exacerbate or alleviate these emotions. The group also discussed the concept of caregiver burnout, with several participants sharing their personal experiences of feeling overwhelmed by their caregiving duties. One participant, who had been caring for her mother for less than a year, described feeling conflicted about her relationship with her mother, citing unresolved issues from their past that complicated their caregiving dynamic. This theme of conflict in parent-child caregiving relationships was a recurring topic throughout the sessions, consistent with existing literature (Laporte Uribe et al. 2017; Lindt et al. 2020; Riffin et al. 2019)

By mid-November, the group sessions had become increasingly interactive, with participants frequently offering advice and feedback to each other. During the fourth session, held on November 10th, 2022, participants discussed how to navigate the Italian healthcare system to access resources and support for caregiving. One participant, a woman whose mother had recently been diagnosed with dementia, shared that she had initially struggled to find help due to a lack of information about available services and financial concerns. Other participants provided practical advice on which offices to contact and forms to fill out to obtain support. This session underscored the importance of peer support in helping caregivers access necessary resources. The first cycle of Gruppo ABC concluded in early December 2022 with a session focused on consolidating the communication techniques learned throughout the course. Participants reflected on the progress they had made in applying conversation trees to their caregiving situations and discussed how these techniques had helped them better understand their care recipients' emotions and reactions. Feedback from participants was positive, with several noting that the structured approach had increased their confidence in managing difficult conversations with their loved ones or patients.

The second cycle of Gruppo ABC began on February 9th, 2023, and ran through late

March 2023. This group consisted of six informal caregivers, including one medical doctor who had recently started caring for an elderly uncle. The participants had varied caregiving experience, ranging from less than one year to over 12 years. One participant, who had been attending Rete Magica courses for many years, had cared for multiple family members with dementia, including her grandmother, mother, and husband. She provided insights based on her long-term experience and was frequently looked to for advice by the other participants. In this second cycle, discussions focused heavily on the interpersonal dynamics between caregivers and care recipients, particularly in family settings. The conversation trees continued to be a core part of the group's activities, with participants exploring how different communication strategies could either reduce or escalate conflicts. During one session, the group discussed the specific challenges of communicating with elderly parents who were resistant to accepting help. One male participant, who had been caring for his father, shared that he often felt like he was "walking on eggshells" to avoid triggering confrontational responses from his father. This led to a broader discussion on the emotional toll of caregiving and the need for caregivers to manage their own emotions while dealing with difficult situations.

Throughout both cycles, the Gruppo ABC sessions provided participants with a structured environment in which they could practice communication techniques, share their experiences, and receive feedback from peers and professionals. The mix of professional and informal caregivers allowed for a range of perspectives and strategies to be discussed, making the group a valuable resource for all participants.

5.1.2.3 Mutuo Aiuto Caregivers

The *Mutuo Aiuto Caregivers* group met continuously from October 2022 through March 2023, offering a supportive environment for caregivers to share their experiences and provide mutual support. The group met weekly on Wednesday afternoons, with each session lasting approximately 90 minutes. Participants in this group were older than those in other groups, ranging in age from 74 to 87 years old. The group had a unique composition, with four male and three female participants, making it the only group where men outnumbered women. This group was also the only one moderated by a male clinical psychologist. The structure of the Mutuo Aiuto Caregivers group was more informal compared to the other groups at Rete Magica. Many participants had been attending these sessions for several years, some even after the passing of their loved ones. Of the seven core participants, four were widowed. Long-standing members had become fixtures of the group, which had been in existence for over seven years, and these individuals continued to attend regularly even after their spouses had passed away. Some participants joined the meetings remotely via Google Meet, although attendance among online participants was less consistent due to technical issues such as poor internet connections.

Each meeting began with an open discussion, where participants voluntarily reported on how their week had gone, any caregiving challenges they had faced, or other personal or current events they wanted to share. This informal structure allowed for a wide range of topics to be discussed, which were often guided by the concerns of the participants. The moderator offered psychological perspectives on these topics, providing professional insights into issues such as depression, burden, and the importance of self-care. The relaxed structure of the meetings encouraged participants to speak freely, often leading to spontaneous and varied discussions. During the first few sessions in October 2022, topics of discussion included social isolation and the challenges of maintaining friendships while providing full-time care for a loved one. One long-time participant, a widower, shared that since his wife's diagnosis, he had found it increasingly difficult to relate to his old friends, as they could not understand the emotional toll of caregiving. Other participants agreed and emphasized that the Rete Magica had become an important social outlet for them, providing a space where they could meet others who understood their experiences.

A significant portion of each session was devoted to discussing the emotional and psychological challenges associated with caregiving. In one session in November 2022, several participants talked about their experiences with caregiver burnout and the emotional toll that long-term caregiving had taken on them. A female participant who had lost her husband to dementia mentioned that she continued attending the group because it provided her with ongoing emotional support, even after her caregiving responsibilities had ended. Another participant, a man who had been attending the group for over five years, spoke about how difficult it was to make new friends after his wife's passing and how much he valued the group's long-term continuity. Despite the informal nature of the discussions, the moderator played an active role in guiding conversations, offering professional advice, and introducing relaxation exercises at the end of each session. These exercises, which included controlled breathing techniques and guided meditation, were aimed at helping participants manage their stress and improve their overall well-being. The relaxation portion of the meetings was well-received by participants, who often expressed feeling more relaxed and grounded after the sessions.

Throughout the months of observation, certain members of the group emerged as key figures who frequently contributed to the discussions. Two women who had been long-term attendees since the early days of the group often shared stories of their spouses' battles with dementia and were active in organizing events at the Rete Magica. Their continued involvement in the group, even years after their spouses had passed, underscored the social and emotional support that the group provided beyond the caregiving role itself. By January 2023, the group had settled into a consistent pattern of open discussion, personal story-sharing, and professional input from the moderator. The informal atmosphere allowed for new participants to integrate quickly into the group, and when a new participant joined, introductions were made, and the group welcomed them warmly. One notable feature of the Mutuo Aiuto Caregivers group was the flexibility in attendance; some participants attended every session, while others dropped in sporadically. Despite this variability, the core group of long-time attendees provided a sense of stability and continuity.

During a session in February 2023, one participant who had been joining the meetings online shared her frustrations with technology, expressing that technical difficulties often prevented her from fully participating in discussions. Other participants offered support and encouragement, with the moderator suggesting strategies for improving her connection and participation. This incident highlighted the adaptability of the group and their commitment to including all members, regardless of physical presence. In the final weeks of observation in March 2023, the group continued its pattern of informal discussion and social support. Topics ranged from personal caregiving challenges to broader discussions on current events and cultural topics. One session included a conversation about the political landscape in Italy, which led to a broader reflection on how societal changes had impacted caregiving services. While these discussions were not directly related to caregiving, they reflected the comfort and camaraderie within the group, allowing participants to connect on various levels.

Throughout its meetings, the Mutuo Aiuto Caregivers group provided a vital social outlet for its members, offering both psychological support and an opportunity to build lasting relationships. Long-standing members continued to play a central role in the group's dynamic, while new participants were quickly integrated into the supportive environment. The group also provided an important space for reflection, allowing caregivers to share their personal journeys and receive validation from others who had experienced similar challenges.

The qualitative insights gathered from the Rete Magica fieldwork offer a crucial foundation for understanding the emotional and social dimensions of caregiving, which complement the quantitative analysis presented in the following section on social demography and populations. These field observations underscore the intricate dynamics of caregiving, including how social support and emotional resilience are shaped by interactions within community settings. As we transition to the exploration of key variables such as loneliness, family dissatisfaction, and confidence, this analysis aims to contextualize these emotional experiences within broader population trends, offering a comprehensive view of the factors influencing caregiver well-being.

5.2 Social Demography and Populations

Drawing on 412 responses from the National Study on Caregiving (NSOC), this section examines how loneliness (`che12moodlone`), family dissatisfaction (`cac12fmlydisa`), feeling upset (`che12moodupst`), and feeling like giving up (`che12gaveup`) interrelate to shape the emotional landscape of caregiving. These variables originate from validated NSOC survey items and are coded on ordinal scales (e.g., “strongly agree” to “strongly disagree”), capturing diverse levels of emotional distress and dissatisfaction. Because many variables do not satisfy normality assumptions, Spearman’s rank correlation is applied as a robust, non-parametric tool to gauge the strength and direction of associations. Particular emphasis is placed on confidence (`che12feelconf`) as a central factor that may mediate or moderate the effects of emotional strain. Below, the correlation results illustrate how these constructs interact—laying a foundation for the subsequent mediation and bootstrap analyses that further clarify the role of confidence in caregiver well-being.

Table 5.1: Spearman’s Rank Correlation

Variable 1	Variable 2	(Spearman’s Correlation)	p-value
che12moodlone	che12feelconf	-0.354	2.46e-11
che12gaveup	che12feelconf	-0.429	<2.2e-16
che12moodlone	che12gaveup	0.203	0.00018
che12moodupst	che12moodlone	0.324	<0.001
cac12fmlydisa	che12moodlone	0.097	0.077
cac12fmlydisa	cac12notime	0.119	0.030

5.2.0.1 Interpretation

We found a moderate negative correlation between loneliness and confidence (= -0.354, $p < 0.001$), indicating that caregivers who feel lonelier tend to report lower confidence in their abilities. There was also a strong negative correlation between feeling like giving up and confidence (= -0.429, $p < 0.001$), suggesting that confidence is a protective factor against resignation. On the other hand, family dissatisfaction showed weak correlations with loneliness (= 0.097) and time constraints (= 0.119), suggesting that it is less directly connected to emotional well-being in caregivers.

5.2.0.2 Mediation Analysis

We then conducted a mediation analysis to investigate whether confidence (`che12feelconf`) mediates the relationship between loneliness (`che12moodlone`) and resignation tendencies (`che12gaveup`). The results, presented in Table 2, show that confidence mediates 71% of the total effect of loneliness on the likelihood of giving up.

Table 5.2: Causal Mediation Analysis Results

Measure	Estimate	95% CI Lower	95% CI Upper	p-value
ACME	0.1215	0.0704	0.1700	<2e-16
ADE	0.0476	-0.0575	0.1400	0.340
Total Effect	0.1691	0.0729	0.2600	<2e-16
Prop. Mediated	0.7149	0.3797	1.6100	<2e-16

5.2.0.3 Interpretation

The **Average Causal Mediation Effect (ACME)** is significant (ACME = 0.1215, p < 0.001), showing that confidence explains a substantial part of the relationship between loneliness and resignation. The proportion of the effect mediated is approximately 71%, meaning that most of the relationship between these two variables is explained by changes in confidence levels. The **Average Direct Effect (ADE)** was not statistically significant (p = 0.34), indicating that loneliness does not directly affect resignation when confidence is accounted for.

5.2.0.4 Bootstrap Analysis for Ordinal Data

To further explore the relationship between perceived burden (`cac12toomuch`), confidence, and health outcomes, we conducted a nonparametric bootstrap analysis using ordinal health outcomes (`che12health`). This method allowed us to account for the ordinal nature of the health variable, which ranged from "poor" to "excellent."

Table 5.3: Bootstrap Confidence Intervals for Ordinal Outcomes

Outcome	ACME (Control)	95% CI Lower	95% CI Upper	p-value
Pr(Y=EXCELLENT)	0.00785	0.00078	0.02007	0.026
Pr(Y=FAIR)	0.02622	0.00276	0.06567	0.020
Pr(Y=GOOD)	0.01442	-0.00194	0.05074	0.094
Pr(Y=POOR)	-0.03305	-0.08076	-0.00211	0.026
Pr(Y=VERY GOOD)	-0.01545	-0.04710	-0.00066	0.034

5.2.0.5 Interpretation

The bootstrap analysis indicates a significant indirect effect of confidence on health outcomes, particularly for those reporting excellent or poor health. For caregivers reporting excellent health, confidence has a small but positive indirect effect (ACME = 0.00785, p = 0.026), while for those reporting poor health, confidence reduces the likelihood of reporting such outcomes (ACME = -0.03305, p = 0.026). These results emphasize the role of confidence in shaping health perceptions under caregiving burden.

5.2.0.6 Findings

In summary, the correlation analysis revealed significant relationships between emotional states and caregiver confidence, with loneliness and feelings of giving up strongly linked to diminished self-efficacy. The mediation analysis demonstrated that confidence plays a crucial role in mitigating the impact of loneliness on the likelihood of resignation. Finally, the bootstrap analysis highlighted the importance of confidence in influencing overall health outcomes, particularly under high caregiving burden.

It would stand to reason that confidence, while results for its significance in mediating the relationship between feelings of depression and health outcomes are, by no means definitive, has a significant role in shaping caregiving experiences. In addition, considering the longstanding notion that vicarious learning increases perceived self-efficacy, caregiving self-efficacy can be increased effectively through meaningful social interaction with other caregivers. That being said, caregiving is not monolithic - with varying experiences and complexities that cannot fully be gleaned from data sets alone.

Quantitative findings offer an important framework for understanding the correlations between emotional states, confidence, and caregiving outcomes. However, these statistical relationships alone do not provide a comprehensive picture of the lived experiences of caregivers. To address this gap, the following section presents qualitative data gathered through interviews. These interviews are intended to provide depth to the quantitative analysis, offering insights into the personal narratives, challenges, and adaptive strategies employed by caregivers across diverse contexts. By integrating these qualitative accounts, we aim to capture the complexity of caregiving beyond what can be observed through quantitative measures alone.

5.3 Interviews

The interviews presented in this section involve a varied sample of caregivers from the United States and Italy, each contributing a unique perspective on the caregiving experience. Participants include individuals caring for spouses, parents, and other family members, each navigating the demands of caregiving in their own distinct way. These interviews provide a detailed exploration of the emotional, social, and practical aspects of caregiving. The participants described below represent a range of caregiving contexts, socioeconomic statuses, and caregiving durations, providing a diverse set of experiences.

5.3.1 U.S Interview Participants

Carolyn

Carolyn, a resident of rural Ohio, has been the primary caregiver for her grandfather since February 2021. She moved in with her mother, who lives next door, to assist her grandmother in managing her grandfather's care after he was diagnosed with vascular dementia following a stroke. Carolyn holds a degree in Social Work with a minor in Gerontology, though her initial career aspirations were not in elder care.

After completing her education at a small college in Indiana, Carolyn worked as a social worker in the foster care system in Dayton, Ohio, before transitioning to gerontology. She worked in a nursing home as a social worker and was promoted to director of social services while pursuing a master's degree in Social Work. Despite initially vowing not to work with older adults during her time in high school, an internship in a nursing home changed her perspective. Since moving back to rural Ohio, she has dedicated herself full-time to caring for her grandfather, alongside her family.

Jack

Jack, originally from rural Indiana, earned his undergraduate degree in Communications and Political Science. He moved to Los Angeles, where he worked in telecommunications for over a decade. Around seven years ago, Jack returned to Indiana to care for his mother, who had been exhibiting symptoms of dementia after a car accident that left her bedridden. A neighbor's welfare check revealed her condition, prompting Jack to step in.

Previously, Jack's father had been diagnosed with Alzheimer's and placed in a nursing home due to the physical burden of care on his mother. Jack suspects that his mother had been showing signs of dementia long before his father's condition worsened, but it went unnoticed. When his mother could no longer live independently, Jack, between jobs and seeking a change, moved back to help. Since then, he has taken on the primary caregiving role for his mother, with support from home health aides.

Kaya

Kaya, 24, has been the primary caregiver for her grandmother, who has dementia, for the past two years. She lives in the house she grew up in, located in a wealthy suburb north of the Loop in Chicago. Originally a student at Columbia College, where she studied creative writing, Kaya put her education on hold to focus on caregiving.

Before becoming a full-time caregiver, Kaya earned her massage therapy qualifications during a trip to Costa Rica. Her plans to pursue further education have been indefinitely postponed due to her grandmother's needs. Kaya is mixed race, with a Black mother and a white father, and comes from a financially well-off family. Despite her family's wealth - her father owns multiple residential and commercial properties throughout Chicago - Kaya often expresses guilt about her privilege. She hopes to eventually return to school but is currently focused on navigating her caregiving responsibilities, with plans to transition toward additional caregiving support.

Sally

Sally, originally from New Bremen, Ohio, is one of seven children who have been actively involved in caring for their father, who has been experiencing cognitive decline for about ten years. Sally's father, now 81, was diagnosed with lymphoma and has a history of dementia-like symptoms, marked by paranoia and confusion. Despite the challenges, Sally and her siblings provide support, with her brother now living with their parents to help manage their father's care and diffuse tensions between him and their mother.

Sally's mother, 75, has taken on the primary caregiving role despite the physical and emotional strain. While Sally's father was once independent and took pride in maintaining their home and handling finances, his condition has left him reliant on his family. The family dynamic has brought them closer, though it has required patience and adaptation from everyone. Sally, who works in healthcare, helps with practical aspects such as transportation to medical appointments and emotional support for her parents.

Katie

Katie grew up in Rhode Island and later moved to California during her high school years. As an adult, she relocated to Indiana with her two children, balancing the challenges of being a single parent. She pursued higher education, starting at a community college in California and later completing her bachelor's and multiple graduate degrees, including a doctorate, at Ball State University. Sociology became a significant part of her academic and personal life, aligning with her natural curiosity about why people behave as they do. Katie has lived in various regions of the United States, which has provided her with unique perspectives on life and caregiving. Her diverse experiences have shaped her understanding of family and illness, and she now applies this insight as a caregiver for her aging father, who has dementia. In navigating this role, she balances the practical demands of care with maintaining her father's dignity, safety, and comfort. Katie's deep sense of responsibility toward her parents stems from the support they gave her throughout her life. She views caregiving as a way to repay them for their unwavering care and love during her upbringing.

Though caregiving has added new demands to her life, Katie finds it rewarding to be present for her parents during their time of need. Despite the emotional and logistical challenges, she remains committed to ensuring their well-being, drawing on her family's history of care, as her mother also cared for her own mother. Katie continues to navigate the delicate balance of being a daughter and a caregiver, making decisions that prioritize her parents' needs while managing her own life.

Sue

Sue moved to California with her family in 1979, when her children were in middle and high school. She and her husband, Carl, raised two children, Katie and a son. While in California, Sue worked at a hospital and in the cafeteria alongside her son, who later sought treatment for addiction. Carl and Sue lived in California for about 40 years before deciding to move to Tennessee due to the rising cost of living and difficulties with Social Security.

In Tennessee, Carl was diagnosed with Alzheimer's, and Sue became his primary caregiver. They sought medical care at Vanderbilt for his dementia. After living in Tennessee for about five years, Sue and Carl moved to Muncie, Indiana, to be closer to their children, particularly Katie, who plays an active role in supporting Sue with caregiving responsibilities.

Sue has a background in church work, having been a secretary at a Baptist church, and her faith continues to be an important part of her life. She previously cared for her own mother, who lived with her for several years before passing away. Sue's experience with caregiving extends beyond her husband and mother, as she also worked in a hospital setting, particularly in geriatrics, which provided her with additional insights into elder care.

Cindy

Cindy, 64, has lived her entire life in Plain, Wisconsin, on the same land where she grew up. After marrying, she and her husband built their home on her family's farm, continuing the legacy of her rural upbringing. Coming from a large family—Cindy is one of 10 siblings, nine of whom are still living—she has always been closely tied to her family. Her strong connection to them has played a crucial role in her life, particularly in recent years as she has taken on an active role in caring for her aging mother.

About five years ago, shortly after the passing of Cindy's father, her mother was diagnosed with dementia. The family has since coordinated a detailed care plan to ensure their mother remains well-supported. Cindy's 71-year-old brother lives with their mother full-time, while the rest of the siblings take turns assisting with caregiving duties. They have also hired outside help for a few afternoons each week to provide additional support.

Cindy has emerged as the primary point of contact for her mother's medical care, handling appointments, managing finances, and keeping track of all necessary paperwork. The emotional burden of watching her mother's cognitive decline has been difficult for Cindy, but she finds strength in the support of her siblings. Their shared commitment allows them to fulfill their father's wish of keeping their mother at home, which brings comfort to Cindy, knowing they are honoring his memory. The family's close-knit bond has become a vital source of stability and solace during this challenging time.

Ted

Ted is an 88-year-old African American man who was born and raised in Muncie, Indiana, residing on the historically Black side of the city. Over his life, he has lived in multiple places, including Chicago, Norfolk, Ohio, and Oklahoma City, but returned to Muncie, where he worked for General Motors. He has traveled extensively across the United States, visiting every state except one.

Ted was married to his wife, Margie, for 60 years. Margie began showing signs of dementia in the years leading up to her diagnosis in October 2014. For seven years, Ted acted as her primary caregiver. Her symptoms included using incorrect ingredients while cooking, forgetting household tasks, and having difficulty recognizing people. Ted managed her care at home, handling tasks like cooking, managing medications, and assisting with mobility. He received assistance from Dr. Daniels, a local community advocate and clinical psychologist who helped Ted get in touch with social services and later hospice care. Ted kept Margie at home rather than move her to a care facility, per her preference. She passed away in 2021 after seven years of living with dementia. Ted continues to live in Muncie, maintaining connections with his children and grandchildren.

5.3.2 Italian Interview Participants

Maria

Maria, a lifelong resident of Forlì, Italy, has taken on the primary caregiving role for her aging parents. Her mother, who has been managing diabetes and high cholesterol for over 30 years, has experienced a series of small strokes, which have led to a decline in her overall health, including the onset of memory problems and cognitive decline. About three years ago, in response to her mother's increasing health challenges, Maria made the decision to bring both of her parents to live with her.

Maria's father remains relatively independent, but her mother's condition has worsened, requiring more intensive care. Maria now provides both physical and emotional support to her mother, overseeing her daily needs and managing the effects of her cognitive deterioration while also attending to her father's needs. As an only child, Maria has assumed full responsibility for their care without external assistance.

In 2022, Maria attended the Gruppo ABC, a course focused on improving communication with individuals living with dementia. During the course, she was an active participant, working to enhance her caregiving skills and better understand how to manage the complexities of her mother's condition. Maria's caregiving responsibilities have become a central part of her daily life as she continues to support her parents through their declining health.

Silvia

Silvia, from Forlì, has been a mathematics teacher at a technical institute for almost 20 years. She lives about 500 to 700 meters from her mother and shares caregiving responsibilities with her sister. Their father passed away 20 years ago, and since then, Silvia and her sister have taken turns checking in on their mother and coordinating care.

Silvia's mother has a history of health issues, including a serious autoimmune disease treated with high doses of cortisone. However, her cognitive decline began in October 2022 after she fell and broke her femur. Since the fall, Silvia has taken on a more active caregiving role, initially staying with her mother full-time for a year. Now, she stays with her mother in the evenings, while a caregiver assists during the day. Although both sisters are involved, Silvia acts as the primary caregiver.

Patrizia

Patrizia, 45, has lived her entire life in Forlì, Italy, where she was born and raised. She comes from a close-knit family and is one of two siblings. Her brother, who is single, lives with their mother and plays a significant role in caring for her since she was diagnosed with cardiovascular Alzheimer's disease in 2019. Patrizia, married and with a ten-year-old son, lives nearby and actively helps with her mother's care.

Patrizia has worked in an industrial laundry for over 20 years, a physically exhausting job that has added to the challenges of balancing work and caregiving. Despite these demands, she has taken on the responsibilities of coordinating her mother's care, managing medical appointments, and making critical decisions regarding her well-being. Patrizia and her brother have worked together to ensure their mother receives the best possible care at home, where she now attends a day center for a few hours each day.

Though Patrizia's caregiving role has been emotionally and physically taxing, she has found ways to cope, drawing strength from her brother's support and the bond she shares with her mother. Patrizia often reflects on the closeness she had with her mother before the illness, and despite the challenges, she finds moments of connection and comfort in caring for her. Along with her family's support, Patrizia has sought assistance from Rete Magica, a local caregiving network, which has provided her with resources and a sense of community. Patrizia's journey has brought her closer to her brother and son, and she continues to navigate the complexities of caregiving while balancing her roles as a mother, wife, and worker.

Alessia

Alessia is an only child who cares for both of her aging parents. Her father has suffered from bipolar disorder since 2000, which eventually led to alcoholism and a physical decline that has left him bedridden since 2018. Her mother was diagnosed with Alzheimer's in 2019 after showing signs of memory loss and experiencing multiple falls. Alessia balances caring for her parents, working at a bank, and raising her three children. She relies on a caregiver to assist while she is at work and uses tools like cameras to monitor her parents.

Alessia is deeply dedicated to her family, managing most of her parents' care while adjusting to the emotional challenges of losing them to illness. She describes her father as once being very strong and hardworking but now struggles with his aggressive outbursts. In contrast, she views her mother as fragile yet always kind despite her memory lapses. Alessia's caregiving is rooted in love and duty, though it leaves little time for herself. Despite the difficulties, she finds solace in maintaining a positive outlook and cherishing moments with her family.

Marco

Marco is a 50-year-old primary school teacher currently on medical leave, having previously worked as a lawyer. He has been a primary caregiver for his mother, who was diagnosed with dementia after the pandemic. Marco's role as a caregiver began in earnest during the summer of 2022, when he recognized that his mother's issues were more than just memory lapses and included cognitive declines that altered her personality. His father, though present, is largely unhelpful, and Marco often feels the weight of responsibility for managing his mother's care.

In addition to caring for his mother, Marco faces his own health challenges. Since December, he has been using crutches due to complications related to a foot injury. Despite this, he continues to manage his mother's day-to-day needs, including her medications and emotional support, while also attending caregiver support programs. Marco has participated in the Gruppo ABC, a communication-focused course designed for family members of those living with dementia, where he shares his experiences and strategies. Initially hesitant to open up, he became more comfortable over time, discussing topics like managing his mother's repetitive behaviors and addressing her care needs.

Marco's background as a lawyer and teacher has influenced his caregiving approach, allowing him to navigate complex emotional and practical situations with empathy and patience. His reflections on caregiving emphasize the importance of balance—ensuring his mother's well-being while maintaining his own health and personal life. Marco sees caregiving as both a responsibility and a learning experience, one that demands continuous adaptation and the support of community resources like the Rete Magica.

Anna

Anna is a 25-year-old nursery educator and master's student in pedagogy living and working in Forlì, Italy. She has been balancing her professional life with her responsibilities as a caregiver for her mother, who was diagnosed with Alzheimer's disease three years ago at the age of 59 and is now 62. Anna's father, aged 79 and retired for many years, is also deeply involved in caregiving, though Anna helps relieve some of his duties, recognizing his increasing exhaustion.

In her role as a caregiver, Anna assists her mother with daily tasks such as dressing, preparing meals, cutting her food, and ensuring that her mother can still maintain a level of autonomy whenever possible. She prepares her mother's plate in a certain way, offering one or two things at a time to prevent her from becoming overwhelmed, as her ability to process what is on the plate has diminished. She also takes on additional caregiving responsibilities, such as helping her mother with small tasks around the house to foster a sense of independence, all while ensuring safety.

Anna describes the challenges of caregiving, noting how she carefully prepares herself to take on this role before she enters the house, shifting from being just a daughter to also being her mother's caregiver. She reflects on how this dual role has shifted her relationship with her parents, especially with her father, with whom she previously experienced conflicts. Over time, their relationship has evolved into a partnership, working together as a team to support her mother.

Despite the challenges, Anna also emphasizes the importance of maintaining her own life and identity outside of caregiving. She continues to pursue her studies and work, and she finds time for herself by relying on the support network of her sister and her mother's friends, who often provide help when needed. This network allows Anna some respite, and she uses this time to study, exercise, and socialize. Nonetheless, she is deeply aware of the limited time she has left with her mother and makes an effort to spend meaningful time with her.

Anna is proud of how she has managed the caregiving role from the beginning, even though she acknowledges that it remains a difficult and evolving process. She reflects on the changes in her perspective since her mother's diagnosis, noting that her view of the future, particularly how she envisioned her mother's role as a grandmother to her future children, has shifted significantly. Despite these challenges, she emphasizes her determination to be there for her mother and to cherish the time they have together.

5.4 Grounded Theory Analysis

Through grounded theory analysis, two distinct themes emerged - Building Lay Expertise and Constellation of Burdens. Building Lay expertise encompasses the following codes and subcodes *encounters, accepting illness, and strategies* Strategies is further divided into learning, reflection, finding gratification, solving problems, changing perspectives, adaptation, and identifying good caregiving; constellations of Burdens are delineated as disruption, perceived isolation, perceived burnout, and constant stressor (with subcodes stressful event, acute symptoms intensity, contextual stressor, internal renegotiation, context-dependent burden, and dependancy level). Codes and subcodes are elaborated in the following sections, including selected interview excerpts with timestamps and line position numbers to reflect code values.

5.5 Constellation of Burdens

This core theme reflects the negative consequences of caregiving journeys. They are essentially the aspects of the caregiving journey that are associated with burden, burnout, and stress. They are the internalized network of stressors that surround a caregiver's life - whether they be mental stressors (*e.g.,* biographical disruption, closeness to loved one affecting care provision) contextualized stressors (living in a rural area, being an only child, having one's own health issues), contextualized stressors specific to the loved one being cared for both physical (*e.g.,* compounding of physical symptoms, such as hearing loss), and mental/behavioral (*e.g.,* loved one having a history of violent outbursts predating diagnosis) and the subsequent internalization of these stressors. The coding for the core category or Constellation of Burdens is as follows:

5.5.1 Disruption

This is closely related to the idea of biographical disruption - coined by Bury (1982), as a rupturing of one's internal narrative. While taking charge of caring for a family member is a watershed event in one's life, what became clear from data collection is that this moment of cataclysmic restructuring was not shared. Notably, participants with large family networks and those living in rural areas did not have this experience. Essentially, this category seeks to explain *how plans change*, and in some cases, they do not. However, one key theme that emerged when exploring stress was the changing of individual trajectories, which was shared by all participants - family conflict. In the case of this study, family conflict can be divided into two disparate substantive codes - one being contextual, that is, family conflict that predates the onset of illness and the assuming of caregiving roles, and one that stems directly from the assumption of that role. Notably, a gendered nature of care could be found in the familial strife that affected participants, largely stemming from men in the family who did not provide assistance. When posed the question - “What would drastically improve your daily life?” Alessia offered her response -

> [Alessia] (1:11:03 - 1:12:17) Well, I’m missing a husband, a partner to help me with this. My husband doesn’t help me; he’s not involved.... Because he’s not the kind of person who can give himself to others unless they’re his own parents. I don’t know if he’ll be able to do it for his own parents. Right now, his parents are healthy. I have serious doubts that he’ll be able to do it even for his own parents because he’s not someone who can sacrifice his life for others. I’ve really missed having a partner who could help me, assist me, support me in this caregiving role. I see many people who are caregivers and have the support of their partner. And it’s wonderful—it helps (Alessia-ENG, Pos. 597-607)

It is telling that this was also shared by Cindy, who mentioned a completely absent brother when posed with the question of whether there was conflict at all in the family -

> [Cindy] (13:48 - 14:32) No, well, at the beginning. So I have three brothers. And the one lives with my mom. The other one lives on a farm that I grew up on. And the other one has his own mechanic shop. So the oldest one lives with my mom, like I said. And the one that has the mechanic shop, he still comes on Tuesday nights. That’s his night. Him and his wife come on Tuesday nights. They have supper on the farm, and they stay until she’s gone to bed. But my brother that lives on the farm, him and his wife don’t help at all. And that was a bit of a conflict at the beginning. (Cindy, Pos. 135-136)

Katie also mentioned that her brother needs to be cajouled into helping with caring for their father, stating, “So he just has to be told.” Marco also mentioned his father’s absence from care;

> [Speaker 2] (14:33 - 14:43) I want to look back for a moment. You mentioned your father doesn’t fully accept her [Marco’s mother] illness. What did you mean by that?
>
> [Marco] (14:44 - 18:57) I think it’s partly his age and his personality. He was an entrepreneur, used to handling everything with confidence, but emotionally, he’s never been very expressive. I’ve never seen him cry.

> He's social, but not emotional. He still helps my mom, but I've been telling him lately that he needs to spend more time with her. In the mornings, he goes to play golf, then brings her along for some shopping. My mom enjoys shopping and sometimes buys strange things like lentil chips, just to satisfy herself. Then, my dad comes home, finds everything ready—because I've usually cooked—and after that, he just watches TV. I told him, "It's not enough to just be in the same house. You need to spend time with her." He says, "I stay home from 5 pm until midnight, isn't that enough?" I said, "Being home doesn't mean you're spending time with her." He admits it's hard for him too, saying, "If I don't go out, I'll go crazy being with her all day." And I tell him, "It's not easy for me either." I haven't said it yet, but I wonder what he would do if it were the other way around. My mom would've cared for him differently. (Marco-ENG, Pos. 48-50)

One aspect which remains clear, is that the provision of care in families opens avenues for potential conflict from a variety of sources. Carolyn, having an exceedingly large family network, cited her aunts' financial scrutiny as sources of stress. Since she provides care for her grandfather, her extended family all chip in to pay for certain expenses. However, consensus on what can be considered a necessity is hard to manage, as was establishing consensus on who should step in to provide care.[1]

> [Carolyn] (16:51 - 22:24) My aunts are all divided in regards to [...] being in agreement with us doing it [caregiving for grandfather] versus not. My aunt Cindy has only seen my grandpa twice. She is very, very mad that we got it [the house], but she will say stuff like, 'well, they got the house.' and I kind of rebuttled a little bit. Like, we *bought* the house - this wasn't a gift. It's been really challenging. I think for me, who is like totally just wanting to keep the peace. My aunt Cindy had made the comment when I first started doing this, like, 'you must think that you're some kind of miracle worker. Like he hasn't known our names for [...] the last five years.' [...] I wasn't trying to act like a miracle worker [...] but I had just said, here's what I'm doing. [she goes on to explain her caregiving regiment and background in geriatrics] So I felt challenged. [...] I think deep down inside, they're all grateful that he's not in a nursing home or that he's alive, but it's kind of a power vacuum. [...] And now, having my aunt Sally in charge, [...] It's challenging because I feel like I want to keep the peace. But my aunt Cindy, [...] makes the comments, like, that.

Family conflict, as highlighted in the data, emerges as a central theme when

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[1] Background noise made Carolyn's transcript especially difficult to transcribe. Since parts of the audio were indecipherable, coupled with Carolyn's remarkable talking speed, certain sections of the transcript are omitted and denoted as [...]. All relevant information was retained.

caregiving responsibilities are assumed. In many cases, participants like Carolyn, Alessia, Cindy, and Marco shared their frustrations about the unequal distribution of care within their families. Carolyn experienced division among her aunts, with some being supportive and others, like her aunt Cindy, showing resentment over financial decisions and caregiving roles. Similarly, Alessia expressed frustration over her husband's lack of involvement, a sentiment echoed by other participants who mentioned absent male family members. The gendered nature of caregiving was evident, as women in these families often shouldered the caregiving burden, while men were either reluctant to help or needed constant prompting. This led to increased emotional strain, as caregivers not only faced the challenges of providing care but also managing family dynamics and expectations.

The internal family strife, driven by differing views on caregiving roles and responsibilities, often compounded the sense of isolation felt by primary caregivers. As we transition to the next category, Perceived Isolation, it becomes clear that family conflict, rather than alleviating the burden of caregiving, can deepen the sense of being unsupported and alone in managing the caregiving role, despite being surrounded by relatives.

5.5.2 Perceived Isolation

Perceived isolation was divided into four subcategories that illustrate the varied sources for feeling loneliness. As mentioned in the previous chapter, much of this project has focused on *perception* that, how certain events are internalized and felt by participants. Ironically, while work is building concepts, categories, and theories from the ground up, perceived isolation grew from the data and was not imposed upon it.

Exclusivity Exclusivity refers to when caregivers feel that they are the sole caregiver for their loved ones. That there truly is no one else that could take the reigns, and if they were to stop providing care, their loved ones would suffer immensely. This idea connects to how isolation is internalized - *e.g.,* that a caregiver is the last line of defense and that no one else can help. This can also hinder caregivers from reaching out for support. A perfect encapsulation of this idea was illustrated by Alessia when speaking on her fears and anxieties when considering the future.

> [Alessia] (19:22 - 21:39) I mean, it's a small thing, but on that morning, not getting birthday wishes from your mother really hurt. But then you get used to it. As I was telling you, right now, I don't fear death. I never really feared death, but at this moment, I'm scared that something might happen to me before them. The thought that I could die, that I, who take care of them, could be gone, terrifies me. Because then, who would look after them? No one, because my children are still young, and my

> husband, no, in the sense that they're not his parents, so I don't think he would be able to do what I do. And that scares me a lot, that something could happen to me before they're gone. So I pray that they stay with us for as long as possible but that they go before me, not because of anything else, but because the idea of leaving them alone terrifies me. And I don't have the same worry about my children. I mean, I know my children will be okay; they're at the beginning of their lives—one is 19, one is 17, one is 14—they'll figure it out, either on their own or with their father or other relatives, but my parents won't. They don't have anyone, and that thought really distresses me. (Alessia-ENG, Pos. 172-173)

This is also connected to Jack's experience caring for his mother, as the vast majority of his extended relatives passed away - which served as one of the catalysts for reaching out for support from a therapist.

> [Jack] (16:30 - 17:24) I mean, it's just been so great for me. Yeah. So, you know, I was, I went to her, and I was really at the kind of end of my rope, and I was like, you know, I don't have a lot of family. I mean, my family is elderly. My sister died. All my aunts and uncles that I would rely on here were like the rocks of our family, they had their own health issues and dementia, and they started to pass away. So, I've lost like four of my aunts and uncles who were really part of my support system when I first moved back here. They all died. My mom's brother has his own mental health issues, and he moved away. My sister died. My dad died. All of this grief, and then when I kind of like, you know, I was like starting to kind of like come out of the, you know, like get to the place where I could like, you know, people's memory were a blessing to me, and I could kind of smile about it and kind of catch my breath. And then I kind of looked around. I'm like, I have zero fucking support in terms of dealing with my mother. (Jack, Pos. 204-212)

This feeling of exclusivity connects with a separate form of perceived isolation, being *rootlessness*. Rootlessness refers to perceived isolation that stems from an absence of resources and connection to the area. As for most of the participants from the United States, perceived isolation stemmed directly from a recent move. Jack, Kaya, and Sue all shared apprehensions about moving to a new area and navigating the dearth of support systems difficult.

> [Sue] (56:40 - 57:03) And here I just got involved with this one. I had the one when we first moved here because they started it just not long ago with that other gal that was doing it And Katie [her daughter] got the notification. She's the one that told me "Let's just go to the first one see what it's like blah blah blah" Katie We haven't been here that

> long I was not interested (Sue, Pos. 646-647)

Jack reflected on the dearth of support systems in rural Indiana compared to where he was living (Los Angeles) for the past few years.

> [Jack] (11:41 - 12:54) Yeah, you're going to, like, ask, well, where's the AA meeting? And any block of the street, and they'll go, oh, it's three blocks that way, you know. Yeah. So, I was so used to having that rich kind of self-help support group kind of system, it's like, zilch. I mean, it's not zero here, but it's super thin, you know. (Jack, Pos. 150-152)

In general, this sense of rootlessness is connected to a specifically arduous event that can occur during a caregiver's journey - *moving.* As interviews progressed, it became clear that caregivers who had to move - especially those interviewed from the United States were likely to express higher senses of rootlessness and perceived burden. This is further expanded on in chapter six: *Interactions of Lay Expertise and Situated Knowledge.*

Loneliness Loneliness is how perceived isolation is internalized. In line with existing literature, perceived loneliness results in negative health outcomes, both mental and physical, in participants and accelerates the acuteness of stress. Kaya explained how loneliness affects her own mental health and sense of wellbeing.

> [Kaya] (8:12 - 9:28) I've definitely lost the art and the joy of ordinary everyday life. The things that used to be shared are now done in my home because I'm on my own... Yeah, I think that I would think of it as an initiation process. Like there's this, I have a new set of responsibilities and I'm in a new role. And from that new role I am recognized by my community as doing this thing that's considered valiant. Yeah, that's the word I'm looking for. Yeah, and in terms of my health and how that's been impacted, it's kind of like you get steamrolled out every day. You get to look back and appreciate the new reality. (Kaya, Pos. 79-86)

Sally explained her mother's daily routine that was largely spent alone caring for her husband.

> [Sally] (8:52 - 9:11) Yes Yeah, and she has to pretty much she has to drive everywhere - my brother can't drive and could have seizures and cannot drive. So my mom has to do all the driving - she is there with him all the time, she can get out if my brother's there and go with her friends some but the majority of the time they stay home. I think you know, we're all so busy in our regular lives, we're all still working so much that we don't realize that they spend the whole week with almost no visitors. And so while they're dying to get company or go out - We're all just wanting to get home and kick back. So that has been a struggle because she did she feel very alone. (Sally-full, Pos. 49-54)

Italian participants did not share this sentiment of missing contact with others. All of those interviewed explained that even during the hardest points of isolation - during rolling lockdowns and stressful periods of daunting care work following accidents, they still maintained social connections with others, family members, and friends.

5.5.3 Perceived Burnout

Finally, a prime aspect of these narratives that was felt by all participants is the perceived burden. This was broken into the following substantive codes - sadness, inefficacy, guilt, loss of self, exhaustion, and anger. Originally referred to as *internalization of stress and negative sentiment*, these patterns address how burdens are felt across all subcategories. In other words, they are signs of caregiver *burnout*.

Sadness

When comparing the difference between taking care of her father with schizophrenia and her mother with Alzheimer's, Alessia found it incredibly difficult to accept her mother's condition.

Kaya spoke on her feelings of brief suicide ideation, in addition to Ted wishing he and his wife could simply pass away together.

> [Kaya] (16:51 - 17:58) Even with the material resources that I received, I still have had these like reoccurring, "I don't know if I'm able to do this." And then the way that that translates is feeling like I want to die. And that's not actually true. I don't want to die. But the ideation is visceral and sometimes daily. And that is not how I'd like to live my life. My life is so precious and valuable to me. And I'm just surprised by my own thoughts. It feels like I'm being split in half. (Kaya, Pos. 123-129)

> [Ted] (29:57 - 31:07) I relied on Dr. Daniels. There were times when she was sick or in the throes of what I thought was a death. I was busy making a pact with the devil. Just take me and leave her. Stupid stuff like that. It goes through your mind. I flushed it out of my mind. Presently, I don't do it, but it was there. And I said, sometimes I thought it would be better if we both got hit by a train. And those thoughts, sometimes those thoughts build up pretty good. Believe me, never did I even think about suicide. I never did. I'd been through that before I met Margie. So, that thought never reached me. But Dr. Daniels could understand what I was going through. She anticipated what I was going through. And she would talk to me. (Ted-full, Pos. 305-309)

This feeling of immense sadness is reflected in fieldwork conducted on Facebook groups. Caregivers who tend to have longer "venting" posts on Facebook groups based in the United States also showed clear signs of *burnout* (suicide ideation, indifference, depression, and potential signs of abuse). This connects to the following substantive

Inefficacy

The theme of inefficacy reflects the pervasive self-doubt many caregivers experience as they navigate the complex and overwhelming responsibilities of caregiving. These feelings of inadequacy stem from the constant pressure to meet the physical, emotional, and medical needs of their loved ones, often without proper training or support. Caregivers frequently question their ability to provide the necessary care, feeling unprepared and overwhelmed by the unpredictability of the conditions they are managing. This sense of inefficacy can lead to frustration, self-criticism, and guilt, as caregivers internalize the belief that they are not capable of doing enough, no matter how hard they try. It is a profound emotional struggle that undermines their confidence, leaving them feeling powerless in the face of their loved one's ongoing decline.

Anna's initial reaction to finding out her mother, who was 58 at the time of diagnosis, had Alzheimer's.

> [Anna] (9:38 - 9:49) Small. I felt very small compared to the problem, which was very big. A very big thing that's hard to manage. I still haven't fully processed or handled it. You think, "Wow, my mom." - You imagine a different life, and you realize that certain things won't happen. [...] And you think, "Wow, I wanted to get married, have children. I saw my mom as the grandmother of my children." And you say, "This won't happen." Because I can already see her struggling with my nephews, Federica's children. It's not easy. You feel small. Like a little mouse next to an elephant. (Anna-ENG, Pos. 101-123)

And Sally, when asked what the most difficult aspect of caring for her father was at the beginning

> Sally Not knowing what to do... not knowing how to like what I thought might be the best way to handle him maybe.... wasn't and trying to... I was so scared because I felt like my dad could go to a place where he was abusive with her, and then that meant I told my mom, "that can't happen." like "you will have to put him in a facility" and I knew he never wanted that. So probably that was the most frustrating is not knowing what to do. (Sally-full, Pos. 96-97)

And Kaya while acknowledging how lucky she was with the financial resources she has at her disposal

> [Kaya] (3:18 - 3:36) And without that, I wouldn't be able to be the primary caregiver in the way that I am. And even with it, I often feel, I

> often question if I'm making the right choice. (Kaya, Pos. 37-39)

The theme of inefficacy emerged as a significant emotional and psychological challenge for caregivers in this study. Participants frequently reported feelings of inadequacy as they confronted the complex demands of caregiving, often without adequate preparation or support. Anna's metaphor of feeling "small like a mouse next to an elephant" vividly captures the overwhelming nature of her mother's Alzheimer's diagnosis, underscoring the perceived imbalance between the caregiver's capabilities and the enormity of the task. Similarly, Sally expressed frustration and uncertainty about how to manage her father's aggressive behavior, fearing that any misstep could have severe consequences. Even Kaya, who acknowledged the financial resources available to her, questioned whether she was making the right decisions as a caregiver. These narratives reflect a broader pattern of self-doubt among caregivers, reinforcing the theme of inefficacy as a key element of the caregiving experience. This emotional struggle compounds the physical and logistical challenges of caregiving, contributing to the overall burden and shaping caregivers' perceptions of their roles.

Guilt Feelings of guilt were shared by many, especially those who had recently assumed the role of caregiving. Namely, guilt stemming from lacking patience or being unable to carve out their own free time away from their caregiving responsibilities. This can also inhibit caregivers from reaching out to much-needed resources such as respite care in the case of Maria -

> [Maria] (48:43 - 50:01) I was advised to take her to a day center, so I could have some freedom, but I couldn't do it—I'd feel guilty. But I did go and inquire.
> (Maria-ENG, Pos. 140)

and feeling guilty for losing patience in the case of Anna

> [Anna] (12:31 - 13:05) Like losing patience. You think, "Come on, it's something you can do, just do it." Because sometimes, in Alzheimer's, I see that she already knows she can't do some things, so she gets confused even before trying. And so you say, "Come on, you know how to do this." And then you feel guilty because you know you shouldn't respond like that. At the beginning, I struggled much more with this. (Anna-ENG, Pos. 135-137)

and feeling guilt for having a higher level of well-being when a medical emergency meant that Jack could receive respite care.

> [Jack] (17:40 - 18:40) She would, you know, have these things where she would have some sort of medical crisis, you know, emergency room, hospitalization, and then a physical rehab or sometimes she'd be in the nursing home for a little bit of time. It was always a question if she'd

> be able to stay or not. And when she, I kind of felt guilty because all of a sudden she would go to the hospital, and then someone would call and check on me a couple days later, and I realized, like, I haven't done anything except stay at home and sleep. (Jack, Pos. 223-226)

Or when personal freedoms of loved ones are traded off in exchange for safety - like the case of Katie when she had to take her father's keys -

> [Katie] (24:10 - - 24:55) So we had to take the keys away. And he just got so dejected, it's like, he's like, I feel like I'm losing everything. And because he's, he was aware enough of what was happening. Even though he knew what was happening, he didn't like what was happening. And he certainly didn't like other people making choices for him. So those are all kind of the big things that we had to get through. And [it was hard] Because… Because I felt like I was, I was the bad guy. But my mom was kind of afraid to. She didn't want to be the bad guy. (Katie, Pos. 340-362)

Or Silvia when asked how her mother feels about going to support group activities -

> [Silvia] (48:47 - 49:24) But in the end, when the person leading the group, I don't know, gives her a compliment or encourages her, she comes back very satisfied. Yes, maybe I don't encourage her enough because if I encourage her, she'll relax too much. Actually, I'm probably a bit strict and always find faults here and there, poor thing. But, well, everyone is the way they are. (Silvia-ENG, Pos. 500-501)

The theme of guilt emerged as a prevalent emotional response among caregivers, particularly those new to the role. Guilt often stemmed from feelings of impatience, the inability to take personal time or decisions that limited their loved one's independence for the sake of safety. Maria's reluctance to use respite care, Anna's regret over moments of frustration, and Jack's guilt over feeling relief during his mother's medical crises all underscore the complexity of these emotions. Katie's guilt after taking her father's keys for his safety and Silvia's strictness towards her mother further demonstrate how caregivers internalize these feelings, often questioning whether they are doing the right thing. These narratives highlight how guilt is closely tied to inefficacy, as caregivers are continually second-guessing their actions, further compounding their emotional burden.

Loss of Self

Loss of self-hood is uniquely centered around how caregivers live are completely interwoven with caregiving tasks. Their perception of their own identities is evacuated, and they are completely consumed in the caregiving role. Loss of self-hood occurs when caregivers feel their personal identities are overtaken by their caregiving responsibilities. As they dedicate themselves entirely to meeting the needs of their loved ones, their own lives, goals, and sense of individuality are sidelined. This leads to caregivers viewing themselves primarily through the lens of caregiving, often feeling disconnected from their former selves. The lack of personal time or space for self-care can result in emotional exhaustion, isolation, and a diminished sense of self-worth. Over time, this loss contributes to feelings of depression and burnout, as caregivers struggle to maintain their sense of identity outside their caregiving role.

When reflecting on the role of self-care in their daily routine of caring for their mother, Silvia mentioned challenges -

> [Silvia] (1:10:01 - 1:10:36) So far, I try to do that. But, of course, it's not always easy. You may have the time, but it's your mind that's always thinking about that. You go for a walk, you say, 'I'm taking half an hour for myself,' but in that half-hour, you're still thinking about the problem that happened that day. That's my problem, though. It's a problem with how I'm wired. I'm wired wrong in that sense; at that point, you have to stay there. I can't disconnect. (Silvia-ENG, Pos. 672-673)

Similarly, when looking back on some of the most time-consuming moments of caring for her mother with Alzheimer's who is also diabetic, Maria in her own words mentioned her own loss of self -

> [Maria] (50:03 - 50:37) Yes, because it means constantly checking her blood sugar levels to calculate how much insulin to give. Last year, in 2023, from May until September—May, June, July, August, September—I only took one day off in May, and that was it. I was always at home. Thinking back, I realized it was too much—I had completely lost myself. (Maria-ENG, Pos. 142)

or losing interest or time for hobbies or activities for Patrizia -

> [Patrizia] (38:00 - 38:12) Before all this, I used to dance. I loved Latin American dancing. But over time, I stopped, also because my husband doesn't dance at all. (Patrizia-ENG, Pos. 410-411)

One aspect surrounding self-hood is the idea of a person's own singular future, with goals, interesting, and desires/milestones of their own. For Jack reflecting on something to look forward to in the future, separate from caregiving duties felt impossible to consider -

> [Jack] (46:10 - 47:09) So I think to me that's kind of like a counter-dependence mode, and then also what I really is, the swamp is kind of like this co-dependence thing - which I really have to work on in therapy

> - where it becomes all-consuming. I don't think about my needs. She eats. He eats [points to their dog]. I don't eat. You know? You say, 'oh, what are you looking forward to?' And you're like, I don't know. I can't think of anything. All I can think about is what my mother needs today. You know? (Jack, Pos. 546-552)

Additionally, considering the future without the person being cared for presents its own source of stress and anxiety - a complex web of renegotiations and self-comparisons to others of similar stages in their lives and one's own plans.

> Carolyn So, like, I, I feel like I'm filled with a lot of, like, stress and anxiety. But it's also hard for me to plan for the future because, like, my husband and I would like to have kids. But I also know that the minute that I announce I'm pregnant, which is supposed to be the really, really exciting thing, also, like, means.... I know the minute that I announce that I'm pregnant that my mom's siblings will not allow me to continue to care give. So, I, like, as excited as what I'm, as excited as I am to have children, like, one part of me is so excited for the future to start a family and have kids, because that's what I always wanted, the other part of me is, like, filled with, like, such sadness and grief, because I know that, like, the minute that I announced that I'm pregnant, that that means that, like, my grandpa's going to a nursing home, and I know he doesn't have forever to live. And a part of me is, like, I just feel guilty that, like, it's almost like I'm pulling that rug from him. And so, it's this hard, it's this hard dynamic of, like, I can, I'm alert and oriented enough to tell you, like, I know that sounds crazy. And I know my life cannot be put on hold for my grandpa. And that, like, my time ticker is ticking, you know what I mean? But on the other, on the flip side of things, I'm also, like, I don't know. So, I think I'm excited, like, I'm guilty of saying it, but I do look forward to the future, like, when he's not here anymore. (Carolyn, Pos. 582-590)

Or when considering her own self-neglect and feelings of loneliness and exclusivity -

> [Carolyn] (1:03:23 - 1:08:10) And so, so I do think that like, different avenues, like not having that, like nine to five, or not having that, like, can add stress. Yeah, like, it adds stress. But I think it also just like, adds It adds another layer of like, like, sometimes I would tell you, like, I probably don't even recognize myself. You know what I mean? Like, I'm so absorbed in caregiving. And like, and it's hard to talk to someone else, because they don't understand. Yeah, like, my mom, I would definitely say my mom understands, but other people don't understand. And it's like, how do you, how do you make them understand? It's not even that I want them to understand, I don't want to make them understand. But

> it's kind of like, and this might be a bad example. But it's kind of like, when someone dies, like, when you lose a loved one, like, you have my sympathy means absolutely nothing. (Carolyn, Pos. 487-489)

It should be noted that a number of caregivers whose narratives touched on the concept of losing self-hood did not actually cite it as a negative consequence of becoming a caregiver. Alessia is a notable example. When asked about what she does to make time for herself, Alessia shared -

> [Alessia] (38:24 - 39:46) I teach catechism. I'm part of several community associations and volunteer groups in my town. I'm always in meetings, even in the evenings—there's this parent group for the scouts, we organize fundraisers. My life is always full. It just keeps getting fuller because every now and then something new comes along, like what we're doing now. But as I said before, this isn't a burden for me—it's a pleasure. You needed this conversation, this interview, and I'm happy to help. So, this is my time for me—doing something for others. That's what makes me happy - my time for myself is doing something for others. I'm content. We had catechism recently, and my kids made their first communion. Seeing them go through that, how well it went, and the celebration - it made all the effort worth it. That's my time for myself. But like I said, even if I had a free day, I wouldn't spend it just on myself. (Alessia-ENG, Pos. 273-283)

The theme of loss of self-hood captures how caregivers often find their personal identities overshadowed by the responsibilities of caregiving. It is also frequently cited in literature as a prime determinant of caregiver burden (Gérain and Zech 2019; Kontos and Martin 2013; Skaalvik et al. 2016). Participants like Silvia, Maria, and Patrizia described how their daily lives became consumed by caregiving tasks, leading to a disconnection from their previous interests and sense of individuality. For some, like Jack and Carolyn, this loss extends to their sense of future, as they struggle to envision life outside of caregiving. However, not all caregivers viewed this as a negative consequence. Alessia, for instance, found fulfillment in balancing caregiving with community involvement, seeing her contributions to others to nurture her own well-being. This interaction between identity and caregiving leads naturally to the next theme, *exhaustion*, as caregivers face the relentless demands of their roles with little reprieve.

Exhaustion

The theme of exhaustion is central to understanding the internalization of burnout among caregivers. Many participants described feeling physically and mentally drained, often recounting moments or events that pushed them to their breaking point. This exhaustion, both physical and emotional, emerges as a direct consequence of the sustained, unrelenting demands of caregiving. Whether through disrupted sleep patterns, the constant need for vigilance, or the emotional toll of watching a loved one decline, caregivers consistently reflect on how these cumulative stressors lead to a profound sense of weariness. This theme underscores the heavy toll caregiving takes on their overall well-being. This can be heightened when a caregiver, like Anna who works in a field where she must be attentive and care for other's needs, feels as though she may be entering a similar situation when she returns home

> [Anna] (19:21 - 19:36) I don't know, maybe because I'm a nursery educator, I'm already used to giving to others... I do that every day, all day, so sometimes I actually want to take a break and focus on myself. (Anna-ENG, Pos. 218-219)

At times, the only way to truly discover that one is exhausted is to be shaken by a specific event leading to a change of perspective making one realize that they truly are completely burnt out. For Maria this came when her father fell, leading to a change in sleeping arrangements

> [Maria] (50:43 - 51:56) Yes, because people around here didn't even understand this excessive dedication of mine. It might seem strange to you, but I was very, very caught up in my role, overwhelmed by it. Then in September, my father fell, and maybe it's like... it's like something had to happen to pull me out of that vicious cycle I was in. It was a nightmare life because, in September, this happened, so routines changed. She had to adapt. Her diabetes check-up went well, so her insulin was reduced. Now, I only give her one shot a day, which, for me, is nothing—just one in the morning. But I had hit rock bottom and couldn't continue that way. (Maria-ENG, Pos. 144)

The analogy of the *Frog in a Pot* emerged as a powerful metaphor used by several participants to articulate the gradual buildup of exhaustion in caregiving. This analogy illustrates how caregivers, much like the frog in gradually heating water, may not immediately recognize the extent of their physical and emotional fatigue until a significant event occurs. For Jack, his mother's hospitalization was a turning point, while for Maria and Carolyn, their realizations came after their loved ones experienced medical emergencies. These moments provided clarity on the magnitude of their burnout and often prompted changes in caregiving routines, such as seeking respite care. Participants emphasized that it was only through these pivotal events that they fully comprehended the degree of isolation, depression, and exhaustion they had been experiencing. This progressive accumulation of stress underscores the ongoing and pervasive nature of caregiving fatigue, which will be further explored in the next section on *Constant Stressors in Caring for a Loved One.*

5.5.4 Constant Stressor

Literature on burden and burnout suggest that determinants, while varied, do have some clear characteristics. Parts of these characteristics are contextualized and relational while others are not. The previous sections on the Core Category of *Constellation of Burdens* are in essence consequences of the intensity and duration of other burdens - that perceived burden is dependant on the acuteness of symptoms, the nature of the relationship with a loved one, long working hours, and preexisting family dynamics. The sections preceding the subcategory of *context-dependent burdens of l.o.* are in essence, the consequences of these intervening conditions.

Contextual stressor Contextualized stressors are preeminent burdens that are magnified through caregiving. These include issues of preexisting family dynamics and family histories, small family networks with limited sources for support, working long hours, having an emotionally stressful job, past relationships with loved ones altering perceived burden (e.g., loved one and caregiver having a history of physical or emotional abuse, closeness to loved one as sole support system) and having one's own health issues. These are unique to the participant's lives. Contextual stressors are fluid and inconsistently felt. At times, one's own health issues may hinder their care provision and inhibit them from carrying out ADLs/IADLs.

Internal renegotiation

Internal renegotiation refers to the stress generated from loss. This is feeling the sense of grief and managing in the day-to-day workings of caregiving. This is double-sided - with one aspect being the navigation of loss. The loss of a loved one, that this person that they knew is going through the process of dying, or that they have effectively died, produces immense feelings of sadness. Caregivers conceptualize this gradual cognitive decline as a sense of loss, with the identity of their loved one fading and leaving in its place a different person, a new identity to be reconciled. For Alessia, the sudden diagnosis of her mother with Alzheimer's left her reeling.

> [Alessia] (17:13 - 18:00) And imagine that until the summer before, in June—remember, we found out in September or October—she was still picking up my kids from school. So, you understand, she was really active, and she was an amazing grandmother, very involved. She'd pick up the kids from school, take them to soccer practice, she was very present. And living so close, it was inevitable to have a deeper relationship because when a grandparent lives far away, maybe you see them once a week, but in this case, living so close, we saw each other every day, so she was everything to the kids as well, and they really suffered because of this. (Alessia-ENG, Pos. 163-165)

For Alessia, the grief of losing her parents (her mother with Alzheimer's, her father with a degenerative cognitive impairment and schizophrenia) is a present reality to be negotiated every second momentum in daily activities is stalled.

> [Alessia] (43:42 - 43:49) It's like mourning, a loss. I've lost my parents to this illness. I haven't lost them physically, but the roles of my parents are gone. You get swept up in the daily routine, in all the things that need to be done, but when you stop, you feel that grief. It's like having a funeral before the time comes. I've already had a funeral. I've already lost my parents. The people who are here now are like delicate glass dolls to whom I give all the love I can, but they're no longer my mom. (Alessia-ENG, Pos. 321-332)

Patrizia, who had always seen her mother as her confidante, best friend, and emotional support, described the profound emotional upheaval she experienced after her mother's diagnosis. For Patrizia, this shift in her mother's identity was akin to loss, as the person she had relied on for advice and companionship was no longer the same. This emotional disconnect made it difficult for Patrizia to maintain the relationship, as she struggled to relate to her mother's changed version. The complexity of this renegotiation was evident in Patrizia's reluctance to even call her mother, as she no longer knew how to communicate with her, despite recognizing that she was still, fundamentally, her mother. The internal tension between seeing her as both the same person and someone entirely different illustrates this complex and burdensome transition.

> [Patrizia] (17:17 - 18:19) At first, since my mom was always my mom, my dad, my friend, everything. I mean, even when I was dating, I would confide in my mom. She was like a sister, you know? A friend, my best friend. At the beginning, I didn't even call her on the phone anymore. My husband would ask, "Why don't you call her?" Because I didn't… I didn't know what to say anymore. I didn't know how to relate to her. I was seeing a different person. The beginning was really hard. Yeah, it was tough at first. I knew she was still my mom, but she wasn't the same as before. I didn't know how to talk to her anymore. (Patrizia-ENG, Pos. 204-209)

Katie, whose father's cognitive health significantly declined after a debilitating fall, described the complex emotional process of reconciling his previous identity with his current condition. She highlighted the painful realization that the father she once knew—capable and independent—was no longer the same yet remained her father. This renegotiation of his identity created an internal struggle as she sought to balance her memories of him with the reality of his cognitive decline. Katie expressed the difficulty of distinguishing between these two identities, finding herself clinging to past memories to maintain a connection to the person he once was while navigating the profound changes in his present self.

> [Katie] (33:00 - 33:58) Yes. Yes. And I think in the, like, especially last

> year, it's like every year is a little bit different. But like last year, when it was really like after his wrist incident, and then with their move up here, and him just unable to do the things that he used to do was very painful. It was very, very painful because it's like, and just realizing that this is not the dad that I knew when I was growing up. But then it comes back to, well, he's still my dad. He's still your dad... But it's not the same person. So there's a lot, like, to reconcile in your head. Right. How do you distinguish the two? Like, he's not the same person, but he is the same person. I think what I cling to are the memories.
> (Katie, Pos. 519-534)

Maria shared her deep emotional struggle in recognizing her mother, often searching for familiar characteristics or behaviors that once defined her. She spoke about the painful journey of watching her mother's decline and the emotional toll of trying to care for someone who no longer feels like the person she once knew. Maria described how difficult it is to assume the role of "parent" to her own parent, a shift that has brought frustration and sadness. Despite reaching a certain level of emotional stability, she still finds herself secretly observing her mother, hoping to catch a familiar gesture or expression. The absence of these small, comforting signs leaves her feeling disconnected. When she looks into her mother's eyes, the lost gaze she encounters brings her great pain as it reminds her of how much has changed. She longs for a smile or some sweet, physical gesture that might restore a fleeting connection to the mother she once knew, but those moments have become increasingly rare.

> [Maria] (12:05 - 14:06) Yes, maybe these are steps we have to go through, probably because we experience the illness, and her illness has been a very painful journey of growth for me as well. Now, I realize that I am taking care of a sick person, but I struggle to recognize my mother. It's like - because being the parent of your parent is very difficult. It's a role we are not prepared for. Now that I've reached, let's say, a certain emotional stability - because before, I was more frustrated because I wanted to make her feel better, but it wasn't possible, it wasn't within my capabilities. Now I'm content; I take care of her as one takes care of a person in need. Sometimes, I notice that I watch her, secretly, I mean, I observe her when she's not looking at me, trying to find something of my mother in her, a gesture, a look, because most of the time, I don't recognize her. [...]I don't recognize her because she no longer has those behaviors she used to have. So, when I look into her eyes - which is hard for me - I see a lost look that causes me too much pain. I look into her eyes and see a lost gaze, as if she's trying to understand - to say - she talks, I mean, it's not that she doesn't speak, but her gaze speaks more than her words, and that lost look, I see her lost. Those lost eyes cause

> me pain. But at other times, I watch her to see if I can catch a smile. What I miss are certain physical behaviors that she no longer has. A smile, something sweet. (Maria-ENG, Pos. 50-54)

Anna reflects on the emotional challenge of remembering her mother as she once was, compared to how she is now. This process of reconciling the gradual changes in her mother's behavior and personality with her earlier memories has led to a sense of loss and confusion. Despite the guidance from her psychologist to focus on the present, Anna grapples with the fading image of her mother's former self and the complexity of accepting her current condition. Yet, through this, she finds solace in acknowledging that her mother, despite the changes, remains fundamentally the same person.

> [Anna] (32:24 - 33:00) I couldn't stop myself from thinking about it, especially the thought that I hadn't spoken to my own mother. And I thought, "I don't even remember exactly how my mom was three years ago, four years ago." You forget a bit. Maybe you miss it because you think she was different, but with the changes, you kind of forget. My psychologist told me, "Don't think about it because it just makes you feel worse." So, I guess - live in the present. She's like this now. She's like this, and it's fine, because she's still my mom. (Anna-ENG, Pos. 344-349)

The accounts of these caregivers underscore the deep emotional burden of internal renegotiation, where they must reconcile their memories of their loved ones with the stark reality of cognitive decline. For each, this process involves navigating a profound sense of loss—not of physical death, but of the identity and characteristics that once defined their loved ones. As Patrizia, Katie, Maria, and Anna illustrate, this gradual transformation often leads to an emotional disconnection, yet also requires acceptance of the present reality. While these caregivers continue to care for their loved ones, the emotional weight of balancing the past with the present remains constant. This tension between memory and the evolving reality of caregiving is deeply linked to the broader, context-dependent burdens that caregivers face, which vary significantly based on the physical health, personality, and duration of care required by their loved ones.

Context-Dependent Burden of Loved One

It became apparent early when interviewing participants that Alzheimer's, Dementia, or cognitive decline in general carries with it additional issues for a person physical health. This is mirrored in medical literature studying ADRD and multimorbidity (Martin Ginis et al. 2021) and literature on caregiver stress and burden (Liu et al. 2020). Care recipients face an increased risk of a number of additional health issues connected directly to the preeminent condition of cognitive decline. For Maria, Sue, and Katie, their loved one's hearing loss makes caregiving exceptionally difficult. As much of daily caregiving tasks are communicative - ensuring safety, answering questions, managing ADLs - hearing loss makes these tasks especially difficult.

Maria's mother also has had diabetes for the past thirty years - an issue that requires continuous surveillance and insulin injections. Sue's husband (Katie's father) does not comply regularly with treatments - between refusing his hearing aids, to removing the cast that was put on him after breaking his wrist from a serious fall. For Sally, her father's recent diagnosis with Lymphoma poses an additional set of stressors and fears

> Sally [...] So, My dad's 81, okay, and so... You know, he's just he's getting older. Yeah, and so And he was just diagnosed with lymphoma last month And I think that's been a little hard because I think it brought it really home to my mom that he's not gonna be here forever. You know what I mean? Yeah, and so probably when he started getting paranoid is when she realized that. (Sally-full, Pos. 14)

The context-dependent burden of loved one highlights how the physical health of care recipients, in addition to their cognitive decline, exacerbates the challenges faced by caregivers. Participants such as Maria, Sue, and Katie noted that conditions like hearing loss and diabetes added layers of complexity to their caregiving roles, making daily tasks such as communication and medical management more difficult. This aligns with existing literature on Alzheimer's and multimorbidity, which shows that cognitive decline often accompanies additional health issues. For Sally, the recent diagnosis of her father's lymphoma brought a heightened sense of urgency and emotional strain, further intensifying the caregiving burden. As these physical health challenges intersect with cognitive decline, they contribute to the increasing burden caregivers face, particularly as acute symptoms of their loved ones begin to intensify, which will be explored in the following section.

5.5.5 Acute Symptoms Intensity

This subcategory refers to the continuous presence of disruptive behaviors or symptoms in care recipients that consistently strain caregivers. These are not isolated incidents or signs of a dramatic worsening of the condition, but rather persistent stressors that occur regularly, contributing to the overall burden of caregiving. These symptoms often manifest as repetitive behaviors, such as repeatedly asking the same questions, constant restlessness, or sleep disturbances that disrupt the care recipient's and caregiver's routines. Additionally, they can include mood swings, such as sudden bouts of anger or emotional outbursts, which the caregiver must manage frequently.

For example, some caregivers have reported their loved ones becoming agitated or irritable when asked to remain still or follow simple instructions. Others describe the physical restlessness of their loved ones, where they would be unable to sit still for even a moment, constantly pacing or needing assistance throughout the night, leading to caregiver exhaustion. Additionally, behaviors like refusing to comply with medical treatments, removing casts or medical devices, or showing signs of paranoia—such as believing they are being persecuted or imagining events that never occurred—are common manifestations of acute symptom intensity. These persistent behaviors require constant vigilance and adaptive strategies, which cumulatively wear down the caregiver's physical and emotional resources. In essence, *Acute Symptom Intensity* captures the relentless and ongoing nature of the symptoms that may not necessarily worsen but remain a constant source of tension and fatigue in the caregiving relationship. These behaviors often feel unmanageable, not due to their escalation but their persistent and unpredictable nature.

For example, Patrizia sharing the overwhelming energy of her mother,

> [Patrizia] (12:26 - 13:23) Mom couldn't keep still [...] she was unstoppable, she walked all day, and by the evening, she had more energy than my kids. You'd sit her down for a second, and she'd stay for just a moment, not even to eat. She'd eat and get up, eat and... It was exhausting because it's something you don't know how to manage - and if you told her to "stay still," she'd get agitated, you know? And my brother, there were nights when Mom didn't sleep for three nights in a row (Patrizia-ENG, Pos. 159-172)

This unrelenting restlessness added significant strain, as Patrizia constantly monitored her mother's movements without reprieve. In this excerpt, another interrelated issue that is intense over a long period of time are noted to cause significant effects on caregiving health and well-being is sleeping issues. Maria described her mother's restless behavior at night, stating -

> Maria The big mistake I made was when I first brought her home. Since she was a bit disoriented at the beginning—because, after all, it wasn't her house—I knew she wasn't well. I have three bedrooms: mine and the two that belong to my kids. But she gets up at night to go to the bathroom.She gets up, and I thought, "If she sleeps in one of the kids' rooms and can't find the bathroom, she might fall down the stairs." and I didn't want to risk it, so what did I do? I let her sleep in my bed. After that, she never wanted to leave... Oh no. Then she was like, "When are we going to bed?" And I'd say, "You go to bed whenever you want—I'm not coming to bed just because you are." But she would stay there, waiting to go to bed. And at night, when she woke up, I'd turn on the light because... it was a nightmare - and then she would get up, go to the bathroom, I'd turn on the light, she'd go, come back, and get into bed. I couldn't sleep because... after 30 seconds, she was out again and

> I couldn't sleep anymore. (Maria-ENG, Pos. 112-120)

Agitation, restlessness, sleep disturbances, and anxiety in general were frequently mentioned in interviews. Across the board, in digital spaces, interviews, and fieldwork conducted in support groups, an exceedingly common problem that was incredibly difficult for caregivers to manage was paranoia, especially during early onset.

> Sally [...] then probably about the time he started going through this Paranoid phase. He started to make things up - they were very real to him and he was he was getting very frustrated and that's when she knew [her mother] - they were both retired at this point - So so it was never an issue of her having to leave and go to work but then she knew like, She needed help. Because he would come over here so mad and so frustrated because she doesn't believe him and so at first she would make these faces, or shake her head like this when he's telling us a story and you would see him like look over at her and he became very frustrated. kind of went through a very angry stage with her so I would just listen to him and I was just like I would never tell him like 'No, that didn't happen dad.' Like he told me like 'two patrolmen came up in their car while he was on his walk and they pulled their guns on him' - And it just, you know what I mean, and so then he became like, he would get worried about like getting in trouble with the law, so then he would like like look through this phonebook to try and find an attorney's number because he had himself convinced. He was gonna be in trouble he thought the neighbors were like putting up nasty signs about him outside I mean, it became this very - the dentist kicked him out handed him all his records - So he's like desperately looking and he would get so mad at my mom... that was the hardest part. yeah, then she knew she needed help.
> (Sally-full, Pos. 10-12)

Beyond paranoia, what on surface value would appear relatively manageable or, at the very least, not a defining characteristic of caregiver burdens, repetition, was, in fact, nothing short of exhausting for those interviewed. Marco shared his experiences of dealing with his mother's repetition -

> [Marco] (7:45 - 10:47) Communicating on that deeper level, recognizing what's really going on - it's hard. But when I manage to connect with her on that level, it's profound. That said, it's still hard. When she asks the same question 3,000 times in five minutes, it's frustrating. It feels like a hammer constantly hitting the same spot. (Marco-ENG, Pos. 27-29)

Also Cindy, who lives with her husband while one of her brothers lives with their mother, placed herself in his shoes

> [Cindy] (25:44 - 26:12) well i can't i can't imagine someone having to live in the house on a constant basis with the like repetitive stories and you know constantly she constantly asked my brother you know are you hungry you know did you eat you know what are we having constantly the same things so i'm sure it wears on him (Cindy, Pos. 245-246)

The continuous presence of disruptive behaviors such as restlessness, paranoia, and repetition create an enduring burden on caregivers, adding to the complexity and intensity of their roles. While not always worsening, these symptoms remain persistent stressors that require constant vigilance and adaptation. This ongoing strain often leads to emotional and physical exhaustion, as evidenced by many of the caregivers interviewed. Whether it's managing nighttime restlessness, frequent emotional outbursts, or dealing with paranoid delusions, caregivers are constantly navigating these stressors in their daily lives.

While acute symptoms create a constant and challenging environment for caregivers, there are also moments of heightened stress triggered by specific events. These stressful events, such as medical emergencies or sudden behavioral shifts, further intensify the caregiving experience and require immediate attention. The following section will explore these events and their profound impact on caregivers and their loved ones.

5.5.6 Events

Caregivers often face stressful events that exacerbate the challenges of their caregiving roles, as illustrated by the variety of incidents shared by participants. Falls resulting in serious injuries, such as broken bones, are a common occurrence, as seen in the experiences of Silvia, Alessia, and Patrizia, who had to navigate the aftermath of their loved ones' femur, wrist, and humerus fractures. These incidents frequently led to hospital stays, lengthy recovery periods, and a noticeable decline in their loved one's health or cognitive abilities. In other cases, sudden health crises, such as strokes or epileptic seizures, left caregivers like Patrizia and Jack feeling shocked and unprepared, adding to their emotional burden. For Katie and Anna, the gradual loss of independence—such as the ability to drive—was another trigger for stress, as it signaled the worsening of their loved ones' cognitive decline. These events often forced caregivers to adapt quickly, heightening the overall strain and anxiety of caregiving.

Notably, almost all interviewed mentioned some form of bone breakage or fracturing. In these cases, participants noted that breaks and fractures were notable signs of decline or worsening symptoms. This connects to the following subcategory identified - *Dependency Level and Intensity*

5.5.7 Dependency Level and Intensity

The code Dependency Level and Intensity (Getting Worse) captures the growing reliance of care recipients on their caregivers as their cognitive and physical abilities decline. This increasing dependency is characterized by the gradual loss of autonomy in performing even basic daily tasks, such as personal hygiene, navigating familiar spaces, or following simple commands. As their conditions progress, care recipients become more dependent on caregivers to manage everyday activities. For instance, caregivers like Sally reported that her father became confused in familiar settings, requiring constant guidance and support. Similarly, Cindy noted that her mother no longer recognized her own home, signaling a deeper cognitive decline that further intensified the caregiving burden.

This escalating dependency is not limited to cognitive symptoms but also includes physical decline, such as the onset of incontinence, mobility issues, or the inability to bathe or feed oneself. Patrizia, for example, described how her mother's cardiovascular Alzheimer's advanced rapidly over just a few years, resulting in significant behavioral changes and increasing physical care needs. Likewise, caregivers like Sue and Maria emphasized how managing the physical health of their loved ones, alongside their cognitive decline, became more challenging as their conditions worsened. This ongoing deterioration requires caregivers to take on more responsibilities, as they navigate the complexities of caring for individuals who can no longer independently manage their daily lives.

5.6 Building Lay Expertise

This category was defined relationally in that it can occur through experiential learning. It encompasses a broad range of consequences and contextual conditions/intervening actions. Essentially, this is what codes build up throughout the coding process.[2] The following categories form the core theme of *building lay expertise*

5.6.1 Encounters

Encounters are aspects of lay expertise that are mediated through contact and interaction. They are broken into two interrelated codes *feeling supported* and *interacting with doctors.* The difference is that, in many cases, interaction with medical professionals, at the very least, could be unpleasant (for Patrizia, for example) and, at worst, traumatic. They are essential to building lay expertise and connecting caregivers with the necessary resources. *Feeling Supported*

The subcode Feeling Supported under the Encounters category illustrates the crucial

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[2] I do appreciate that these studies are both named after articles of clothing.

role of external emotional, social, and practical support systems in building lay expertise for caregivers. Caregivers repeatedly describe moments where support, whether from family, friends, or organized groups, directly influenced their capacity to navigate the complex responsibilities of caregiving. This support often provided much-needed relief, practical advice, and reassurance, helping caregivers feel less isolated in their roles.

The importance of feeling supported cannot be overstated, as it directly shapes the development of lay expertise. Caregivers often enter their roles with little formal training, and the expertise they build is heavily influenced by the support they receive from family, friends, healthcare professionals, and community resources. This sense of support not only alleviates the emotional burden but also offers practical insights and strategies that enhance caregiving abilities. Many caregivers describe how being surrounded by a supportive network allowed them to gain confidence, seek advice, and access valuable resources.

For instance, being steered towards the right medical professionals or community services helped caregivers like Cindy navigate bureaucratic and logistical challenges. Similarly, peer support, such as shared experiences in support groups or family meetings, helped others like Katie and Alessia feel less isolated and more equipped to handle caregiving demands. These supportive encounters foster a sense of collective knowledge, enabling caregivers to develop lay expertise through shared learning, emotional validation, and practical problem-solving. In essence, feeling supported is not just about emotional reassurance; it plays a fundamental role in the evolution of caregivers' knowledge, skills, and confidence, directly contributing to their lay expertise.

Cindy's experience highlights how external support can direct caregivers to vital resources. By connecting with the right people through her county's services, she was able to find the appropriate care for her mother. This shows how practical support can guide caregivers in making informed decisions, which shapes their expertise over time.

> [Cindy] (11:01 - 12:24) Well, so our county that we live in has an Aging and Disability Resource Center. So I contacted them and a person came out to my home. It was during COVID. So my sisters were all here and she [the representative] kind of ran us through a scenario. She, you know, put clothes on us to make us see what it was like for a dementia person. Why they, you know, why they just all of a sudden are moving things around or why they're trying to keep busy because they don't know what they were going to do. So, yeah, she kind of gave us some helpful suggestions and some reading material. I was [already] dealing with them with some of my mom's medical stuff and Medicare and all that kind of stuff. And they kind of steered me towards the right person

> that deals with this type of stuff through the county. So that's kind of how we got together with her. (Cindy, Pos. 102-117)

Maria credited the Rete Magica support group and her doctor for providing her with practical guidance that enabled her to accept her mother's illness and adjust her caregiving approach. This example is crucial because it shows how both professional and community support can help caregivers develop a more nuanced understanding of their roles, enhancing their lay expertise.

> [Maria] (48:01 - 48:38) They provided knowledge that brought me to awareness. Then, the experiences of the people in Rete Magica, their unity, their sensitivity, their ability to understand certain things—all of that led me to the goal, which, for me, was accepting the illness and the changes in my mom. (Maria-ENG, Pos. 138)

Jack's network of friends who had also experienced caregiving offered him practical and emotional support. This segment shows how shared experiences with peers who have been through similar situations help shape Jack's caregiving expertise. It highlights the collective knowledge that arises from shared life events, which is critical in caregiving environments.

> [Jack] (1:14:57 - 1:16:24) Yes, I go – basically, I do like the elder care support group. I do – I do individual therapy. I talk to – I mean, I have friends that I talk to regularly. I have my friend Misty, who's like a long – lifelong, like since high school friend. I check in regularly with her because she assisted with the care of her grandmother and also her uncle, and they both passed away. She also helped out with the care of her mother who passed away. So I have, you know, a lot of my peers were all in their 60s. You know, Misty I kind of lean on in terms of friends. I have my best friend in Los Angeles. He just lost his mother from Alzheimer's. He just lost his uncle in Washington, D.C. from Alzheimer's. So he's not the primary caregiver, but he's involved. Right, right. So, yeah, I guess I, you know, I kind of touch base with friends who have – we all have like a shared kind of lived experience dealing with, you know, elder care or Alzheimer's dementia and that kind of stuff. (Jack, Pos. 871-874)

Anna's journey with her psychologist helped her embrace the shift in her role from being a daughter to a caregiver. This external support was key in helping her feel more confident in navigating her caregiving responsibilities, and it also highlights how professional support can play a pivotal role in shaping a caregiver's understanding and approach to their role.

> [Anna] (11:54 - 12:28) Well, I've been seeing a psychologist since I found out, since we got the diagnosis. And it has helped me a lot to embrace

> a role. Because it's no longer a daughter's role; it's a different role. At first, entering the house was harder because you know it's a different role, and sometimes you're afraid of making mistakes. (Anna-ENG, Pos. 130-132)

While caregivers often gain invaluable insights and emotional support from their personal networks and support groups, another critical element in developing lay expertise comes from their interactions with medical professionals. These encounters, however, are rarely straightforward or consistently positive. The way caregivers are treated by doctors can either hinder or facilitate their capacity to manage caregiving effectively. Nevertheless, understanding the medical professional's perspective and integrating their insights is essential to becoming a well-adjusted and competent caregiver.

Interacting with Doctors

Caregivers' interactions with healthcare professionals are complex and can be both empowering and disheartening. On the one hand, doctors provide the essential medical knowledge that caregivers rely on to manage conditions like Alzheimer's and dementia. Yet, many caregivers describe their experiences with the medical system as frustrating or alienating, where their concerns are often minimized or dismissed. The strain of these negative interactions compounds the emotional and physical burdens of caregiving. However, even in difficult encounters, caregivers acknowledge that understanding the medical professional's perspective, insights, and advice is critical in developing their own caregiving skills and confidence. Despite the challenges, these interactions remain key to the development of lay expertise, as caregivers must learn to navigate the intricacies of the medical system while continuing to advocate for their loved ones.

Patrizia highlights the difficulties of communicating her mother's condition to healthcare professionals, especially when they fail to consider her Alzheimer's diagnosis. This instance underscores the lack of empathy and understanding that caregivers sometimes experience.

> [Patrizia] (35:35 - 37:02) Some are kind, and some couldn't care less. We often went to the ER because she'd fall or get hurt, and one doctor just blurted out, "Ma'am, how long have you had Alzheimer's?" My brother got so mad. I wasn't there, or I would've gone off on that doctor. My brother was furious. We've never told her that to her face, and then this guy comes in and blurts it out. It was such a stupid question. Exactly. My mom looked at my brother like, "What on earth is he talking about?" - He repeated it two or three times! I thought, "What's wrong with you?" Another time, when she went for a mammogram, I didn't know how to explain it. I wrote it on a piece of paper: "Alzheimer's." They said, "Oh, Alzheimer's." Then they told me, "She has to go in alone because of the

> radiation." I told them, "Look, I'm just saying she might not understand what you're asking her to do." I didn't want to go in, but I just wanted them to understand that she needed special attention. Some people get it, others don't. (Patrizia-ENG, Pos. 381-390)

Cindy highlights a more supportive experience with her doctor, who not only understands her mother's situation but also acknowledges and appreciates Cindy's efforts to provide home care. This recognition emphasizes the importance of doctors validating caregivers' choices, particularly when faced with the difficult decision of keeping a loved one at home versus moving them into a care facility.

> [Cindy] (36:52 - 37:52) um… you know i think they realize i mean as far as i have the same doctor that my mom has so um i can talk to him when i go to my appointments about my mom no that's but um i think as far as he goes he understands what we're doing because every time i take her he always thanks me for um everything we're doing - "you're doing everything you can to keep her home" which is which is, he says, where she should be because once they go into a facility they go downhill fast because it's not it's not a a a surrounding that they're familiar with. (Cindy, Pos. 347-348)

Sally expresses regret about not consulting a neurologist earlier in her father's diagnosis. Her experience highlights how primary care doctors may not always provide the most specialized advice, leading to missed opportunities for early intervention.

> [Sally] (12:35 - 13:20) I think we probably should have… we never went the specialist route when it first started happening, and I think I wish we would have seen a neurologist to get a better idea because it's been kind of a… we were in the dark about where he was - when we even first started kind of noticing I know they have different stages evidently, and so he was never formally diagnosed with Alzheimer's. Okay, and so we were never sure, if it was just dementia, we knew it was definitely different than sometimes you see 'senility'[3] … and so I wish we would have gotten confirmed diagnosis earlier. (Sally-full, Pos. 249-250)

The challenges caregivers face when interacting with healthcare professionals highlight the complexity of navigating medical systems while advocating for a loved one. Many caregivers struggle to find the right balance between respecting medical authority and asserting their own insights and observations. While these encounters often carry a level of frustration or disappointment, they play a crucial role in shaping the caregiver's journey toward becoming more informed and capable. In

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[3] an important note here is recognizing that senility does not equate to either dementia or Alzheimer's; however, based on Sally's father's symptoms and specialists' opinion, he has developed a marked form of dementia.

this journey, caregivers begin to develop their own methods of caregiving, drawing from their interactions with doctors, personal experiences, and shared advice from peers.

5.6.2 Strategies

As caregivers engage in their roles, they embark on a journey of continuous learning and growth. Previous sections have highlighted the challenges they face, but caregiving involves far more than just responding to external demands. It requires the internal development of new skills, perspectives, and emotional capacities. Caregivers do not merely cope; they are actively building something—an evolving approach to caregiving that strengthens over time through reflection, adaptation, and the pursuit of meaningful connections.

The following section delves into the unique strategies caregivers develop as they navigate the complexities of caregiving. These strategies are not just reactions to daily challenges but represent a deep process of reflection, learning, and growth. From finding gratification in small moments to solving complex problems, caregivers continually adapt to their changing roles. This personal evolution—through reflection, shifting perspectives, and identifying what good caregiving looks like—creates a foundation upon which their caregiving practice is built, allowing them to not only care for their loved ones but to also grow through the experience.

Reflection Literature points to the significance of self-reflection when presented with chronic illness (Charmaz 1991; Kleinman 1988). For caregivers navigating the choppy waters of providing for their loved ones, self evaluation is paramount. This means understanding how the individual fits broader societal schemes or expectations and what activities and viewpoints construct the caregiving role. An internal negotiation is continuous - the wheels are constantly churning. Caregivers engage in continuous self-assessment as they adapt to the complexities of providing care. As caregivers transition into new roles, many struggle with the shift from being a spouse, child, or family member to becoming the primary decision-maker and caretaker. This reflective process is crucial for caregivers as they confront caregiving's emotional, practical, and relational challenges. Through this reflection, caregivers come to terms with their new responsibilities and the reality that caregiving often entails a reversal of roles, where they must now parent their own parents or take on the heavy responsibility of supporting a loved one through their decline.

This shift is deeply personal and multifaceted, involving an evolving understanding of what it means to be a caregiver. For example, caregivers like Katie and Maria express the emotional toll of this change, recognizing that the caregiving role transforms their previous relationships with their loved ones. This reflection allows caregivers to redefine their relationships, understand their own limitations, and build a more nuanced perspective on what caregiving entails. Through this introspection, they are able to continually learn and grow, navigating the difficulties of caregiving while building a deeper sense of empathy and understanding for their loved ones.

Anna shares her experience of transitioning from daughter to caregiver and the difficulty of embracing this new role

> Anna Because it's no longer a daughter's role; it's a different role. At first, entering the house was harder because you know it's a different role, and sometimes you're afraid of making mistakes. (Anna-ENG, Pos. 131-132)

Katie reflects on the shifting responsibilities within her family, where her mother has had to take on the role of decision-maker and provider after her father could no longer fulfill these duties. This significant change has redefined her mother's role and highlights how caregiving requires family members to assume unfamiliar responsibilities:

> [Katie] (26:04 - 26:32) And so he was the - He was the decision maker. He was the provider. He did all of those things. And now she's having to pay the bills. She's having to make sure that they have what they need. And make these decisions when they had to move. Yeah. She was the one that was making the decision. What house to buy. What to bring. What movers to call. All of those decisions are now hers. (Katie, Pos. 393-398)

Almost all participants likened the behaviors of their respective lones to those of a child, that the outward display of child-like characteristics was initially unsettling but in reality not necessarily unfamiliar, especially those who had already had children. Carolyn understood this feeling of empathy and child like support differently.

Reflecting on the emotional complexity of caregiving, Carolyn likened her feelings of guilt towards her grandfather to what parents often experience. She describes moments where she feels she hasn't given him enough attention or regrets not being as patient as she could have been, revealing how deeply this newfound role can affect personal emotions:

> [Carolyn] (47:18 - 48:03) But I think like, it adds another layer of empathy or kind of like, even like that mom guilt, like, sometimes when my grandpa goes to bed, like, I'll be like, Oh, my gosh, I didn't give him much attention today. Or like, or I yelled at him and like, I feel bad or like, I could have been nicer to him, you know, like, again, like kind of like that mom guilt thing. So that's interesting. (Carolyn, Pos. 435)

Additionally, reflection is intertwined with caregivers sense of self hood, personal qualities, and newfound perspectives. The first iteration (originally titled *caregiver self reflection*) of which is shown in figure 5.11 shown below.

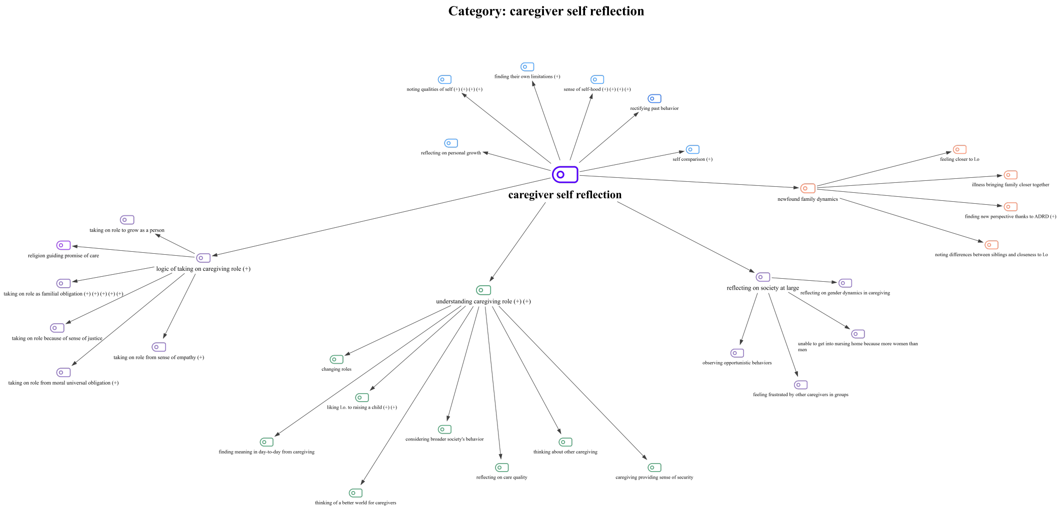

Figure 5.11: Strategies Caregiver Self Reflection

Reflection is not only reserved for the caregivers themselves or their roles within the care providing arena but also related to self reflection. Caregiving for a person means confronting some of the more prickly or uncomfortable qualities of oneself, that self discovery is also a part of this journey., including one's own limitations, or personality traits.

> [Silvia] (1:06:44 - 1:08:39) I don't know. Honestly, I don't know. Perfect seems impossible because we're all human beings, and as Fausta used to say, I remember her saying, 'A mother should be good but not too good.' She can be good but not too good. At some point, even she's only human and will have flaws. I don't know, also because I've never considered myself to be particularly good. I'm not a patient person; I'm not calm; I have little patience. So, I get annoyed easily, and if someone gets anxious, I tend to get anxious too. So, I lose things, I can't keep calm either. So, to me, a good caregiver might be someone who can transmit calmness, security, reliability, all these things. I feel reliable, but not patient or calm.
> (Silvia-ENG, Pos. 664-665)

Through caregiving, participants frequently began to reassess their values, priorities, and relationships, often experiencing a deeper connection with their loved ones despite the overwhelming challenges they face. The qualities that link these experiences include empathy, personal growth, gratitude, and a redefinition of roles.

> [Kaya] (27:54 - 28:36) But well, the end of the sentence is that there is a… I do wonder if there's some sort of value that I'm adding to this as being like the one and getting like recognition for that because there's other places in my life that I feel like I failed. But at least I can be like a granddaughter who took care of her grandma until she died and then I did that correctly. (Kaya, Pos. 715-716)

As caregivers reflect on their roles, the journey of self-awareness becomes an integral part of their experience. This reflection brings forth a recognition of personal growth, limitations, and new perspectives. While confronting the challenges and embracing the responsibilities, caregivers are also given the opportunity to learn from their circumstances and grow in their abilities to provide care. In addition to self-reflection, learning plays a crucial role in the caregiving journey. Caregivers must constantly adapt, learn new skills, and navigate the complexities of their loved one's condition. Whether it involves practical aspects like medical care or emotional support, caregivers find themselves in a continuous process of education and development. This learning is not merely formal but often experiential, gained through trial, observation, and the support networks they engage with.

Caregivers frequently describe the acquisition of knowledge as being fundamental to their role. This learning is not static but evolves as their loved one's condition changes, requiring the caregiver to stay attentive and adaptive. Whether it's through trial and error, advice from professionals, or insights gained from other caregivers, the knowledge and skills accumulated over time shape their caregiving practices. Learning, then, is not only about becoming a better caregiver; it also involves a broader personal transformation, influencing how caregivers view their roles, relationships, and themselves. The process of learning, as we will explore in the following section, becomes a tool of empowerment, allowing caregivers to handle the complexities of their situations with greater confidence and adaptability.

Learning This image shows the first iteration of the learning subcode Learning was one of the first themes identified in interviews. They can effectively be divided into for additional subcodes - learning legal, learning from others, learning from past experiences, and Learned ADRD characteristics and meaning. The most frequently assigned was learning from past experience and learned ADRD characteristics and meaning.

To address the complexities revealed in this set of coded segments, it is crucial to acknowledge that caregiving involves continuous learning, reflection, and adjustments. Caregivers are frequently confronted with unexpected situations that challenge their emotional and physical endurance. As they navigate through these experiences, they begin to accumulate valuable insights, developing an instinctive understanding of their loved ones' needs. These lessons shape their caregiving approach, enhancing their ability to cope with future challenges. In the following examples, we see how caregivers learn from their mistakes, face moments of fear and panic, and adapt to the evolving demands of care:

Jack reflects on the overwhelming sense of panic when his mother's consistent issues with falling triggered unexpected reactions, and he learned to manage those intense feelings over time.

> Jack And it's like, boom! And it was like, it would rattle the floor, you know? And so I would kind of have this, I mean, I would kind of have like this panic feeling, you know?"_
> (Jack, Pos. 8)

Sue learned the hard way that dementia changes how pain is experienced, a realization that shifts her understanding of care and patient management.

> [Sue] (13:38 - 14:00) Every cast that they put on him. And that's when I found out that dementia people, Alzheimer's people, their pain is different. (Sue, Pos. 144)

In Maria's case, her choice to have her mother sleep in her bed turned into a long-term habit that became difficult to undo, demonstrating how well-meaning actions can sometimes complicate caregiving.

> [Maria] (35:09 - 36:56) At first, it was overwhelming because from breakfast to dinner, we were always together—I couldn't breathe, I felt suffocated. And then, at the beginning, I did something out of love, but looking back, it was a huge mistake. When I brought my mom home, my house is on multiple levels, so now it's better because last year in September, my father broke his femur—a big problem, but from that problem came something positive. (Maria-ENG, Pos. 104)

Jack expresses how he moves forward after setbacks, believing that havning not intervened earlier and the lack of timely support led to increased complications in care, a mistake he vows to learn from moving forward.

> [Jack] (1:11:10 - 1:11:45) I can tell you like if we don't do some sort of intervention – I mean, I've learned over time because I think – I mean, because we fucked it up. You know, we totally missed it. Like, oh my gosh. She shows up in the emergency room - Okay, "she's got a complex UTI. She's anemic. She's dehydrated - She's got this, that, this. She's had an AFib." I mean, and you're like – 'How did we get here?' Yeah. Like, you know, and it's like we didn't have enough intervention and enough support soon enough. (Jack, Pos. 829-834)

Through their reponses, it becomes evident that caregiving is not only about immediate tasks but about the constant growth and adaptation required to provide better care. Every mistake or challenge becomes a lesson, shaping how caregivers approach future decisions, interactions, and their loved ones' well-being. This is illustrated visually in 5.12.

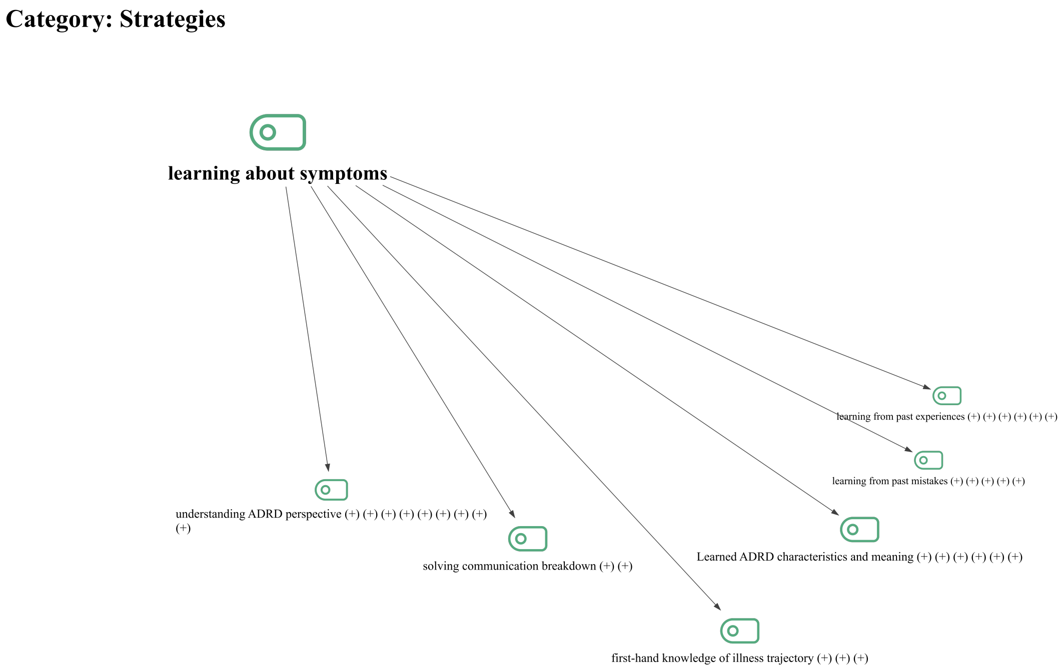

Figure 5.12: Strategies Learning About Symptoms

As caregivers navigate the complexities of their roles, many find that caregiving offers more than the anticipated challenges—it provides moments of unexpected fulfillment. While often subtle, these instances of gratification become a meaningful part of the caregiving experience, allowing individuals to connect more deeply with their care recipients. These moments reflect a significant shift from focusing solely on the difficulties of caregiving to recognizing the emotional rewards that emerge from these intimate responsibilities. The next section will examine how caregivers find gratification in their roles, highlighting the emotional and personal growth that occurs throughout the caregiving process.

Finding Gratification

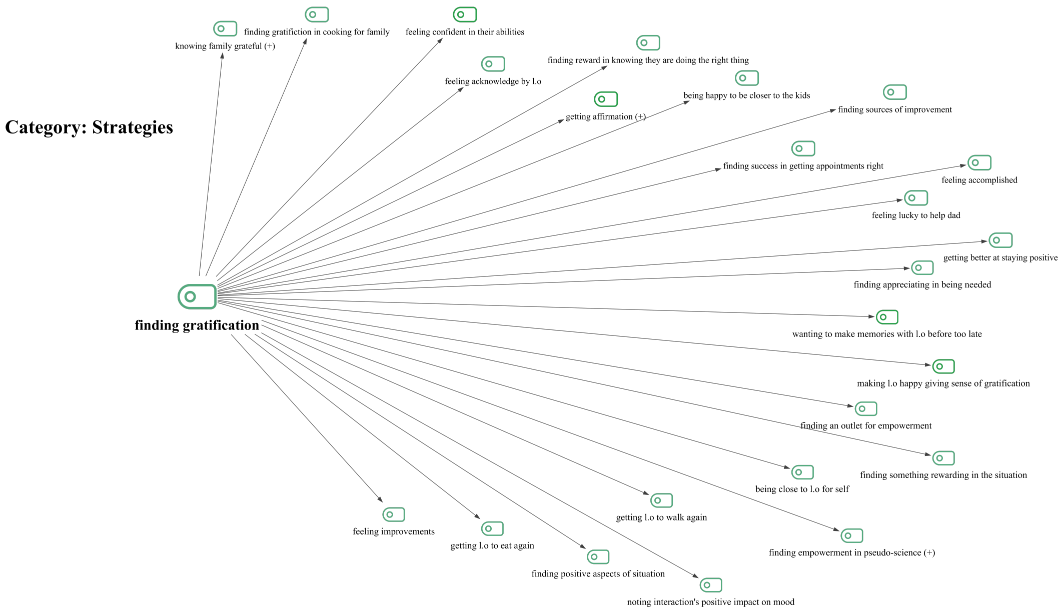

Figure 5.13: Strategies Finding Gratification

The 5.13 shows the first iteration of the finding gratification subcode. The experience of caregiving is characterized not only by its challenges but also by moments of deep personal gratification, which can sustain caregivers through the emotional and physical demands of their role. Throughout the data, participants described the nuanced ways in which they find meaning, fulfillment, and pride in their caregiving responsibilities, even in the face of overwhelming difficulties. These moments of gratification are closely tied to the unique and irreplaceable nature of the caregiver's role, small acts of connection with the care recipient, and a sense of accomplishment in providing dignified care.

Many caregivers expressed a profound sense of pride in their ability to fulfill a role that no one else in their family could assume. Kaya, for instance, articulated a feeling of personal significance in being the sole family member capable of providing such care: "I feel really proud of knowing that this is something that literally no one else in my family is capable of doing, and I'm priceless." This sentiment was echoed by several other participants who described how caregiving allowed them to demonstrate their resilience, expertise, and devotion to their loved ones. For these caregivers, the acknowledgment of their unique contribution created a deep sense of accomplishment, serving as an essential source of emotional reward.

Gratification also emerged from the ability to provide care in a familiar home environment, a preference that many caregivers worked diligently to honor. Cindy described the comfort her family felt after her father passed away, knowing they had respected his wish to remain at home rather than enter a facility: “When he passed, it gave us comfort that we had done what he wanted.” The fulfillment of these preferences, particularly in the context of avoiding institutionalized care, was frequently framed as a central aspect of the caregiving experience, with caregivers feeling they had succeeded in providing the best possible care by keeping their loved ones in familiar surroundings.

In addition to this broader sense of purpose, participants found gratification in small, intimate moments of connection. Even as dementia progressed and communication became limited, these moments served as powerful reminders of the bond between caregiver and care recipient. Patrizia, for example, recalled how her mother’s simple act of smiling at her continued to bring immense emotional reward, stating, “She doesn’t say my name anymore, but she knows it’s me. When she smiles at me, that’s everything for me.” These moments, though fleeting, were imbued with significance and provided caregivers with the validation that their efforts were recognized, even if only nonverbally.

Caregivers also demonstrated creativity and adaptability, finding gratification in their ability to improve their loved ones’ quality of life through innovative methods. Kaya described using her skills as a craniosacral therapist to provide relief for her grandmother, which allowed her to feel a sense of control and achievement in a context that often felt unpredictable. This application of personal knowledge and expertise, even in non-traditional forms of caregiving, contributed to caregivers’ sense of agency and purpose, reinforcing their belief that they were providing valuable and meaningful care.

Kaya reflected on how her role gave her a unique sense of worth and accomplishment that went beyond the caregiving tasks themselves:

> [Kaya] (47:11 - 47:36) I feel really proud of knowing that this is something that literally no one else in my family is capable of doing, and I’m priceless. (Kaya, Pos. 332)

Caregivers’ ability to creatively address challenges extends beyond physical care to encompass emotional and cognitive problem-solving. This process of finding solutions often emerges as a way to regain a sense of control and purpose in an unpredictable environment. Kaya’s experience of using craniosacral therapy for her grandmother is a prime example of how caregivers apply their own expertise to manage their loved one’s well-being, finding satisfaction and empowerment in the process. This sense of pride and fulfillment, however, does not come without the constant need to overcome new hurdles, both practical and emotional.

As caregivers navigate these challenges, the focus often shifts to developing strategies that help them not only manage the caregiving responsibilities but also preserve their own emotional resilience. By framing caregiving tasks as problems to be solved, they can create a sense of structure and efficacy in an otherwise overwhelming situation. This need to approach caregiving through a lens of problem-solving becomes critical in adapting to the multifaceted demands of caregiving.

Solving Problems

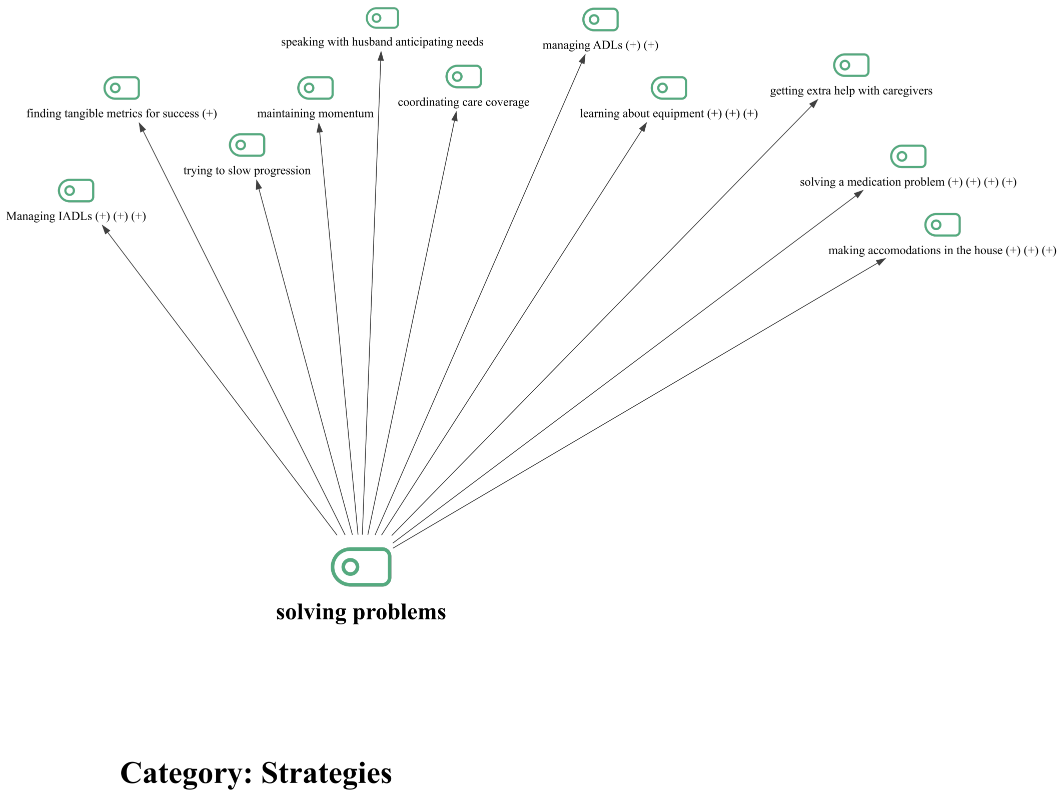

Figure 5.14: Strategies Solving Problems

Caregivers often face significant challenges in managing day-to-day care, requiring them to adopt problem-solving strategies to mitigate various stressors. These strategies are not only practical but also emotional, reflecting the dual nature of caregiving as both a logistical and deeply personal experience. Caregivers are often tasked with managing complex health conditions, addressing the emotional needs of their loved ones, and navigating the fragmented healthcare system. Problem-solving, therefore, emerges as an essential skill that caregivers develop and refine over time.

For some caregivers, reaching out to external resources was a key problem-solving tactic. In the case of Jack, he describes how he took the initiative to seek help from others to address care-related issues, reflecting a proactive approach to solving problems.

> [Jack] (0:45:12 - 0:45:35) I, no, I reached out to them. I called, I contacted the people I thought could help us. That was probably the first time I felt like I was doing the right thing in all of this. (Jack, Pos. 134)

Jack's experience illustrates a significant turning point where he began to feel agency in the caregiving process by leveraging available networks of support. This highlights how problem-solving is not just a matter of finding solutions but also a means of regaining control and confidence in an often overwhelming caregiving environment.

Similarly, Cindy expressed a sense of relief after contacting a professional to assist with her caregiving responsibilities.

> [Cindy] (0:56:01 - 0:56:45) So I contacted them and a person came out to me and went over everything we needed. That helped a lot because we were starting to feel lost, like really lost. (Cindy, Pos. 107)

This excerpt underscores how professional intervention can provide much-needed clarity in an otherwise uncertain situation, reaffirming the importance of external support systems in the caregiver's problem-solving repertoire.

On the other hand, Sally recounts her husband's urgent attempts to handle the situation, suggesting that problem-solving can also take on a more desperate tone when caregivers feel ill-equipped or overwhelmed by the demands of the role.

> [Sally] (1:15:30 - 1:16:05) So he's like desperately looking and he would get so frustrated. And I'm sitting there thinking, this isn't going to work, but what else do we do? It's like you try everything you can and just hope something sticks. (Sally-full, Pos. 12)

Sally's story points to the emotional strain involved in solving problems when solutions are not immediately clear or easily accessible. The process of trial and error in caregiving often leads to frustration and a sense of futility, reflecting the challenging dynamics between the caregiver's desire to provide the best care and the limitations they encounter. Taken together, these examples demonstrate that problem-solving in caregiving is multifaceted, requiring not only practical interventions but also emotional resilience. Caregivers must often contend with the challenges of uncertainty, frustration, and limited resources, yet they continue to find ways to navigate these obstacles through a combination of external support and internal determination.

Changing Perspectives

The figure 5.15 shows the first iteration of the changing perspectives subcode.

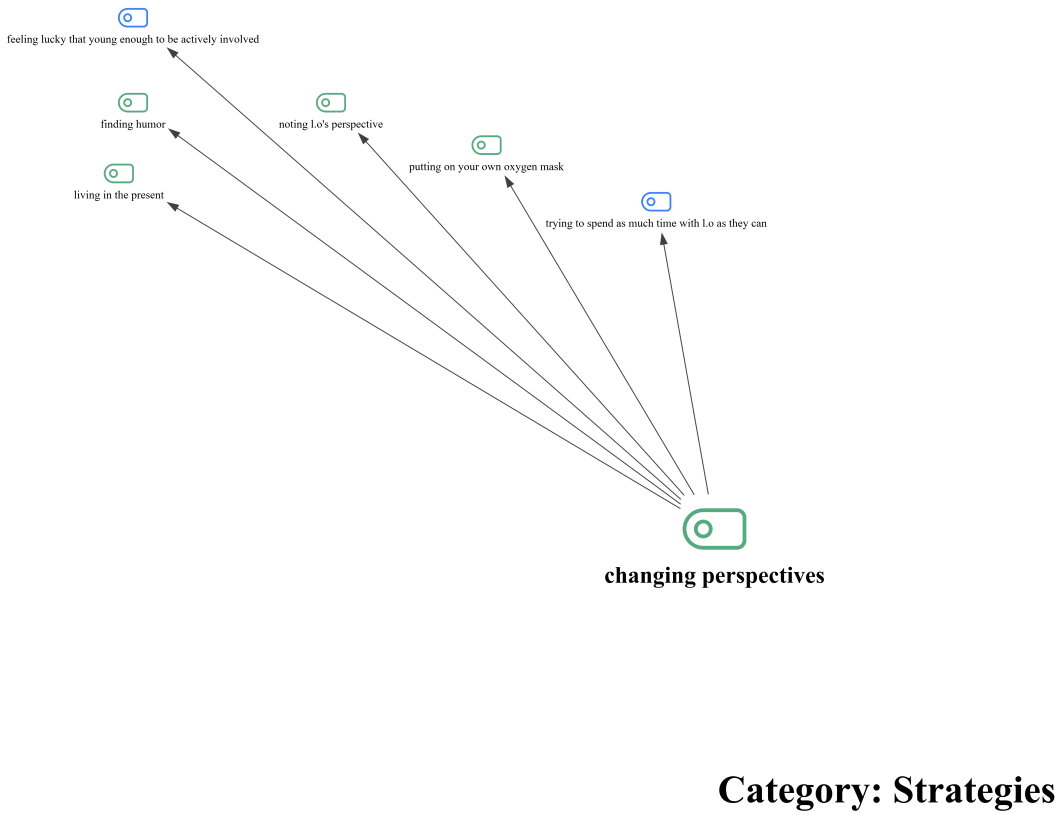

Figure 5.15: Strategies Changing Perspectives

One of the most significant transformations caregivers undergo is a shift in how they perceive both their role and the person they are caring for. This process, though often gradual, is profound as caregivers are forced to adapt emotionally, cognitively, and behaviorally to the realities of a progressively degenerative condition such as Alzheimer's or dementia. This evolving perspective reflects the ways in which caregivers move beyond conventional ideas of obligation or duty and enter into more nuanced understandings of time, emotional boundaries, and self-preservation.

A consistent theme across many caregiver narratives is the necessity of focusing on the present. The progressive nature of diseases like dementia means that caregivers frequently find themselves letting go of expectations for the future, as the uncertainty of how the disease will unfold makes future planning emotionally draining and often futile. As Alessia explains, "I live very much in the present. I don't think about what my mom will be like in a year because I can't know that" (Alessia-ENG, Pos. 185). This acceptance of uncertainty is critical for caregivers as they recalibrate their emotional investments away from future expectations and toward what can be managed and controlled in the immediate day-to-day context.

This need to reframe one's relationship with time and expectations is echoed by Anna, who similarly highlights the toll that focusing on the past or future takes on caregivers. She recalls the advice she received:

> [Anna] (31:30 - 32:17) No, I've realized I shouldn't think about the future or the past. My psychologist tells me not to think about those things, and I see why. You have to live day by day, in the present, because that's what it is. (Anna-ENG, Pos. 337)

Living in the present is not merely a survival strategy but also a psychological adjustment that many caregivers are compelled to make in order to maintain emotional stability. Without this shift, the weight of anticipated losses and the overwhelming nature of caring for someone with an incurable, degenerative illness could lead to burnout or emotional collapse.

Beyond the temporal shift, caregivers also find themselves reassessing their perceptions of the person they are caring for. As dementia progresses, the person's cognitive abilities deteriorate, and they may cease to resemble the person they once were. For many caregivers, this requires a redefinition of who that person is now, and how best to maintain a relationship with them. Maria shares an example of this redefinition, recounting how her mother, deep in her illness, confuses Maria with her sister and believes that Maria's daughter is her own child.

> [Maria] (1:25:43 - 1:26:15) She thinks my daughter is hers. She thinks I'm her sister and that my daughter is her daughter because she believes she's younger. She thinks she's younger, so Lucrezia is her daughter. (Maria-ENG, Pos. 128)

This disorientation, while difficult, also leads caregivers to shift their emotional responses, often requiring them to find new ways to emotionally connect with their loved ones, even when those loved ones are cognitively distant. While this can be a source of deep sadness, caregivers like Maria manage to maintain emotional connection by accepting their loved ones' altered perceptions.

Another facet of changing perspectives involves reframing the caregiving experience not as a burden, but as an opportunity for providing joy in small, immediate moments. Sally, for example, speaks about recognizing that her father finds happiness simply from the presence of family, even though he is cognitively diminished. For her, the challenge became finding value in these small, present-centered moments of joy:

> [Sally] (0:45:30 - 0:46:05) I think it's become more about realizing we just… he finds happiness when we're there. (Sally-full, Pos. 117)

This shift, from a sense of obligation to finding meaning in the provision of comfort and happiness, marks a significant emotional evolution. Sally's reflections highlight the capacity of caregivers to adjust their expectations of what caregiving can and should be. Rather than seeing themselves solely as caretakers for physical needs, caregivers are increasingly aware that emotional and psychological caregiving is just as important, if not more so, particularly as cognitive decline accelerates.

Humor, as a coping mechanism, also features prominently in these transformations of perspective. For many caregivers, humor becomes a way to alleviate the emotional burden of repetitive behaviors or frustrating misunderstandings that occur during the progression of dementia. Cindy's account reflects how laughter, while sometimes lighthearted, also represents a deeper recalibration of emotional expectations. For her, laughter is not about belittling her mother's condition but about managing the emotional toll it takes on the family:

> [Cindy] (1:05:30 - 1:06:05) We always say we're not laughing at her. We're trying to keep our sanity. So we kind of make little jokes about different things and then it gets the conversation going. (Cindy, Pos. 307)

By introducing humor, caregivers like Cindy construct an emotional buffer that allows them to better navigate the frustrations of caregiving. Humor allows caregivers to confront their own emotional fatigue and sadness without fully succumbing to it, enabling them to provide more consistent care while maintaining their own mental well-being.

Ultimately, the process of changing perspective reveals itself as an ongoing negotiation between the caregiver's emotional needs and the practical realities of caregiving. For some, like Jack, this shift involves recognizing their own limits and the importance of self-care. Jack recounts how he came to the realization that he must prioritize his own mental and physical health if he is to continue caregiving effectively:

> [Jack] (1:05:15 - 1:06:01) I realized like, you know, I got, I have to, uh, like put my own, you know, it was a cliché, but I put my own oxygen mask on first. (Jack, Pos. 354)

Jack's acknowledgment speaks to a broader recognition among caregivers that while caring for their loved ones is central, they must also address their well-being if they are to avoid burnout. This reflects an evolving perspective wherein the caregiver's health and autonomy are integrated into the caregiving process, rather than being entirely subordinated to the needs of the person they are caring for.

The 'changing perspective' in caregiving is not a one-time event, but a continuous and crucial process. Caregivers are constantly required to reassess their relationships, redefine emotional boundaries, and adjust their perception of time as they navigate the complexities of caregiving. Whether it's by focusing on the present, redefining their loved ones' evolving identities, or finding solace in humor and emotional readjustment, caregivers demonstrate an impressive capacity for emotional and psychological resilience. This evolving perspective is not only essential for sustaining the caregiving relationship, but also for safeguarding the caregiver's own well-being.

Adaptation

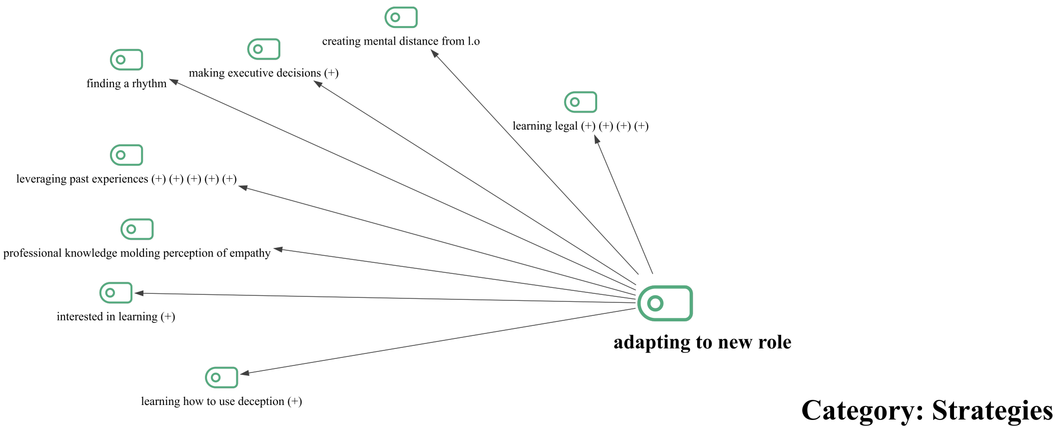

Figure 5.16: Strategies Adapting to New Roles

The 5.16 shows the first iteration of the adapating to new roles subcode.The 'adaptation' code in caregiving encapsulates the dynamic and evolving adjustments that caregivers must make to meet the changing needs of their loved ones. Adaptation involves acquiring new skills, revising expectations, managing unpredictable situations, and recalibrating emotional responses. Caregivers find ways to modify their roles, adapt to new routines, and maintain stability while dealing with the progressive nature of dementia or other caregiving challenges. This process often includes seeking external support, changing personal habits, and finding a rhythm that works for both the caregiver and the care recipient. Adaptation is integral for managing stress, preserving emotional health, and providing continuous, compassionate care. It captures the ongoing and fluid adjustments caregivers make as they navigate the challenges of caring for someone with dementia or other chronic conditions. Caregivers adapt by redefining their expectations, creating new emotional and mental boundaries, and modifying their daily routines to align with their loved one's needs. They manage to strike a balance between their own life and the constant demands of caregiving, often leveraging past experiences and learning new skills to manage tasks better.

Understanding how caregivers navigate their changing roles and responsibilities makes it clear that adaptation is not just practical but deeply emotional. The reversal of dependency, where caregivers shift from being cared for to providing care, is a recurring theme. Emotional acceptance and adjustment to the new normal often accompany this transition.

> [Anna] (1:17:33 - 1:17:59) “It’s no longer your mom who takes care of you, but you who takes care of her. I have to accept that it’s not like before. I used to depend on her. Now she depends on me. We’ve switched roles, and that was hard to accept at first, but over time, I’ve adjusted.” (Anna-ENG, Pos. 157)

Anna’s reflection speaks to the difficulty and eventual acceptance of this role reversal, where she learns to cope with a dynamic that fundamentally changes her relationship with her mother. Similarly, caregivers often come to terms with aspects of their loved ones’ illness that are beyond their control. This process is critical to emotional adaptation and the ability to find peace within the caregiving journey.me.

> [Silvia] (1:10:21 - 1:10:55) “No, the memory, I’ve learned to live with it, even though it’s tough. I don’t try to fight it anymore, and that’s made things easier for me. I think I’ve found some peace in accepting what I can’t control.” (Silvia-ENG, Pos. 597)

Silvia’s account reveals how letting go of the struggle against the inevitable allows caregivers to focus on the aspects of caregiving that they can manage, promoting a more sustainable approach to their role. Other caregivers describe the importance of adjusting expectations, particularly in relation to their loved ones’ prognosis. Accepting the permanence of decline can help caregivers reframe their outlook, enabling them to manage their emotional well-being more effectively.

> [Sue] (00:05:20 - 00:06:45) “And we finally, the last two years, I got used to it. I accepted that my father wasn’t going to get better, and I stopped hoping for that. It was the hardest, but also the best thing I did for myself.” (Sue, Pos. 418)

Sue’s reflection shows the pivotal moment when caregivers relinquish hope for recovery, which paradoxically provides emotional relief and allows them to engage in the reality of caregiving fully. Each of these narratives highlights how emotional and psychological adaptation is essential for caregivers to cope with the demands and stresses of caregiving. Adjusting expectations, finding acceptance, and reframing emotional responses are strategies that emerge through the caregiving experience.

Identifying Good Caregiving

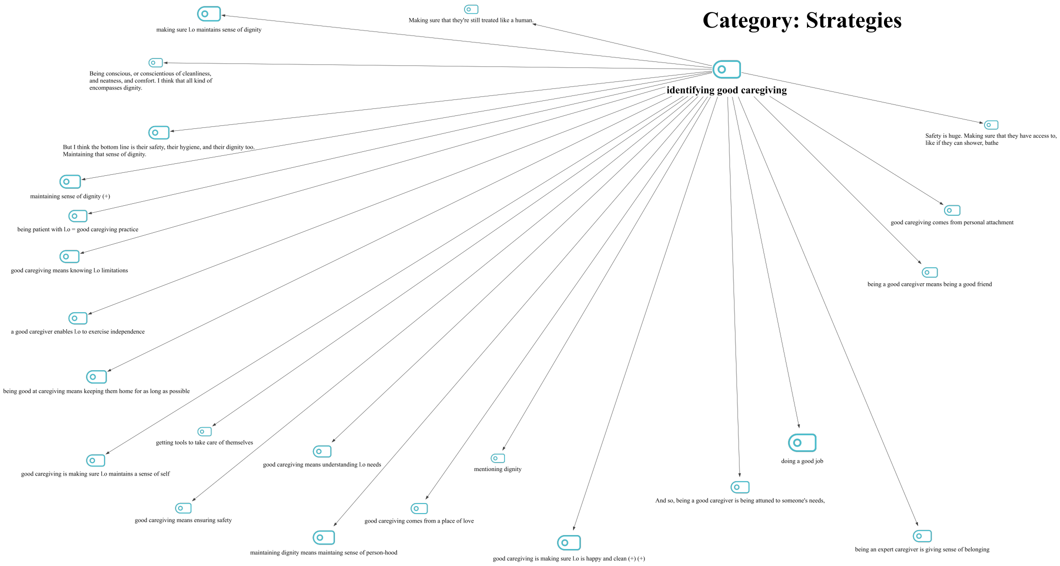

Figure 5.17: Strategies Identifying Good Caregiving

The “identifying good caregiving” code revolves around how caregivers assess their effectiveness and the quality of care they provide to their loved ones. Through their narratives, caregivers highlight qualities such as attentiveness, emotional presence, practical competency, and maintaining dignity and comfort for their loved ones. Good caregiving is often seen as a balance between the emotional and practical aspects, where caregivers measure success not only by the care recipient’s well-being but also through their own sense of fulfillment and accomplishment. In caregiving, identifying what constitutes “good caregiving” is not always clear-cut, but it often emerges through a caregiver’s ability to adapt, balance, and find meaning in their actions. Caregivers frequently reflect on their caregiving styles, grappling with whether they are doing enough and what it means to be a “good” caregiver. This reflective process is crucial in shaping their caregiving identity and improving their approach over time.

> [Maria] (00:12:33 - 00:13:22) “I think a good caregiver is someone who can provide both practical help and emotional support. It’s not just about feeding or dressing them, it’s about listening, too. I think the best thing I’ve done is to stay present for her, even when I’m tired.” (Maria-ENG, Pos. 120)

Maria’s reflection underscores that caregiving is not just about completing tasks but about being emotionally available. This speaks to the dual nature of good caregiving, where emotional attentiveness is equally as important as practical support. Maria’s reflection on caregiving emphasizes the importance of providing emotional stability. For her, the essence of good caregiving lies not in fixing everything but in offering comfort and reassurance amid uncertainty.

> [Patrizia] (1:09:44 - 1:10:01) “I’m still learning, every day, to be better at it. There are days when I’m not patient, but I’ve found that being patient is more important than being perfect.” (Patrizia-ENG, Pos. 503) Patrizia articulates the ongoing learning process inherent in caregiving, suggesting that the quest for perfection is less important than cultivating patience and empathy. Her narrative underscores how caregiving is a continuous journey of self-improvement.
>
> [Sally] (00:03:45 - 00:04:22) “I feel like I did the right thing by keeping him at home, where he feels safe. That’s what matters, right? To make sure he feels secure and that he’s still surrounded by love.” (Sally-full, Pos. 50)

Sally’s narrative centers on providing a sense of security and emotional stability for ther father, which is seen as a fundamental aspect of quality caregiving.

> [Katie] (00:15:12 - 00:16:00) “Good caregiving, to me, is about anticipating needs. It’s knowing what’s coming before she even has to ask for help. When you can do that, it shows you really understand them, and that’s what makes a difference.” (Katie, Pos. 930)

Katie highlights the anticipatory aspect of good caregiving, emphasizing that understanding the care recipient’s needs ahead of time defines effective caregiving.

> [Kaya] (1:27:30 - 1:28:12) “I try to listen more, because sometimes it’s not about solving the problem immediately. Sometimes the best thing I can do is be there, and that’s enough.” (Kaya, Pos. 680)

Kaya’s insight reflects a shift in her understanding of caregiving. Rather than focusing on immediate problem-solving, she recognizes the value of presence and listening, which points to a more relational and holistic view of caregiving.

> [Katie] (00:42:18 - 00:42:52) “I’ve realized that sometimes the best care is knowing when to step back and let him do what he can on his own. It’s about giving him the dignity of independence, even if just for a moment.” (Katie, Pos. 612)

Katie’s narrative reveals another facet of good caregiving—knowing when to step back and allow her loved one some autonomy. Her reflection touches on the importance of preserving the dignity of the person receiving care, which is an integral aspect of quality caregiving. Through these narratives, it becomes evident that “good caregiving” is multi-dimensional. It involves emotional intelligence, patience, and an ability to balance providing care with allowing independence. Caregivers continuously redefine what “good caregiving” means to them as they evolve in their roles, learning from both successes and challenges along the way.

And finally, here is the full map of the strategies category, with all subcategories - Identifying good caregiving, Adapating to New Role, Changing Perspectives, Solving Problems, Finding Gratification, Learning, Reflection alongside their substantive codes.

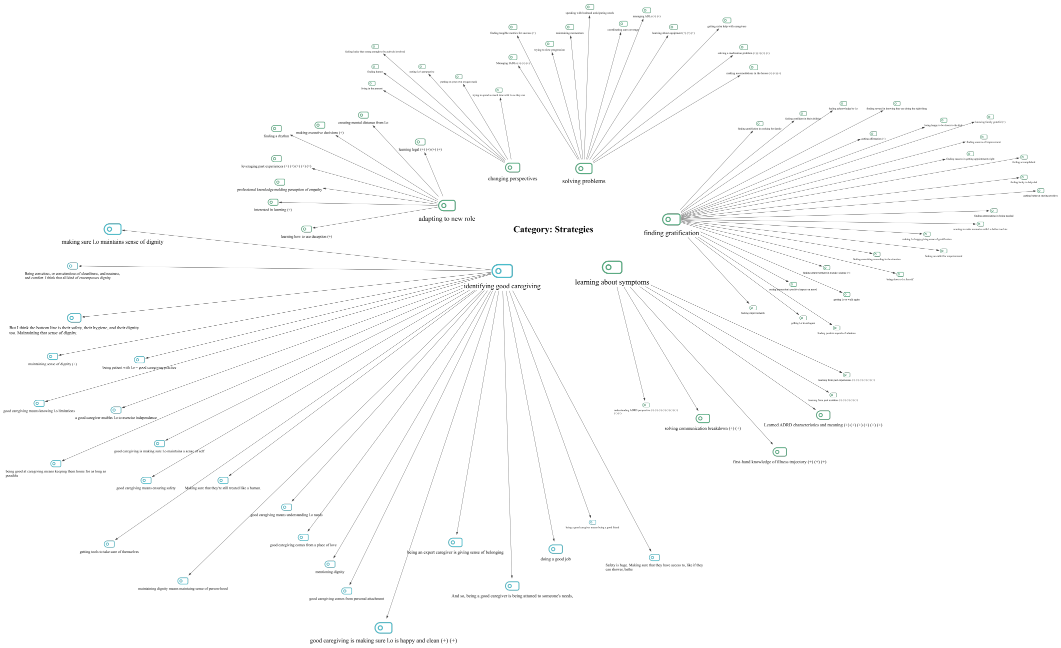

Figure 5.18: Full Strategies Coding Mapping

5.6.3 Accepting Illness

The process of "accepting illness" represents a complex emotional trajectory that caregivers navigate as they come to terms with the irreversible deterioration of their loved ones. This emotional work is not linear, but rather involves fluctuating phases of denial, reluctant acknowledgment, and eventual acceptance. Caregivers often find themselves reorienting their expectations and relationships as they recognize that their loved ones will never return to a previous state of health. This acceptance goes beyond physical decline—it extends to the emotional and psychological transformations that caregivers must undertake, often involving renegotiating roles within the family structure.

Anna, for example, reflects on the role reversal that has reshaped her relationship with her mother. In traditional family structures, parents care for their children, but illness disrupts this norm, forcing caregivers to assume responsibilities they previously associated with the other:

[Anna] (1:17:33 - 1:17:59) >"It's no longer your mom who takes care of you, but you who takes care of her. I have to accept that it's not like before. I used to depend on her. Now she depends on me. We've switched roles, and that was hard to accept at first, but over time, I've adjusted." >(Anna-ENG, Pos. 157)

This role shift reflects how caregivers are compelled to reconceptualize their familial identities. The emotional strain in this adjustment is compounded by the realization that caregiving does not offer a linear path to improvement or recovery. Silvia articulates the necessity of emotional adaptation in the face of an uncontrollable decline:

> [Silvia] (1:10:21 - 1:10:55) No, the memory, I've learned to live with it, even though it's tough. I don't try to fight it anymore, and that's made things easier for me. I think I've found some peace in accepting what I can't control." (Silvia-ENG, Pos. 597)

Here, Silvia illustrates how the process of acceptance is not merely a passive response but an active adjustment to the emotional landscape of caregiving. Her narrative reveals a form of adaptive coping, wherein the recognition of uncontrollable factors becomes a strategy for reducing emotional strain. The caregiver's emotional reconciliation with the limitations of caregiving becomes critical in sustaining their long-term involvement.

Sue's account further underscores the emotional labor required to relinquish the hope of recovery. Her experience emphasizes how the act of acceptance, while difficult, ultimately allows caregivers to regain a sense of control over their emotional health:

> [Sue] (00:05:20 - 00:06:45) And we finally, the last two years, I got used to it. I accepted that my father wasn't going to get better, and I stopped hoping for that. It was the hardest, but also the best thing I did for myself. (Sue, Pos. 418)

Sue's narrative reflects the need for caregivers to manage their emotional investments carefully. Letting go of expectations for improvement marks a turning point in the caregiving journey—where emotional adaptation becomes as important as managing physical caregiving tasks. Moreover, the acceptance of illness also brings with it a reevaluation of time. Caregivers, like Alessia, illustrate the importance of living in the present rather than dwelling on a future that remains uncertain:

> [Alessia] (Pos. 185) Well, in that sense, I live very much in the present. I don't think about what my mom will be like in a year because I can't know that. (Alessia-ENG, Pos. 185)

Alessia's reflection highlights a coping mechanism that prioritizes present-focused care over future anxieties, allowing caregivers to remain engaged without being overwhelmed by what lies ahead. Thus, the process of accepting illness is not simply a matter of recognizing decline but also involves deep emotional and cognitive work. Caregivers must continually adjust their roles, redefine their expectations, and manage their emotional well-being in a context where hope for recovery gives way to an understanding of sustained care. Through these adjustments, caregivers maintain their relationship with the loved one and safeguard their emotional health in the face of immense psychological challenges.

5.7 Conclusion

This study comprehensively explores caregivers' experiences for individuals with Alzheimer's Disease and Related Dementias (ADRD) in the United States and Italy. Utilizing a mixed-methods approach—including online observations of caregiver support groups, in-depth interviews, and quantitative data analysis from the National Study on Caregiving (NSOC)—the research delves deeply into the multifaceted challenges and adaptations that define the caregiving journey.

The netnographic (*i.e* digital ethnographic) analysis of online communities, specifically two Facebook groups (one English-speaking and one Italian-speaking), reveals how caregivers use digital platforms for support and information sharing. Three primary types of posts emerge: informational posts that share practical advice and resources; engagement posts focusing on humor or shared experiences; and cathartic posts that provide space for emotional expression. While digital spaces offer accessible advice and emotional validation, online communication's anonymity and fragmented nature can limit the depth of connection, often leaving caregivers seeking more profound support.

Fieldwork observations of support groups in Italy underscore the significance of face-to-face interaction in building caregiving expertise. Groups like Spazio ai Caregivers, Gruppo ABC, and Mutuo Aiuto Caregivers provide spaces for shared experiences, practical advice, and emotional validation, fostering a sense of community among caregivers. The diverse perspectives shared in these groups contribute to the development of expertise by exposing participants to different approaches and coping mechanisms.

In-depth interviews with caregivers from both the United States and Italy offer rich, nuanced insights into their individual journeys. A key theme that emerges is the "Constellation of Burdens," where caregivers face interconnected challenges impacting various aspects of their lives. These include disruptions to personal plans and careers, family conflict due to unequal distribution of caregiving labor (often along gender lines), perceived isolation stemming from the demanding nature of caregiving, and feelings of burnout characterized by exhaustion and a loss of self. Caregivers also grapple with the emotional struggle of their loved one's changing identity, termed "internal renegotiation," and face additional complexities from care recipients' other health issues and acute symptoms of ADRD. As the disease progresses, increasing dependency for basic tasks adds to the caregiver's responsibilities, intensifying the physical and emotional demands placed upon them.

Despite these challenges, caregivers develop significant expertise in managing the demands of ADRD care. Access to robust support systems - including family, friends, medical professionals, and support groups - is crucial for their well-being and expertise development. Caregivers learn to navigate interactions with healthcare professionals, often advocating for their loved ones despite frustrations when their concerns are dismissed. Continuous self-assessment and reflection allow caregivers to adjust their approaches and cope with emotional and relational shifts. Through learning—via trial and error, observation, professional advice, and peer support - they acquire practical skills, medical knowledge, and emotional intelligence to adapt to new challenges.

Caregivers find moments of fulfillment and pride in their roles, celebrating small victories and connections with their loved ones. They become adept at solving problems, drawing on knowledge, networks, and experiences to overcome obstacles and manage crises. The caregiving journey often necessitates a shift in perspective regarding time, expectations, and definitions of success. Focusing on the present moment and finding joy in small interactions emerge as key coping mechanisms. Caregivers develop personal understandings of quality care, emphasizing attentiveness, emotional presence, practical competence, and preserving dignity. Accepting the illness involves coming to terms with the irreversible nature of ADRD and adapting to the changes it brings to relationships and expectations.

Quantitative analysis of the NSOC dataset explores relationships between perceived social support, burden, and health outcomes for caregivers. Significant correlations are found between loneliness, family dissatisfaction, feeling overwhelmed, and negative emotional states. Confidence emerges as a mediating factor, mitigating the negative impact of loneliness on a caregiver's likelihood of giving up, and shows a significant indirect effect on health outcomes.

This comprehensive examination highlights the multifaceted nature of the caregiving experience for individuals with ADRD. Caregivers navigate a complex array of burdens while simultaneously developing expertise that enables them to manage these challenges effectively. Recognizing the intricate dynamics of caregiving is essential for providing the resources, validation, and understanding caregivers need. By addressing the emotional, social, and practical needs of caregivers, society can better support these individuals in their challenging yet rewarding roles. Enhancing support systems, providing education and training opportunities, improving communication with healthcare professionals, and ensuring access to mental health services are critical steps in this endeavor. As caregivers continue to adapt and find meaning in their experiences, their journeys offer valuable insights into compassion, dedication, and the human capacity for growth in the face of adversity. Acknowledging and supporting their efforts not only honors their commitment but also enriches the understanding of caregiving within our communities.

Chapter 6

Interactions of Lay Expertise and Situated Knowledge

6.1 Introduction

This work applied a multi-faceted approach to data collection focusing on an array of qualitative methodologies. I have applied a combination of *ethnographic* and *netnographic* methods to explore *narratives*, which was guided by the pragmatic interpretivist application of *grounded theory.* Since data has been compiled from a number of sources, several places, and a varying degree in form, it is at its core *multi-sited*, gathering data from caregivers in Italy and the United States.

The core of the data collection came in the form of *interviews* with caregivers, *observational fieldwork* in support group settings, and *analysis of online caregiver forums.* I recognize that this may appear long-winded, that the application of a rich laundry list of methodologies goes against the conservative approaches to best practice. Critique that often follows work such as my own is that there is too much data, too much variation, and too convoluted a framework; that the author, when finally drafting up their results, will inevitably be overwhelmed by the sheer mountain of data before them, and that the application of all of these forms of qualitative inquiry implies that their dilution. That is, trying to do too many things simply means doing none of them particularly well. I disagree and hope that the work that has come out of this dissertation illustrates how these methodologies complement and reinforce each other in a profound and exciting way. I argue each method provided unique insights into the research question: *"How do caregivers for individuals living with dementia cultivate lay expertise?"* Interviews allowed for in-depth exploration of personal experiences, highlighting individual narratives of challenges, coping mechanisms, and the development of caregiving knowledge. Fieldwork provided context, illustrating the social dynamics within support groups and the ways caregivers learn from and support each other. Netnography offered insight into how caregivers utilize online platforms as resources for information, advice, and emotional support. By combining these methods, I worked to move beyond individual experiences to uncover broader patterns and develop a theoretical understanding of lay expertise in ADRD caregiving.

A central focus of this chapter is the concept of "embodied knowledge" and its relationship to lay expertise in caregiving. Rather than viewing expertise solely as the acquisition of technical skills or medical knowledge, this chapter explores how caregivers develop an intuitive, embodied understanding of ADRD and its impact on their loved ones. This embodied knowledge emerges through the day-to-day labor of care, the emotional bonds of the caregiving relationship, and the caregiver's evolving sense of self within the caregiving role. This nuanced understanding of expertise, informed by the theoretical frameworks laid out in chapter one, challenges traditional notions of knowledge acquisition by highlighting the significance of lived experience, emotional intelligence, and the caregiver's ability to adapt and respond to the ever-changing needs of the care recipient.

This emphasis on the embodied nature of caregiving knowledge aligns with the theoretical perspectives of Chapter 1, particularly the principles of interactionism and constructionism, which stress the importance of social interaction, meaning-making, and the fluid nature of identity in understanding social phenomena. The sources emphasize that caregivers do not simply apply pre-existing knowledge to their roles but actively construct their understanding of ADRD and caregiving through their daily interactions with their loved ones, healthcare professionals, and fellow caregivers. Their expertise arises from a combination of observation, trial-and-error, emotional attunement, and the ongoing process of adapting their care strategies to the unique needs and preferences of the individual they are caring for. Cultural practice therein is embedded in caregivers' perspectives (drawn from interviews and fieldwork observation) these practices.

6.2 Situated Narratives of Care

Narrative work in sociology has, as many authors much smarter than I have pointed out, been exhaustingly descriptive (Atkinson 2009) and detached from the larger world (Charmaz 2006a). I, too, found this to be the case when deeply analyzing transcripts - that I, as a sociologist, have spent an incredibly large amount of time reading both theory and method - studying lofty concepts and social ills and the tools and tricks of the trade, e.g., *best practice* - I firmly believed that I was equipped with what was necessary to study what these people had said, finding a pithy answer to my research question and being able to connect it with the larger theoretical streams of thought. To my surprise, when staring blankly at the deeply personal and decontextualized transcripts of our interviews, I found it challenging to connect them to the foundation of literature that I had studied throughout the years - and to connect them to broader themes and issues that implicate policy or at the very least the vague idea of *action*.

I am happy then that, during the first write-up of my methodology section, Adele Clarke's work offered a way to affronting the daunting task of analysis through *situational analysis*. Situational Analysis, in this sense, is the glue that holds the various elements of this dissertation firmly together: multiple forms of data from multiple places and a cultural milieu (e.g., practices) that needed to be identified. Analysis on Caregiving and the elements included through my ordered map - visible in the table below - is shown in the following tables - draws heavily from the work of Adele Clarke in (Clarke et al. 2022; Friese et al. 2022).

Table 6.1: Individual Human Elements/Actors and Non-Human Elements Actors/Actants

1. Individual Human Elements/Actors	**2. Non-Human Elements Actors/Actants**
People taking care of family members with ADRD	Medical equipment
Loved ones (PLWD)	Internet
Primary care physicians	Cable
Family members	Cellphones
Other Caregivers	Medical bills
	Delivery services
	Medications

Human and Relational Actors in Caregiving

The analysis first identifies caregivers themselves as central human actors whose experiences are shaped by interactions with both close family members and broader networks of professionals and support systems. In Marco's case, for instance, caregiving for his mother has been influenced by a tense relationship with his father, who offers little support. The strain this places on Marco, a former lawyer and now a teacher on medical leave, reflects the significant relational tensions that emerge in caregiving situations. In contrast, Maria's caregiving for her mother, while equally challenging, has benefited from her proactive involvement in support groups like Rete Magica, as well as her intense commitment to learning through courses like Gruppo ABC.

This relational complexity extends beyond family dynamics. Caregivers often describe frustration with healthcare professionals who, as in Sally's experience, are slow to diagnose or provide referrals. This medical limbo exacerbates caregiver stress, as they are left to navigate the healthcare system with limited guidance. In these cases, caregivers themselves become lay experts, acquiring knowledge and skills through lived experiences. The situational maps indicate how caregivers transition from novices to experts in managing complex medical conditions, reflecting a significant shift in their roles and identities.

Table 6.2: Collective Human Elements/Actors and Implicated/Silent Actors/Actants

3. Collective Human Elements/Actors	**4. Implicated/Silent Actors/Actants**
Memory Centers	“Loved ones” or the PWLD
Hospitals	Extended family members
Rete Magica	Nurses and home-health aides
Life Stream	
Digital support groups	
AARP	
Alzconnected	

Non-Human Actors: Technologies, Resources, and Space

Beyond human actors, non-human actors play a crucial role in caregiving practices. Medical devices, from walkers to pill organizers, become critical tools that structure daily routines and caregiving practices. Maria, for instance, has had to carefully manage her mother’s declining mobility, relying on guardrails, mobility aids, and digital reminders to ensure her mother’s safety. Similarly, Marco emphasizes the importance of keeping his mother occupied with television programs, which serve as a form of distraction and comfort for her.

The internet also emerges as a pivotal non-human actor, providing both invaluable information and overwhelming amounts of data. Caregivers describe relying on online forums, YouTube videos, and medical websites to find solutions to everyday challenges. However, digital spaces can also heighten caregivers’ anxiety, with endless search results adding to the emotional load. Situational mapping highlights the internet’s dual role as both a resource and a source of stress, revealing its influence in shaping caregiving experiences.

Geography and physical space also appear as important non-human elements. Caregivers in rural areas of the U.S., such as Kim who had to move from Florida to rural Indiana, describe the isolating nature of caregiving, where long distances to healthcare facilities and limited access to services heighten their sense of responsibility. In these environments, delivery services, like Amazon and pharmacy delivery apps, become crucial actors, enabling caregivers to maintain essential supplies without having to leave their care recipients unattended. These actors help mitigate some logistical challenges but also reinforce the caregiver's physical and emotional isolation.

Table 6.3: Discursive Constructions of Individual and/or Collective Human Actors and Key Events

5. Discursive Constructions of Individual and/or Collective Human Actors	**6. Key Events**
Aging stereotypes	Learning to take care of someone
Preconceptions on illness	Diagnosis event
Discourse on aging	Traumatic events affecting care
Discourse on retirement homes	Reaching out for help
Lay expertise	Death
Familial role and moral obligations	Breaking Bones
Religion and spirituality	
Cold and indifferent doctors	
The 36-hour day, chained to a corpse, a slow 'death'	
Selfhood	
Self-efficacy	
Nursing homes = "death sentence"	

Table 6.4: Political/Economic Elements and Discursive Constructions of Non-Human Actants

7. Political/Economic Elements	**8. Discursive Constructions of Non-Human Actants**
Medicaid policies	Learning from the internet
Power of Attorney issues	Having good TV to watch to stay entertained
Debt	Rising costs of medication
Health insurance	Being able to order equipment online
Healthcare economics (Italy)	Staying in touch with extended family through the Internet
Amazon and 24-hour logistics	

Table 6.5: Temporal Elements and Sociocultural/Symbolic Elements

9. Temporal Elements	**10. Sociocultural/Symbolic Elements**
Histories of aging, gender roles	Expectations to take care of family and kin
Past experiences of caregiving	Cultural practices around elder care
Past work experiences in related/unrelated fields	Filial obligations
Length of time caregiving	Horror stories of nursing homes
Caregiver age	
L.O. and CG history of substance abuse	
L.O. and CG history of violence	

Discursive Actors: Social Norms, Cultural Expectations, and Time

Situational mapping also uncovers the discursive actors that shape caregivers' perceptions and actions. The societal discourse around caregiving as a moral or familial duty significantly impacts how caregivers understand their roles. The family remains a primary caregiving institution in Italy, with the discourse around "caring for one's own" deeply embedded in cultural expectations. Maria's decision to bring her parents to live with her reflects these normative pressures, as she navigates her caregiving role not just as a daughter but as a cultural imperative.

In contrast, in the U.S., caregiving is often framed within a more medicalized and individualistic discourse, where families grapple with the tension between providing care at home or relying on institutional care facilities. Sally's reluctance to place her father in a nursing home reflects the pervasive stigma surrounding these facilities, often seen as "places of abandonment" or "death sentences." These discursive pressures create additional emotional burdens for caregivers, who must balance personal well-being with societal judgments. These tables revealed several positions taken on specific issues surrounding "care." A further pass towards data abstraction comes via positional mapping.

Positional mapping, a key technique in Situational Analysis, visually represents diverse perspectives within a specific discourse or situation. *Rather than focusing on individual opinions, it analyzes the positions themselves as they surface from interviews, documents, or other sources* (Clarke et al. 2016). By pinpointing central issues and visually plotting the spectrum of positions along axes, researchers can identify patterns, tensions, and even silences within complex data. This approach helps simplify intricate discourses, reveal nuanced relationships between different stances, and illuminate areas of agreement, disagreement, or absence within a particular field of study. This proved an invaluable tool in demonstrating the complexity of care provision and what contested territories existed in an otherwise unimplicated setting.

In turn, positions surrounding the provision of care were simplified through a dichromatic mapping of positions. For simplicity, positions on care were mapped through the graph below, with the Y axis representing *Autonomy and Dignity* vs. *Safety*, and *Person-Centered Care* vs *Medically Oriented Care.* I want to stress that these are not objective realities - instead they are how care provision is perceived by individuals in the social milieu of care provision. These are not real dichotomies; it is quite possible to be autonomous and safe and receive person centered medicalized care. This is a way to demonstrate visually *how* touchy subjects like in-home health aids (*badante*) or institutionalization is perceived by both caregiver and care recipient.

Four main entities are positioned along the graph axis. With In-Home Caregiving positioned to illustrate the person-centered model of care provision while varying in degrees of autonomy and dignity vs safety, nursing homes at the very bottom of the y-axis represent a full loss of autonomy, primary care physicians placed centrally along the y-axis and ranging from mid -x to +x. This was done to show how primary care physicians, while carrying credentialed and medicalized knowledge surrounding care, carry personalized or, at the very least, informed knowledge about care recipients' personalities. In the center of the positional mapping are support centers, which frequently vary between all positions taken as they frequently incorporate elements of medically oriented care and person-centered care while seeking to aid caregivers trying to reconcile the agency vs. safety dichotomy stressed in interviews and fieldwork. Finally, a line ranging from (+y, -x) to (-y, -x) illustrates care recipient symptom intensity over time. This reflects increased medically oriented care needs as symptoms become increasingly complex. This theme was evident from fieldwork observations (both digital and in-person), and interviews.

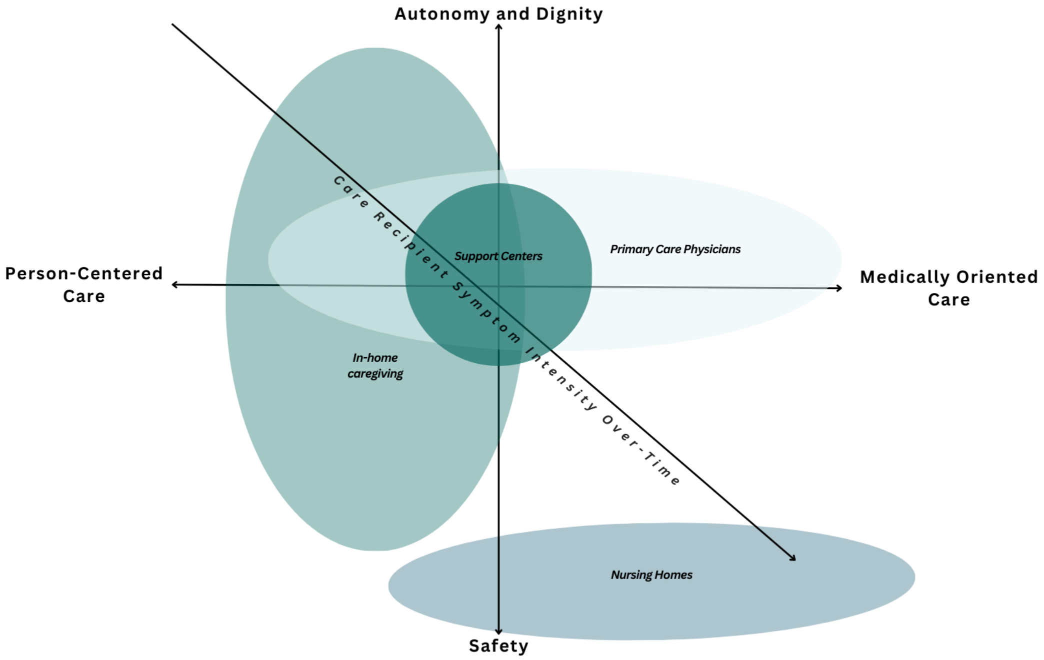

Figure 6.1: Positional Mapping and Of Contested Spheres of Care Provision

These positions, however, are not taken in a vacuum. They are, in fact, actively constructed and deconstructed and continuous iterations within dynamic and fluid social settings. These interactions exist in an active and complex social world, where multiple social arenas are at play in shaping caregiving experiences. To illustrate that, this mapping shows how broader social structures interweave with one another and make narratives situated within the web of social interactions that formulate them. Social arenas are sites of action where interconnected social worlds interact. They are arenas, not so much as physical boundaries but discursive issues. In practice, they seek to demonstrate how power dynamics and collective actors navigate social landscapes.

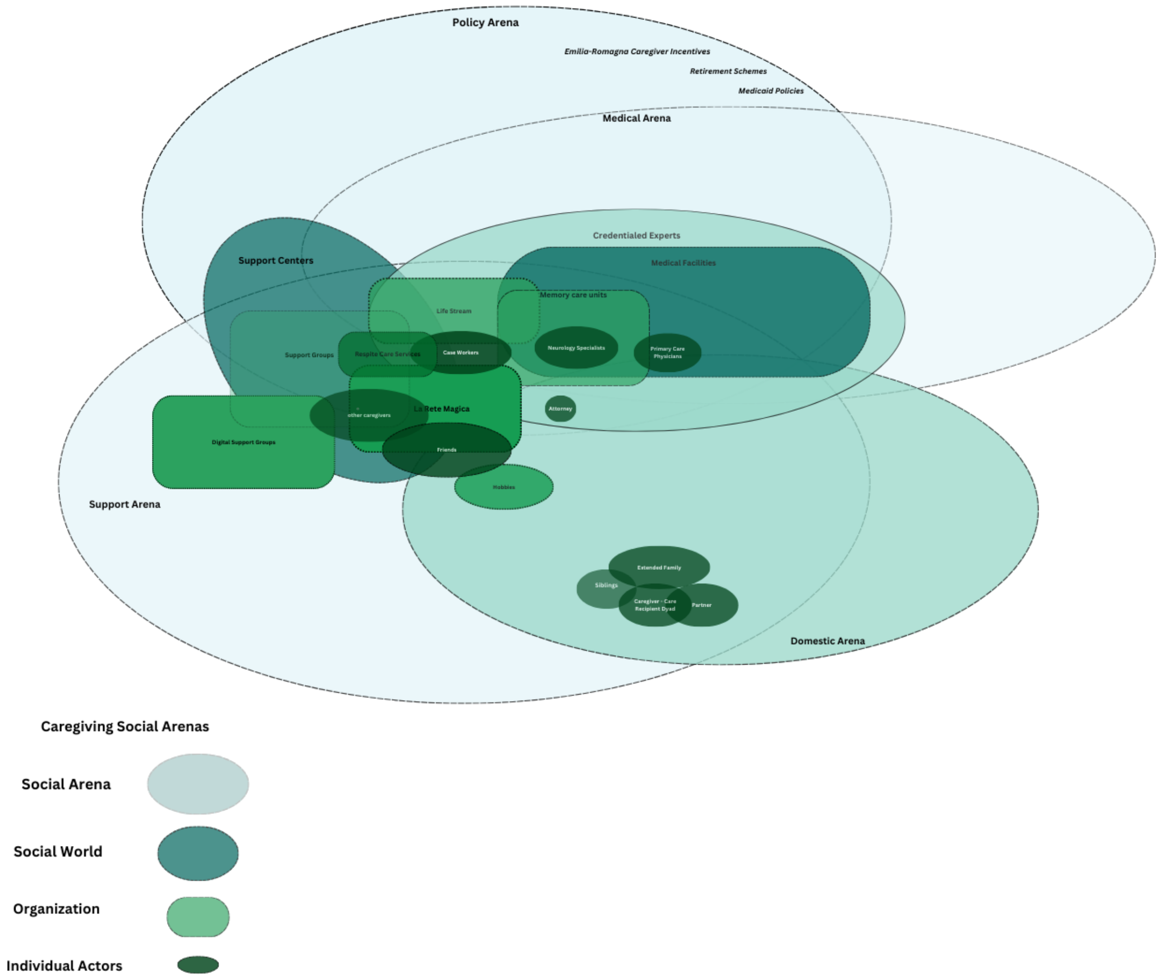

Figure 6.2: Caregiving Social Arenas: A Situational Analysis

These interwoven worlds are rife with possible comparisons and analyses of the interactions between discursive elements and social worlds - specifically those present in digital forums and group settings. However, as this work's focus has been on narrative and knowledge, pragmatic interactionist lenses (like the one being applied to the social worlds/arenas) aid in setting the stage for analysis and interpretation, as opposed to being interpretive in its own right. In addition, culture as a driving force for caregiving experiences has been stressed throughout this text; to argue that culture is a static and embodied experience independent of the social world is not my intention. For that reason, as opposed to defining each difference in the impressive chasm of diversity that exists in comparative research, the precedent analysis and the following are intentionally drawn to similarity and *observed difference*; that is, differences that emerged from grounded theory and not my own reading of comparative literature. In this case, I am comparing how caregivers navigate a unique process of "becoming" a caregiver, a process that is *situated* in larger social processes - not comparing Italian vs American, Men vs Women, etc. - as variables can only get us so far in understanding mechanism and forces (Abbott 1988).

Key Events And Cultural Practice: Turning Points in Care Trajectories

Finally, situational analysis reveals how key events act as catalysts, pushing caregivers into new roles or forcing them to reconsider their caregiving strategies. Traumatic events, such as falls or sudden health crises, often necessitate a shift in caregiving dynamics. For Marco, a fall that resulted in his mother's broken hip marked a significant turning point, leading him to reevaluate how much care he could provide on his own. Similarly, for Samantha, the gradual cognitive decline of her mother forced her to seek external support, though the emotional burden of caregiving remained deeply personal and tied to her identity as a daughter.

In both the U.S. and Italy, the moment of diagnosis plays a pivotal role. In the U.S., caregivers often describe the moment of diagnosis as a formal acknowledgment of their new reality, while in Italy, the onset of dementia is frequently described as a gradual realization, rather than a singular event. These key events serve as critical junctures in caregiving trajectories, reshaping relationships and care strategies. This inherently changes how caregivers perceived themselves, their roles, and what *dementia* means for both an individual and their respective carer.

Abbott in Processual Sociology, which is a text that I have consistently cited throughout this dissertation, argues that sociology, particularly that which involves thoughtful and extensive interpretative frameworks and analysis, must reconsider the significance of text and form. Abbott refers to this careful appreciation for content as *Lyrical Sociology* that is, sociological writing that transcends the boundaries of a description, and explicitly pronounced indignation. Lyrical sociology is, descriptive, but it is also reflective - it is empathetic while maintaining a pragmatic lens. In this sense, *lyric* is a temporally and contextually bound snapshot of what the writer has in their field of vision. To do these stories justice, it would be best to expand on the caregivers themselves. In the previous chapter, I provided a pithy and concise overview of the participants. I would like to pose readers with a singular defining characteristic shared by all who allowed me to enter their lives for an afternoon. Consider a preeminent theme in medical sociology - that is, our own identities and our sense of selfhood are intimately linked with how we perceive the future. Our plans, our time, and how we look at it are significant to understanding ourselves.

6.3 Events

Carolyn

On a Wednesday, escorting her grandfather to his audiology appointment, Carolyn received a phone call that would drastically alter the course of her life. On the other line was one of her six aunts, telling her that her grandmother, who had been diagnosed with cancer only three weeks prior, was in an ICU in Columbus, Ohio, and was likely going to die within the day. Carolyn rushed into the van, driving the two and a half hours from the rural Ohio hamlet she was staying in temporarily to care for her grandfather while her grandmother underwent cancer treatment.

By the time she arrived, the throngs of cousins and extended family had arrived – pickups lined the parking lots, and children had been taken out of school. To greet Carolyn was her mother, who initially told them to wait in the car; now frantic, she tells Carolyn to get herself and Grandpa up there. Clearing the numerous sterile stairwells and glossy floors of the Ohio State University hospital to arrive at the ICU – Carolyn grabs her grandmother's hand. Before passing – Carolyn tells her - "you have nothing to worry about with grandpa [...] I'll take care of him [...] we've got this, and she squeezed my hand" (Carolyn, Pos. 97) Carolyn's grandmother passed 15 minutes after her arrival, and just a few minutes after, she was able to share this moment – promising to carry the torch of caring for her grandfather, moving her life and husband from Dayton to what would soon become their house. Filling the physical void that once a family matriarch occupied.

Kaya

Confusion, anxiety, and apprehension, that's how Kaya felt in her words when she saw a fork in her grandmother's toaster. Having just returned from massage school in Costa Rica, Kaya now lived in her childhood home in a wealthy area just north of the loop of Chicago. Her grandmother, at this point, has lived on the ground floor for many years prior. An only child, Kaya was confronted with a reality she had known since her adolescence that she would face: that she was now a carer – after only beginning to care for herself as an adult. Her duty – her promise is both to herself as an avid and curious learner – seeking to grow vivaciously through experiencing all elements of the ‘human experience’ – and to her family, as the only kin to her grandmother, who, in her view, was capable of doing the job, and providing a level of care that she believed anyone loved should receive.

Katie

On one of the many trips to Muncie made by her parents to visit the grandkids and her father’s favorite daughter, Katie was eager to get her Dad to help her fix something around the house. A handyman by trade, Katie’s father had renovated old jeeps, taken apart and put back together countless mechanical devices, built his own tools, and took her camping across the hills of southern California. Knowing her Dad likes to keep his hands busy, she asked him to help with a ceiling fan. She brings her Dad into the living room – placing the ceiling fan on the ground, a toolbox, and says ‘have at it’ Carl obliges and starts working. Katie leaves to see her mother after their long 9-hour drive from Tennessee. She still couldn’t fully understand why they had moved to Tennessee from California at this point – far away from the coast, any family, and any large cities, but it was her Father’s choice, and her mother half-heartedly agreed to follow. A few minutes later, Katie returned to the living room to find her father standing, looking back from the instructions booklet to the fan on the ground and the empty hole in the ceiling. He looked back at her and back to the instruction booklet -

“This is really complicated,” he said, picking up the fan to see the screws on its topside. Katie answered, “Well, that’s ok, we can get David to come and help.” Katie got onto the phone and called her brother David who arrived to assist in the ceiling fan. After a few hours of switching wires, taping frayed ends, and finally attaching the fan to the ceiling, the lights shorted in the house. Unfortunately, neither Katie nor David were electricians. At that point, they decided they would sort it out the following day and call an undesired guest with electrical experience (Tom). Leaving the fan on the ground and the wires hanging above, they went to bed. That morning, Katie’s father asked her about the ceiling fan – “I want to check on that ceiling fan to see how we ended up getting it sorted last night.” Katie, surprised, said, “Dad, we didn’t get it done.” her father rebutted, “Well yeah, we did, Tom came over, and we did it together.” He walked into the living room to find the fan waiting for him on the ground and loose wires above. At this moment, for Katie and her father, something was clearly not normal. Katie, David, and Linda were confronted with something that could not be chalked up to benign ‘forgetfulness’. In Katie’s words – “he had a moment of being very surprised [...] from there, it was just more instances of things like that. And then he started to realize that something was not right... something’s not right.”

(Katie, Pos. 294-298)

These events are remembered because of their significance to these speaker’s experiences, bearing an enormous weight on their life trajectories. They are distinctive, ongoing, and consequential. The events outlined above show a pattern that emerged in interviews, that the moment of discovery was consequential, with ripples transcending their paths, present, and future - that moment of discovery – of promise – of obligation – the catalyst that puts in motion their current state of being a caregiver. While all have a tendency to retrospectively assign meaning to our past lives – to create a narrative that fits into our own personal biographies – what is unique about the action of 'becoming' a caregiver is the immediacy of these recounts. That is, as Jack once put it – "It's all crisis-driven". This, as many of my more read colleagues would most likely already extrapolate – implies a rupturing of biography – but also stresses another emergent theme in these images that is also present in their daily lives – *Time*. As some would argue, time and temporality are aspects of sociological narrative work that are largely absent – so much so that they may call for a renunciation of narrative research as a whole – however, simple idioms offering succinct proses on babies and bathwaters stand to address concerns of understated lyricism in sociological text (Abbott 2016). Time is of the essence (at least in the beginning). Caregivers are thrust into roles as if handed a puzzle with half the pieces missing, told to assemble an image they've never seen.

Narratives surrounding illness give our lives meaning and explanations. We assign values to the past to extrapolate and explain it, as well as the present and future, creating suitable narratives for ourselves. For those above, they explain why they do it - why they carry out these tasks that are so difficult. Whether it be a promise to a loved one in their last moments, a feeling of familial obligation to kinship ties, or an embodiment of adulthood - they are prompted by a singular event. However, these singular events of realization are not found in narratives expressed by Italian caregivers, and they are not crisis-driven responses.

Maria

In the Spring of 2020, Italy was at a standstill. A collective fear of infecting older parents, grandparents, and older adults was very real. Covid-19 for Italy was exceptionally lethal, especially in high-density areas of northern Italy. Maria was her mother's carer, going twice a day to visit, chat, and make sure her mother was healthy. Maria's mother has lived with diabetes for the last 30 years and has always been exceptionally independent - taking care of doctor appointments and medication regimens and paying close attention to her diet.

With the advent of COVID-19, and since Amanda had two children at home, out of fear and love for her immunosuppressed mother, she made the decision to visit less frequently. On one of the occasions when Maria did make the trip to her parents, out of curiosity, she began inspecting her mother's pill boxes. Noting one of the pills missing from its daily slot, she asks -

> "Mom, did you take your meds?" to which her mother responded

> “ ‘Meds’? What do you mean ‘Meds’? I don’t take med*s*, I only take one medication”. Maria froze, looking at the boxes and back to her mother;- “Wait, Mom, one? You take this and this.” raising an unopened box - her mother pushed back “No, no, that’s not true, I do not take any others!” Maria acted quickly, rushing to the ER to run tests, finding that her mother’s diabetes was out of control following months of not taking her medications. Following this event, Maria assumed all responsibilities for managing her mother’s medications - organizing them in the morning, lunch, snack, and dinner doses in advance. Maria ascribes her mother’s cognitive decline resulting from a sense of loneliness because of her reduced visits.

Patrizia

In 2019, Patrizia’s mother lost her partner. This cascaded into a deep sense of depression for the whole family - as Patrizia’s mother’s partner was like a father to the family. Patrizia would visit her mother on a regular basis. Her mother was her best friend, a person that she could share all aspects of her life with - from high school woes to adult worries - from dating issues to child-rearing; Patrizia’s mom was her confidante.

During lockdown, Patrizia’s mom began to show signs of something other than depression. While visiting her mother, Patrizia opened the pantry, and six packs of spaghetti rolled from the shelf onto the counter. She looked through the cupboard’s contents - eight cans of tuna and ten jars of sauce, all purchased from different stores. Patrizia’s mother’s behavior, too, began to become repetitive - constantly repeating the same movements and words. Patrizia and her brother decided it was time to take her mother to a specialist. After troubling results from a memory test on initial screening, A CT scan revealed micro ischemia and a meningeal tumor in her brain. Patrizia and her brother have consistently picked up the slack since that moment. As Patrizia’s mother’s symptoms worsened, their care duties increased.

Narratives surrounding diagnosis and caregivers’ first exposure to ADRD in their loved ones in these cases are gradual - they are noting signs and identifying moments of confusion, delirium, and incremental loss. They are also notably interconnected with the environments in which symptoms were identified, whether they be COVID-19 and the effects of isolation on their loved ones’ health or the breaking or fracturing of bones resulting in loved ones being bedridden. Symptoms were identified, events were given meaning retrospectively, and caregivers became so over time. Gradual shifts, increasing responsibilities, incremental schedule adjustments - these were hallmarks of Italian interviews. The pronounced singular event of behavior in loved ones leading to an immediate and large shift was nowhere to be found. Caregivers assign meanings to ADRD through these singular events and assign watershed moments of increased care responsibilities as well.

Anna

Anna was 18 and living at home. Her mother was a geography teacher at a local high school. Her mom had been a teacher for decades but was starting to have trouble with handling the digital platforms and online grading. Initially, Anna chalked her mother's difficulties to her age - virtual learning is not for everyone, and online schooling is tricky for even the most tech-savvy student to navigate. Eventually, the issues started to reflect something different - it was not only the platform that was difficult for Anna's mother to use, but it also became grading papers - something that she had been incredibly efficient at for years before. From papers to simple tasks, riding a bike produced an immense sense of anxiety in her mother's motor skills, from taking a roundabout the wrong way on a bike to driving extremely slow while Anna and her father followed.

Anna and her father were deeply concerned, reaching out to a neurologist to run tests. Neither believed that the source for the family matriarch's motor skills could possibly be Alzheimer's. Anna explains:

> For me, it was hard to accept such a diagnosis for my mom. Partly for emotional reasons, and partly because, as we said before, you see her every day. You see the stress, the anxiety, the worries. Maybe you think it's just that, and you don't think of anything else. One of the first things, yes, was riding a bike, driving, which she couldn't do anymore. I remember a moment when the doctor, the neurologist, told us this. "How did you not notice?" [and that made me feel] Bad, very bad because you feel guilty. Yes, it's partly my fault for not noticing. We got to this point, but objectively, nothing changed. We couldn't have done anything, even if we had noticed earlier. But seeing her every day and not noticing... At first, we all felt guilty. [...] I'm not a doctor. I remember telling the neurologist that. "I'm not a doctor, and I can't know." I don't have the skills to recognize something like this. If it's a physical illness, if something hurts or you can't move your arm, you think, "I need to see a doctor." But if you can't do something you used to do, you might think it's anxiety, stress, or something else going on in your life. It's hard to self-diagnose. (Anna-ENG, Pos. 93-94)

For Italian caregivers, cognitive decline is not defined by a singular isolated event where a flip of the switch hurdles them into the role of caregiving. Even prior to Anna's mother's diagnosis, her father was helping her grade homework - reading line by line since her ability to read had declined significantly.

From the Italians surveyed, caregiving was a gradual transition that followed perceived illness intensity. Their American counterparts, on the other hand, conceptualize the illness in clearly defined chapters, with explicit steps that catalyze others. A temporal restructuring of narratives occurs when reading

American interviews, which is largely absent from Italian narratives. Where for Americans, succinct chapters follow a familiar pattern of ADRD being an abrupt 'flip of the switch' following a specific event and quickly reaching out for help or assistance - Italian caregivers interviewed do not share this narrative pattern.[1] This finding reflects literature on cultural variances in ADRD treatment and recognition outlined in *chapter 2* (Chee and Levkoff 2001). This could also demonstrate Americans' frequency of diagnosis early and quickly.

As mentioned in the previous chapter, cultural expectations for one's life course carry with them contrasting notions of selfhood. Multiple bodies are needed to attain a formal diagnosis of Alzheimer's or Dementia - that is, a "sick body" and a healthy one to recognize symptoms. In all cases of those interviewed, the body that noted symptoms was to become the *sick person's* caregiver. Clinical progression or biometric worsening of ADRD does not necessarily intertwine with a perceived worsening of physical symptoms (Balard 2022). Instead, what largely determines diagnosis is the receptivity of their future caregivers. This receptiveness is dependent on the severity of stress e.g., *burdens* or multiplicity of tasks in providing care (Balard 2022; Boise et al. 1999; Lock 2013). In essence, illness is recognized when tasks become excessive of that which is expected for certain roles (spouses, children to parents - what is effectively "owed" based on kinship ties).

For caregivers in a cultural milieu that does not carry pronounced "individualism" or has differing values concerning kin-ship responsibilities, understanding ADRD stems from

1) social interactions - sickness is related to *poor social relations* or contextualized factors.
2) The noting of symptoms is based on an excess of duties or tasks expected of loved ones - duties that, for many of the Italians previously listed - are already numerous.

It would stand to reason that, when focusing on the form and structure of the narrative, caregivers based in Italy connect a number of social elements to ADRD that lockdown, conflict with the family, reduced in-person visits, or experiences of deep pain or grief were in part to blame for their loved ones cognitive decline. For Italians interviewed, their loved ones' sickness was, in part, a socially bound one. For Americans, it was not.

Autonomy is considered an essential part of selfhood in cultural contexts, which exhibit a strong sense of "individualism" (Hashmi 2009). Agency in the case of a person living with dementia or Alzheimer's disease is limited - touching on a point raised by Hazan (1994) - that those living through dementia experience the

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[1] The implications of this pattern, if proven on a large scale, indicate that caregivers in Italy may prolong diagnosis, meaning that treatment for ADRD could be significantly delayed. Further study would be necessary to determine whether this relationship is, in fact, a reality.

"death of selfhood" or, when applied discursively to narrative can be explained as *death before dying*. Goffman writes that losing one's mind is the "most pervasively threatening thing that can happen to a self in our society" (Goffman 1961:131). In a sense, while the care recipient's body may not show clear signs of "death", the identity of the care recipient is altered in such a way to be unrecognizable, thus requiring reconstruction of identity and creation of the giver-recipient dyad (Hayes et al. 2007; Karner and Bobbitt-Zeher 2005; Pearlin 1989). As this new identity is situated in context, for American caregivers, noting a loss of agency in themselves at any point lead to a diagnosis; noting a decline in their loved one's agency, in turn, catalyzed a trip to a specialist. For American caregivers, narratives are constructed around what Scheper-Hughes and Lock (1987) would argue that American's sense of "Individuation". That is, once their kin-ship responsibilities implied a loss of agency in both bodies; sick body and healthy body, a diagnosis soon followed. In the case of American caregivers, this was the first sign of a reduction in body autonomy that was to follow - and a *flip-of-the-switch* moment: they were now the primary caregivers for a sick body.

6.4 Situated Knowledge and Situated Self

Throughout this text, I have consistently cited the importance of *roles* and identity; however, I believe that I have not given these concepts due consideration. Schumacher (1995) poses a promising conceptual framework for the *caregiving role* and its acquisition. For Schumacher, this process of acquisition is made by doing. That is, caregivers assign meaning to what *caregiving* is through situated interactions. For Functionalist perspectives on "roles," they are argued to be prescribed with clearly defined norms of behavior (, *e.g.,* scripts) coinciding with the position or status of a specific social system (Linton 1936; Parsons [1951] 2005) and are learned by a person's predecessors. For interactionists, they are improvised - that, while scripts exist, they are subject to change and modified consistently according to the interaction between actors (Belgrave and Charmaz 2015; Mead 1934). Bridging these perspectives is the situated nature of the *caregiver*; where strict societal norms or adherence to defined roles are considerably more murky. That is, caregiving is situated within the cultural milieu of time, place, and status, yet rule sets and expected behaviors are not nearly as clearly defined. Caregivers undergoing initiation into their roles are

1) learning how social structures define caregiving
2) fashioning their own definition to their role - imbued with their own personal style and
3) reflexively appraising their own personal identity and self.

These first two points highlight an ecology of caregiving — where individuals find meaning in their role by engaging with broader social structures and, in turn, infuse it with personal significance. Through this process, caregivers discover their own traits and idiosyncrasies. In other words, caregiving becomes an ongoing act of self-discovery, a way of learning about oneself, one's beliefs, and how these ideals are situated within larger contexts.

6.4.1 Identity and Selfhood

The term identity has a number of varied uses; however, for the purpose of brevity and relevance, this work understands identity to reflect the parts of the self whose meanings individuals assign to the varied roles they play. In other words, identity is the sum of meanings individuals assign to multiple roles they embody (Mead 1934; Stryker and Burke 2000). At its core, identity is a social *process* where the significance of the self and others are consistently rebuilt through interaction (Blumer 1969). The self, created through engagement with the social world, is, in turn, shaped by attitudes and beliefs that are created by that social world (Berger 1963).

In the context of care, as early as 1992, Skaff and Pearlin (1992) defined what can occur when an individual becomes engulfed in caregiving. The "loss of self" refers to the salience of the caregiving role in an individual's assessment of their identities (e.g., "engulfment"). Individuals' lives and identities become so embedded in the caregiving role that any other possible self-defining characteristics - goals, interests, desires, and identities are subsumed by the dominant role of the caregiver. As caregivers are left with fewer outside sources of self-evaluation, the caregiver role dominates, creating a feedback loop. Where one's identity had previously been associated and conceptualized in reference to a number of components; career paths, activities, and other responsibilities - as care provision intensifies, the scope and purview of individuals' lives is constricted (Skaff and Pearlin 1992:657). Skaff and Pearlin (1992) explains that the engulfment of the caregiver self is defined by: "the compression of self-image expressed by loss, shrinkage, or diminishment of identity. It represents the very personal meaning to the self that the caregiver attaches to the situation" (p. 658). In short, a loss of self coincides with greater restriction on an individual's life after assuming the role of caregiver.

Findings from interviews indicate that this development is contingent on cultural practices and expectations - namely, the level of social interactions across the life course and one's expected degree of autonomy in a given situation - imbued with personal traits - cultural practices - and broader societal expectations for behavior. The more contact an individual has with others outside the caregiver and care recipient dyad, the more varied the sources of feedback and the broader the sense of self. When the sole point of reference for self-evaluation is the caregiver role, the more likely the individual is to be engulfed in it, the more likely they are to experience heightened levels of stress, burden, and burnout.

In chapter Two, a pillar of 'lay expertise' in providing care is an individual's strategies for maintaining a sense of self-hood - which represents a novel conceptualization of expertise extending the purview of *knowledge* to encompass one's capacity for cultivating varied sources of feedback. In this case, knowledge also refers to how much an individual "brings to the table," implicating knowledge streams that encompass knowledge of one's self, society, and role.

6.4.2 Knowledge and Know-how

Caregiving is often likened to a career, with identifiable stages and trajectories (Aneshensel et al. 1995; Lindgren 1993). These trajectories are frameworks researchers use to understand the lived experiences of caregivers. However, narrative accounts often diverge from these expected paths. By framing interviews as *situated narratives*, they are deeply embedded in the unique social contexts surrounding the caregiver. The caregiving role is not entirely shaped by broader social structures but is instead variably defined through specific cultural practices. Before assuming the caregiving role, many caregivers are unaware of these cultural definitions, yet at the moment of exposure to "norms," embody them and fashion them to their own needs in time. What is, however, a constant that can be used as a measure for caregiving *health* in role creation is **insufficiency** vs **role mastery**. Through analysis of survey data (NSOC) and interview data, these two concepts are considered (in accordance with axial coding) the "consequences" of lay expertise development; in other words, they are burnout and lay expertise. The hypothesis underlying this work is that these two concepts are relationally bound (e.g., defined by caregivers' perception of a variety of interactions).

In the case of lay expertise, I chose the word "encounters" to define a specific category - that is when caregivers interact with experts, both medical and lay, throughout their caregiving journeys. These meeting points are where caregivers ascribe value to caregiving health; they compare their indicators of 'health' or progress or success with those created by others, thereby creating multiple sources of feedback while focusing on their "career" specific role.

6.4.3 Gendered nature of Care work and Age

Two aspects of caregiving experiences contextual conditions that shape how burden is perceived were a person's age and gender. Care work has been consistently cited as a gendered form of labor, with its associated burdens and responsibilities being heterogenous (Akpinar, Kucukguclu, and Yener 2011; Doucet 2009; Henning-Smith et al. 2018; Navaie-Waliser, Spriggs, and Feldman 2002; Oliker 2011; Skaff and Pearlin 1992). For women embodying the role of caregiver, specifically women over the age of 40, becoming a caregiver comes with its own unique challenges with regards to selfhood and agency.

Research suggests that women in high-status careers feel an acute sense of burden when assuming the caregiving role (Chee and Levkoff 2001); in addition, Pearlin argues that women rely on diverse sources of feedback in defining selfhood (Skaff and Pearlin 1992). Active social lives and active careers coupled with implicit societal expectations towards kinship ties create a challenging constellation of stressors. In addition, externally defined gender roles mean a lack of flexibility in role creation - social structures and cultural practices have predefined scripts for women that take on the role of caregiver, leaving little room for women to embody this role according to their own faculties or abilities. While women may receive varied sources of feedback, gendered expectations dominate. In some respects, this can heighten perceived burden (Akpinar et al. 2011; Swinkels et al. 2019; Yan, Zhang, and Sun 2024); in others, it can encourage women to reach out for additional help - knowing beforehand what to expect from caregiving duties (Lauritzen et al. 2015; Varik et al. 2021). Excerpts from interviews divulged in the previous chapter illustrated this experience; namely Alessia's experience with her husband's reluctance to assist, Katie's frustration with her brother's lack of initiative, Marco's father's indifference, and Cindy's experience with one of her brother's that lives very nearby on the farm with her mother refusing to help - through one's care network, if a person who was expected to help with providing care and did not provide it to the extent which they were expected to, they were most likely men.

There is also a generational divide in providing care that is cited in the literature (D'Amen, Socci, and Santini 2021) and in findings, stressing that age does have a part to play in shaping caregiver experiences. Age, however, can have a greater effect on the retention of selfhood in caregiving experiences. For younger caregivers, there is not a clearly defined playbook for behavior and skill development. Throughout interviews with younger caregivers, interacting with support groups did not offer the same benefits as for older caregivers. An essential component of reducing perceived burden is vicarious learning and bolstering a sense of self-efficacy(Au et al. 2009; Beckett 2024; Gilliam and Steffen 2006; Semiatin and O'Connor 2012). [2] For younger caregivers lacking a reference point or a network of individuals experiencing similar life experiences can increase levels of isolation, therein feeding perceived burden.

Kaya has tried consistently to connect with caregivers but was never fully able to find one that fit her criteria. When asked about online support groups, she offered her perspective:

> [Kaya] (7:03 - 7:12) I've tried. I've tried. I'm in a caregiver support group,

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[2] the concept of Expertise has befuddled the minds of social scientists for the better part of the last decade, raising important questions on who gets to be called an "expert" and who is simply knowledgeable. The lay expert, adding an additional stratum of complexity as an uncredentialed knowledgeable individual, further complicates this discussion - one which I elaborated on in chapter two.

> but that's virtual, and I realize that that's not good for me. [because] it's virtual. I want to hang out with people. I'm already isolated. But when I try to connect with caregivers and try to create some sort of friend group of caregivers, I realize that I'm incredibly young. I've been an adult for about six years. It's [adulthood] a very recent development - I'm very new to this. I've been in my 20s for four years. And so, most caregivers are in their 40s, 50s, and 60s and preparing for their spouses and their parents. And so that is something else that's really isolating because most people are building up their careers and building up their education. One perspective is that I'm stagnating, but there are also other perspectives where I'm really thriving. There are lots of things that I'm learning that no one else will ever know. (Kaya, Pos. 342-350)

Carolyn

> Oh, yeah. Like, when somebody talks about, like, I can talk about my grandpa all day long, you know what I mean? Like, he is like, literally, like, the center of my world. but it's hard because like, I can recognize that I'm 31 years old. And this is not normal, in theory, you know, but what is normal? And so like, I could talk about him a lot or like, but it's hard even, it's hard for me even as like, a support group, or it's hard for me - There's not really support groups, and the support groups that do exist are for like, older people, like take care of spouses. But additionally, like, I don't have time to shower, you know and I don't have time to go to a support group. (Carolyn, Pos. 439-442)

Without a point of reference, acquiring the role of caregiver is a critical point of both career development and personal identity formulation; for young adults, providing care for a loved one presents a unique set of challenges.

6.5 Lay Expertise and Flourishing

There are in fact, longstanding measures and metrics for gauging what, in nursing literature, casework studies refer to as *mastery.* In this case, there is an objectively defined favorable caregiver output/behavior. These are shown below and are quite thorough (Schumacher et al. 2000). They outline a clear conceptualization of "good" caregiver behavior. For Schumacher et al. (2000), skilled caregivers exhibit the following.

1) including monitoring the care receiver by noticing subtle changes,
2) keeping accurate records, and
3) using appropriate tools.

They interpret observations by recognizing deviations from the norm and considering multiple explanations for symptoms. Decision-making involves balancing care priorities, considering potential consequences, and addressing multiple care demands. They take action efficiently by:

1) organizing tasks,
2) pacing activities to match the care receiver's needs, and
3) using systems for tracking.

And adjustments are made by

1) modifying routines,
2) environments, and
3) strategies until optimal care is achieved.

Caregivers also seek and use resources wisely, advocating for themselves and the care receiver when necessary. Finally, skilled caregivers provide hands-on care with attention to both safety and comfort and work collaboratively with the care receiver while also navigating the healthcare system to ensure proper support and care.

These are the qualities that ideal caregivers exhibit; if a person embodies these traits, they are an expert carer - the "ideal type" of care provider. On the surface, it would appear that care provision outcomes and whether an individual could be categorized as a 'lay expert,' at least according to how lay expertise is conventionally defined (Epstein 2023),[3], have very little to do with one another. Where skill looks at care provision outcomes, lay expertise looks at caregiver transformations and the creation of *knowledge*. However, following fieldwork analysis, they are interrelated phenomena; one appraises their own standing and performance and gives it value.

For Epstein (2023), lay expertise implies:

> the hybridity of knowledge, tools, and techniques that fuse together formal, experiential, embodied, evidence-based, and so on. [...] they marshal their knowledge to take action to advance pragmatic and expressive goals defined by criteria and values drawn substantially from *outside* the domains of routine bureaucratic activity where professionals go about their work. (Epstein 2023:85)

On the one hand, lay expertise is evidence-based (e.g., specific outputs) - rallying their know-how to advance situated goals. In this case, the goals of caregivers I spoke with were shared: make care provision efficient, ensure their loved one was comfortable and maintained a sense of dignity, and make their own experience less burdensome. On the other, it is internal and embodied as it necessitates self-

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[3] Self-efficacy, in its most basic conceptualization, is the expression of perceived confidence. When an individual expresses a high level of perceived self-efficacy, they believe that they have the necessary tools to manage stressful situations. This ties in directly with the mediating effect of perception on a number of social health outcomes (loneliness, support, etc.).

deconstruction and reconstruction - in other words, from not knowing oneself and one role to being and knowing it. And, while early on in the research process, knowledge was arguably the most difficult aspect of the caregiving experience to qualify, as it would relate to expertise, Epstein (2023) offers that pithy definition shown above, from formal, experiential, embodied, and evidenced-based (p. 85). While defining what constitutes lay expertise is relatively straightforward, how that know-how is cultivated is not as direct.

6.5.1 Encounters

Finding Support

While support stems from various places, meeting varied sets of explicit needs, it does accomplish the same goal across the board: to shield individuals from stress. Support can mean getting a nurse's aid at home (also known as a *badante* in the case of Italy), reaching out to respite care services, and meeting with friends for a coffee. There are care-specific forms of support - e.g., support in providing care to one's loved one, and there is support for its own ends. Each is equally important; however, the lines between the two are sometimes blurred.

Friendship and Family

For Jack, moving back to his hometown and being able to connect with friends in California who had similar experiences in taking care of their parents served twofold. On the one hand, these individuals knew ADRD care; what to expect, who to call, and what resources could be available. On the other hand, they also knew Jack; they knew his limitations, his personality, and his character and they could recognize when his health was on the decline. In this case, for him, his friends were more than just well-learned caregivers who had entered and exited their careers. As such, they offered moral support from a place that credentialed authority rarely can: friendship.

For Cindy, Patrizia, and Sally, this support came from immediate family members. Patrizia was able to count on her brother to handle much of their mother's needs with regard to ADLs, while she mainly assisted with IADLs. For Cindy, she reflected on feeling lucky to have her siblings to rely on as a springboard for ideas and as space to bring levity to challenging situations. Sally and her siblings rallied to get the support their mother needed to care for their father; echoing a trend found among most families following stressful events. Anna and Federica's extended family and friends aided them in making sure their mother was not alone, with their mother's longtime friends taking an active role in helping their mother combat isolation; from taking her on trips to the movies, and out for walks - a robust support network acted as a buffer between the family and the lonely realty experienced by many people living with dementia. For Katie, while requiring a bit of prodding to take initiative, her brother was instrumental in helping their parents move cross-country to be closer to the family.

Caregiving is already an isolating process, both for the carer and recipient, reducing streams of feedback and, in some cases, leading to the issues of “engulfment” previously mentioned. To combat being subsumed in the role, getting external validation and assistance is paramount. What these experiences illustrate is that, while the caregiving journey is arduous and at times nothing short of traumatic, if our carer feels that they have necessary social resources that can be called upon when faced with the burdens of care provision, they are in some part shielded by stress.

However, as illustrated in the literature, while men in general face the unique challenge of network size, density, and social interaction related to demographic status (Kim and Jung 2022), women have markedly more burdensome experiences with caregiving (Chiao et al. 2015; Kim et al. 2012).[4] This was reflected in interviews; however, it carries with it the limitations of sample size and collection methods.

Interacting with Credentialed Experts

Caregivers’ interactions with healthcare professionals are complex and can be both empowering and disheartening. On the one hand, doctors provide the essential medical knowledge that caregivers rely on to manage ADRD. Yet, many caregivers describe their experiences with the medical system as frustrating or alienating, where their concerns are often minimized or dismissed. The strain of these negative interactions compounds the emotional and physical burdens of caregiving. However, even in difficult encounters, caregivers acknowledge that understanding the medical professional’s perspective, insights, and advice is critical in developing their own caregiving skills and forming their expectations and confidence. From Patrizia’s experience getting her mother to walk again after being hospitalized, she found, on the one, a source of gratification, and on the other, learned the limited situated knowledge of credentialed experts. Cindy found a strong source of confirmation when her family’s primary care doctors assured her that her family was doing everything right. Medicalized language also reflected this interaction; Patrizia’s interaction with doctors through her mother’s diagnosis process taught her important terminology and the biomarkers for cognitive decline alongside the tests that needed to be done. Maria’s knowledge of her mother’s dementia was also informed by her tending to her mother’s diabetes for years; being receptive to changes in her mother’s behavior and connecting them to distinct medical pathologies. In addition, it was Maria’s interaction with a family doctor that encouraged her to reach out for support - recognizing the tell-tale signs of burnout.

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[4] For a specifically *Italian* case of analyzing burden and caregiving experiences (*see*(Chiari et al. 2021).

Cindy's engagement with her county's Aging and Disability Resource Center connected her with credentialed professionals who provided practical guidance and resources for her mother's care. Anna's collaboration with her psychologist helped her accept the transition from being a daughter to becoming a caregiver. This professional support was essential in boosting her confidence as she navigated her caregiving responsibilities. Her experience highlights how guidance from credentialed experts can play a crucial role in shaping a caregiver's understanding and approach to their role.

Looking Back Discourse

From interactionist/interpretivist perspectives, role acquisition involves the fashioning of meaning to one's experience from their unique situation. Through narrative analysis, it became clear that this meaning was bound to an individual's own biography and personal history. While the following section and the previous chapter on lay expertise and *strategies* stress the significance of reflection in cultivating lay expertise, a reassessment of life experiences through ADRD is intimately connected to an encounter - e.g., the interaction between a sick body and a healthy one.

Caregivers would rewrite the script. In medical sociology, the idea of biographical rupturing in chronic illness implies that individuals' narrative and life course trajectories are ruptured as a result of being ill (Bury 1982; Charmaz 1991). This event is challenging, wreaking havoc on self-image and necessitating a reconceptualization of one's identity. From the wreckage of disjointed self-assessment, people with chronic illnesses are tasked with assigning newfound values to their experiences. For caregivers, this means facing the initial casualties of ADRD diagnosis: the relational selves of the caregiver and care recipient (Karner and Bobbitt-Zeher 2005). A reassessment of one's life framed through the lens of *care* to create acceptable narratives enables caregivers to navigate this transformation by creating continuity, order, and familiarity with an otherwise unfamiliar situation.

This trend is reflected when interview participants reframed their life experiences as preparatory events leading to the culmination of becoming caregivers. Kaya notably mentioned that she, as the only woman in her immediate family and the only child, had also anticipated becoming the caregiver for her grandmother. Linda also mentioned that her choice of a career in nursing was based on the belief that she needed to take care of her family, and in a different vein, Ted amassed the financial capital needed to ensure that his wife would always be taken care of. Throughout caregiver's lives, experiences are reinterpreted in the context of ADRD - they are given added meaning and weight to the present - "I have always been X" - "we always knew Y" - these sorts of responses reflect this trend - while pathology and illness subsume the narratives of caregivers pasts, it is seen as a source of strength - by reshaping one's personal narrative to center the idea of 'preparation', they are able to project confidence. In other words, by redefining their past experiences as *intentional*, they create empowering narratives that instill confidence and a sense of purpose in their current roles.

Lay expertise extends also to specific strategies or actions. These actions are contextually fluid in that they reflect personal qualities and also broader cultural practices.

6.5.2 Strategies

Learning

The first action that caregivers undertake in cultivating lay expertise is learning. This rests upon individuals' receptivity to acquiring new sets of information from a range of different forms of knowledge.[5] In chapters four and five, five substantive codes that reflect learning were explained with their respective examples. By conducting an added layer of abstraction, these forms of learning reflect three types of knowledge: Embodied, Experiential, and Vicarious.

Embodied knowledge refers to the internalized knowledge that an individual has - it is implicit and does not require preparation for it to be executed. Embodied knowledge refers to caregivers' ability to understand the perspective of the care recipient and their "duty" as caregivers. Anna would explain how she empathizes with a person grappling with the initial signs of ADRD

> Anna If it's a physical illness, if something hurts or you can't move your arm, you think, "I need to see a doctor." But if you can't do something you used to do, you might think it's anxiety, stress, or something else going on in your life. It's hard to self-diagnose. (Anna-ENG, Pos. 94)

Or Carolyn reflecting on how frustrating it must be to not be heard:

> Like, I didn't know what he was saying. And like, then of course, you know, Tim getting agitated because he's trying to say something and we don't understand [...] in reality, he probably was like, "No, I'm telling you I have to go to the bathroom. Can you help me go?" (Carolyn, Pos. 988) So, how do I explain to people like, look at him - every few minutes, he's got anxiety because he thinks he lost his wallet, and that sucks to

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[5] To not lose sight of the forest for the trees, I avoid using the term reflexivity here. That being said, in some respects, individuals' capacity to digest, receive, and internalize new sets of information (at times coming into clear confrontation with their own preexisting sets) could be considered *reflexive* inasmuch as it is they are constructing their own social realities - bearing in mind that they are drawing from their own source material (e.g., background). For further exploration of reflexivity and knowledge, please refer to chapter 2 of this work and to the seminal text *The Social Construction of Reality: A Treatise in the Sociology of Knowledge* Berger and Luckmann (1966).

> have that much anxiety all day long. You know what I mean?
> (Carolyn, Pos. 580)

While how care recipient behaviors are managed depends on one's skillset, empathizing and understanding the ADRD experience is a form of embodied knowledge, touching on a knee-jerk reaction to help others in discomfort. Cultivating lay expertise in this sense implies learning to distinguish between symptomatic behaviors and individual discomfort and pain - to be patient, to listen, and to empathize, the recognition of a separate reality no less real than their own.

Experiential knowledge refers to how caregivers learn by doing. This is connected to both learning from mistakes and learning from exposure. These experiences are formative, memorable, and at times painful. Caregivers develop their expertise by engaging with challenges firsthand, learning through personal reflection and emotional responses to the demands of care. For example, Jack, through repeated emergency room visits, realized that his mother's health crises were often the result of earlier signs he had missed. His journey of learning to intervene earlier is reflective of how caregivers adapt their strategies over time, gaining insights that shape their caregiving approach.

This form of knowledge, which emerges through doing, is not just practical but deeply personal. It involves trial and error, the emotional labor of providing care, and the intuitive understanding that caregivers develop in response to their loved one's evolving needs. While caregivers like Linda and Maria reflect on lessons learned from specific experiences - whether it's discovering how dementia changes the perception of pain or realizing that a seemingly small decision can have lasting consequences - these stories highlight how caregiving becomes a process of constant adjustment and growth. In this experiential framework, each action and reaction teaches something new, turning daily tasks or pivotal events into a learning process.

Vicarious is informed by Bandura's Social Cognitive Theory, positing that an individual's ability to engage in a specific task is largely mediated by the perceived ability to accomplish a given action (Bandura 1977, 1997). This is defined as self-efficacy - therein one's appraisal of their abilities (Clark and Lippe 2022). Bandura argues that self-efficacy stems from a number of sources, namely through vicarious experiences (Bandura 2002). By observing peers with shared traits engaging in similar situations and successfully performing certain actions, individuals are likely to perceive that task as achievable. For caregivers seeking to gain skills or navigate burdensome experiences, interacting or hearing from others in similar situations offers an incredibly useful source of feedback and assistance.

Support, as previously elaborated, can serve twofold. On the one hand, support groups, support centers, and virtual spaces offer emotional guidance, and on the other, they are clearcut pathways to building lay expertise through vicarious learning. When caregivers actively engage with their peers with a clear goal of *learning*, they can avoid the missteps of others and the traumatic experiences associated with them. Patrizia explained that she both gave and received helpful information from others, offering advice to those new to caregiving who didn't know where to begin. By exchanging tips and sharing her own experiences, she felt it was important to give back the support she had once received, as it had been difficult to know what to do in challenging situations. This reflects a trend Maria shared: the knowledge and experiences provided by those in Rete Magica helped her reach a deeper awareness. The group's unity, sensitivity, and understanding had guided her toward the goal of accepting both her mother's illness and the changes it had brought.

Silvia's experience, however, highlights the potential emotional toll that vicarious learning can bring. Unlike Patrizia and Maria, who found shared experiences empowering, Silvia struggled with the overwhelming nature of hearing about the later stages of the illness from other caregivers. While the course provided useful insights, Silvia felt that knowing what was inevitably coming, especially from those further along in their caregiving journey, left her feeling depressed and burdened by the weight of future challenges. Although her mother still communicated relatively well, the course made Silvia confront the reality of decline in a way that was emotionally difficult. This shows that while vicarious learning can enhance a caregiver's knowledge and self-efficacy, it can also bring an emotional strain, depending on where the caregiver and care recipient are in their journey. To manage this, it is important to understand one's own limitations. While Silvia's experience with the support group she attended (Gruppo ABC) was painful, it did teach her important qualities about her own caregiving style and her own emotional capacity, highlighting another aspect of lay expertise in caregiving experiences - *reflection.*

Reflection

In chapters four and five, some of the themes of caregiver reflection were roughly explained. Below, I will elaborate on them, explaining their nuances and implications for building lay expertise. Literature places weight on how individuals reassess and redefine preexisting relationships when creating new roles (Greenwood et al. 2019; Schumacher 1995). As individuals navigate uncharted waters, they are tasked with establishing continuity and definitions for their experiences that they find acceptable (Kleinman 1988). These meanings and values are evident in narratives alongside embodied cultural practices.

This process of reflection means giving personal significance to the logic behind taking on the caregiving role. Manuel was adamant about this, arguing that, since this process is so hard on a person, they need to have a powerful driver for continuing on the arduous journey (e.g., being a spouse, a child, or a partner to the care recipient). Participants' reasons for assuming their roles were markedly similar, with all citing a sense of filial obligation; however, one stark contrast emerged between caregivers in Italy and the U.S. American caregivers added a transactional component to their motivations and a morally universalist principle to their beliefs surrounding care. *Rectifying past behavior* emerged as a powerful theme that caregivers in the U.S. touched. Notably, from children of care recipients reflecting on their adolescence, this could be described as a sense of "atonement" connecting to possible feelings of guilt. Additionally, American caregivers added a moral obligation to aid a sick person, regardless of their family ties. These two points may reflect a divergence from Italian caregivers who, save for Patrizia and Maria, did not share the same belief. Instead, Italians interviewed stressed that the only way a person could assume the role of caregiver would be if they had a deep familial connection to the care recipient.

Participants also assigned varied meanings to their roles as caregivers, as illustrated in the previous chapter. All participants I spoke with stressed that there are eery parallels between assisting a person living with ADRD and raising a child. Which, as Katie explained - is a lot to reconcile. While a care recipient's body remains that of the person whom the caregiver shared a relationship with in the past, the mind, behavior, and idiosyncrasies are foreign. It is an eery valley of personhood where this all-too-familiar figure behaves in a completely unrecognizable way. Caregiving was likened to raising a child by all those interviewed. In one instance, Maria reflected on negotiating this shifting identity while coming to terms with the loss of her mother and establishing a new perspective in the process that stresses a responsibility to care for a person in need.

> Maria It's like - because being the parent of your parent is very difficult. It's a role we are not prepared for. Now that I've reached, let's say, a certain emotional stability - because before, I was more frustrated because I wanted to make her feel better, but it wasn't possible, it wasn't within my capabilities. Now I'm content; I take care of her as one takes care of a person in need. (Maria-ENG, Pos. 51)

It is evident that Maria has passed a threshold - one which experts on the discursive structures surrounding death, dying, and grief could refer to as *acceptance*. This point will be returned to later on. For some, caregiving means being the executive decision maker, taking on new responsibilities, something which participants mentioned as being challenging - not because of fear of making incorrect decisions or being saddled with extra mental labor surrounding important planning - but removing the care recipient from the process altogether was cited as difficult. For them, it meant that they were, in part, taking agency and independence away from their loved ones. In a sense, this represents the qualities of selfhood loss discussed previously - a death-before-dying scenario where it is the caregiver who is tasked with acknowledging this loss early on in the caregiving journey. Participants also noted that the role of caregiver requires active participation and a desire to *learn*.

Linda vented her frustration with other caregivers in group settings - citing that they had little interest in *learning.* Marco stressed that since he was an avid reader, he had turned his focus to texts that help him become a more competent carer. For those interviewed, caregiving also means reflecting on the situation one finds themselves in and the qualities of one's self. Becoming a caregiver often prompts deep self-reflection, where individuals confront their strengths, limitations, and emotional responses. Participants recognized the need to reconcile their personal qualities with the demands of caregiving. Alessia, for instance, described her need for control and meticulous planning, while others acknowledged struggles with impatience or emotional exhaustion. Jack highlighted the burden of over-responsibility, leading to heightened self-awareness and the realization that external support might be necessary.

A critical aspect of this reflection is the preservation of one's sense of self. Caregivers like Anna and Maria spoke of the importance of maintaining personal identity amidst caregiving responsibilities. Anna emphasized the need to continue cultivating personal passions, while Maria shared her efforts to reclaim her personal space and engage in activities that nourish her soul. Kaya echoed these sentiments, questioning her identity beyond caregiving and striving to stay connected to her imagination and dreams. These reflections underscore the balance between self-care and caregiving, which is essential to both personal well-being and the development of lay expertise. By continually evaluating their own capacities and preserving a sense of self, caregivers not only refine their caregiving skills but also ensure their ability to sustain their roles in the long term. This self-awareness and ongoing adaptation are as vital to caregiving as the practical tasks they perform, deepening their understanding of how best to support their loved ones while maintaining their own identity; in a way shielding themselves from engulfment (Skaff and Pearlin 1992).

Caregivers frequently engage in self-comparison as they navigate their roles, reflecting on how their approach to caregiving aligns or differs from others. Patrizia, for instance, observes how some families unite during illness, while others distance themselves, which she finds incomprehensible, especially given the inevitability of aging. Similarly, Silvia reflects on her own abilities, noting that in comparison to others, she doubts whether she could ever be a "good caregiver." Linda expresses frustration with the competitive nature she perceives among caregivers, while Kaya grapples with feelings of solidarity and alienation, especially within her community. She highlights the stark contrast between those with the means to avoid caregiving and those, particularly people of color, who have no choice but to embrace it due to structural inequalities. Katie, on the other hand, advises her children not to take care of her, revealing another layer of self-comparison as she assesses her own future caregiving needs. Finally, Carolyn reflects on how different cultures handle caregiving, comparing her situation to others, such as the Hispanic tradition of extended family living together. This touches on the “situatedness” of how caregivers conceptualize their roles; Carolyn’s reflection (whether holding truth or not) shows an outwards gaze - appraising care practices of “others” and finding shared experiences. This process of self-comparison is crucial in shaping caregivers’ understanding of their roles and contributes to the development of lay expertise. By comparing themselves to others, caregivers gain insight into their own strengths, limitations, and values.

Literature shows that caregivers often experience a shift in perspective as they navigate their roles, gaining newfound insights into their relationships and priorities (Karner and Bobbitt-Zeher 2005; Kitwood 1993; Pozzebon, Douglas, and Ames 2016). This was also illustrated in interviews. Anna, for example, shares how caregiving has reshaped her outlook on time and priorities, prompting her to spend more meaningful moments with her mother and encouraging friends to seize opportunities with their own parents. Similarly, she reflects on her relationship with her father, recognizing a deepened understanding and sense of teamwork that emerged through caregiving. Alessia, too, acknowledges a change in how she views her parents, growing to appreciate her mother more as time goes on, while also finding a way to see the positives in challenging situations, like her mother’s memory loss - that while her illness and memory loss is painful - she does not remember pain. This shift in perspective extends beyond the caregiver’s immediate family. Patrizia notes how caregiving brought her closer to her brother, fostering emotional openness between them, while Sally highlights how shared caregiving experiences have drawn her family together, even when personalities differ. Others, like Kaya, reflect on the value the caregiving role brings to them, recognizing its importance despite perceived shortcomings in other areas of life. Jack, meanwhile, speaks to the process of finding peace in memories -

These reflections on newfound perspectives contribute significantly to the development of lay expertise. As caregivers shift their understanding of relationships, priorities, and the nature of caregiving, they cultivate a deeper emotional resilience and insight. This growth not only enhances their caregiving capabilities but also allows them to find meaning and strength in their evolving roles. Through these newfound perspectives, caregivers become more adept at navigating the complexities of caregiving while fostering personal and familial growth. While the meaning of caregiving is deeply personal, common definitions emerged that transcended both demographic and geographic boundaries. For all participants interviewed, caregiving involved: reconciling the evolving identity of the care recipient, assuming new responsibilities, making critical decisions, and showing empathy toward someone in distress. This last point is particularly significant, as it hinges on caregivers’ reconciliation of care recipients’ loss of self - e.g., *death before dying*. For those interviewed, being a caregiver means taking care of a stranger in need while also grappling with the death of a loved one.

Changing perspectives and Adaptation

Having examined how key events and situational crises push caregivers into new roles, the following section explores how these caregivers' perspectives shift over time, both in how they see their role and how they perceive their loved ones. This ongoing change, tied to their evolving role, reflects a dynamic exchange between self-identity and caregiving demands. In other words, it is:

> *When caregiving becomes embodied knowledge through the transformative property of role acquisition.*

Changing Perspectives on the evolution of a caregiver's journey are the shifts that mark the transition from being a set of tasks into embodied knowledge. This transformation occurs through the property of role acquisition, wherein the caregiver internalizes their role not merely as a duty but as a core component of their identity and self-conception (Carpentier 2012; Schumacher 1995; Skaalvik et al. 2016). Findings suggest that through this process, caregiving knowledge becomes lived experience—embodied, instinctual, and integral to the caregiver's sense of self.

This transformation is evident as caregivers move beyond their initial, often reactive, responses to caregiving into a more reflective and integrated understanding of their role. For instance, Anna's evolving relationship with her mother highlights a profound change in perspective. What began as an external obligation eventually became part of Anna's core identity, where caregiving was no longer something she did but something she was. As Anna reflected on her mother's illness, her actions and outlook became part of her deeper understanding of both her mother's needs and her own emotional growth. This shift illustrates how the process of caregiving itself transforms the caregiver, making the role embodied knowledge - a seamless integration of self and action.

Adaptation, on the other hand, complements this internal evolution by manifesting practical responses to the caregiving challenges that arise. Where changing perspectives recalibrate emotional and cognitive understanding, adaptation requires tangible adjustments in behavior, routines, and strategies. In this sense, the transformation through role acquisition is both a mental and physical process. It is through adaptation that caregivers begin to enact the lessons learned from their shifting perspectives, grounding their emotional insights into actionable caregiving practices. For example, Silvia's decision to keep her mother active in small, autonomous tasks is a reflection of her adaptive strategy, enabling her mother to maintain dignity while lessening the burden of care. This kind of adaptive action signals the moment where caregiving shifts from learning by doing to mastering the intricate balance of emotional and logistical demands, both incorporating skillsets (Schumacher et al. 2000) with reflexive know-how (Epstein 2023).

This convergence of changing perspectives and adaptive strategies defines lay expertise in caregiving. Caregivers continually build their skills by integrating their emotional evolution with practical problem-solving. Through adaptation, they transform not only how they perceive their caregiving role but also their execution. These adaptations reinforce caregivers' growing self-efficacy, fostering a sense of mastery over their role that goes beyond simple caregiving tasks and reflects their ability to navigate its complexities on both an emotional and practical level. Thus, the process of changing perspectives and adaptation represents a significant milestone in the acquisition of embodied caregiving knowledge. This interpretation, while similar, does deviate significantly from more mechanistic theories on caregiving *phases* (Montgomery et al. 2007) as care identity and strategies do not follow precise chronicity, and many of the identifiable "stages" bleed into one another.

As caregivers internalize these perspectives and refine their strategies, their caregiving knowledge deepens, enabling them to navigate even greater challenges. This stage becomes the foundation for the subsequent sections, which will explore how caregivers solve problems, identify the qualities of good caregiving, find personal gratification, and ultimately reach acceptance. Through the dual process of changing perspectives and adaptation, caregivers are not only solving problems as they arise but are also cultivating a more profound understanding of their role—a mastery born of experience, emotional growth, and ongoing adaptation to the unique demands of caregiving. With this new role, caregivers must also *perform*. For participants, this meant tackling the daily issues that came up. Touching on another aspect of strategies of lay expertise, *solving problems*, can also serve as a source of gratification, increased sense of well-being, and caregiver self-efficacy.

Solving Problems

Caregivers develop their expertise by actively solving problems and adapting to the challenges of caregiving through a combination of practical solutions and emotional resilience. For instance, Anna emphasizes the importance of her network, relying on her sister and friends to fill in when she cannot be present, allowing her to find time for herself. This highlights how building and maintaining support systems is essential to managing the emotional and logistical burdens of caregiving.

Alessia approaches caregiving with meticulous organization and a strong desire for control. She monitors her parents with cameras, organizes their medications weeks in advance, and implements strict routines to ensure their safety. Her approach demonstrates how solving problems is not only about addressing immediate issues but also about preemptively preventing future complications. This proactive problem-solving reflects her deep commitment to managing every aspect of her parents' care and her effort to maintain her own peace of mind in the process.

Similarly, Patrizia engages in problem-solving by adapting her caregiving strategies as new challenges arise. After her mother's hospitalization, she took charge of her mother's care at home, following medical instructions precisely to help heal bedsores and restore her mother's mobility. This example illustrates how caregivers like Patrizia creatively address caregiving challenges, often stepping into roles traditionally filled by medical professionals.

For other caregivers, problem-solving involves a balance between logistical planning and emotional management. Silvia, for instance, uses technological tools like Seremi bracelets to alleviate her anxiety about her mother's potential falls, allowing her to monitor her mother's health remotely. This practical solution gives her a sense of control, even when she cannot be physically present, further reinforcing how caregivers adapt to their specific circumstances through creative problem-solving.

Across these examples, caregivers employ various strategies—ranging from organizing networks of support to leveraging technology—to address the complex demands of caregiving. This continuous process of solving problems is central to their development as lay experts, allowing them to navigate caregiving challenges with increasing confidence and competence.

Identifying good caregiving

In the face of the complexities of caregiving, the question of what defines "good caregiving" remains central to caregivers' self-reflections. Many caregivers arrive at definitions through lived experience, trial and error, and a deepening attunement to their loved ones' needs. For Anna, a good caregiver is someone who resists focusing on the deficits of the person they are caring for. Rather than dwelling on what her mother cannot do, Anna emphasizes her mother's remaining capabilities, allowing her to continue tasks that provide a sense of independence and dignity. This perspective—rooted in seeing the care recipient as more than a patient—is a key marker of caregiving quality, where the ability to preserve autonomy and respect underpins much of the ethics of care -

Alessia offers a more emotional framing, asserting that caregiving is only sustainable when grounded in love. The total immersion in caregiving, she argues, can only be sustained through emotional bonds and dedication to the care recipient. Her reflections touch on the existential core of caregiving, where the deep emotional labor of caregiving defines its quality. A good caregiver, by Alessia's account, must possess not just the skills to manage care but also the emotional depth to carry the weight of the caregiving relationship, reinforcing that caregiving is as much about relational quality as it is about task performance.

In contrast, Maria stresses the importance of maintaining emotional distance. To her, the emotional involvement of a caregiver should be tempered with enough detachment to avoid being overwhelmed by the care recipient's suffering. This view introduces a necessary tension between closeness and professional distance, where a good caregiver must be both emotionally present and not consumed by the illness of their loved one. Maria's narrative highlights the importance of maintaining one's own emotional health as a key feature of caregiving quality, emphasizing that good caregiving is as much about managing the caregiver's well-being as it is about attending to the needs of the care recipient.

Sally expands on this idea by focusing on her father's need for dignity and self-worth. To her, success in caregiving involves creating an environment where her father can still feel like "somebody," despite his cognitive decline. The preservation of dignity—whether through ensuring safety, maintaining a peaceful environment, or fostering feelings of inclusion—emerges as a core tenet of good caregiving. Sally's emphasis on minimizing fear and maximizing reassurance demonstrates how caregivers conceptualize success in deeply personal, emotionally resonant terms.

Finding Gratification

Caregivers derive gratification through a process of continuous learning and adaptation, which aligns with the concept of role acquisition. For example, Anna finds fulfillment in mentally preparing for her caregiving tasks and in helping her father by taking on responsibilities for her mother, which provides him with a necessary reprieve. Similarly, Ted expressed joy in knowing that his loved one's happiness directly shaped his own, stating, "if it pleased her, it pleased the hell out of me," illustrating how caregiving becomes a source of personal satisfaction.

Kaya, who provides alternative therapies such as craniosacral therapy for her grandmother, finds deep pride in being the only family member capable of offering this specialized care. This expertise not only boosts her self-efficacy but also solidifies her identity as a caregiver with unique skills, highlighting the role of lay expertise in caregiving. Her sense of being "priceless" in the caregiving context reinforces the connection between flourishing and the cultivation of lay expertise.

Patrizia's experience of helping her mother regain mobility, despite doctors' doubts, further illustrates how caregivers derive gratification through the mastery of caregiving tasks. By stepping beyond the expectations of medical professionals and successfully supporting her mother, Patrizia exemplifies how caregivers who flourish as lay experts feel competent in their caregiving roles. In this context, flourishing caregivers are those who have cultivated lay expertise, mastering both practical and emotional caregiving skills. Their ability to adapt, learn, and find meaning in caregiving not only enhances their self-efficacy but also positions them as lay experts, demonstrating that caregiving mastery is tied to both role acquisition and personal growth.

6.5.3 Acceptance

Acceptance of illness within the caregiving context is not a singular moment of resignation, but a dynamic, ongoing process that reflects both cognitive and emotional adaptation. It is characterized by a profound internal shift where caregivers reconcile themselves to the irreversible trajectory of dementia or Alzheimer's, integrating this reality into the rhythms of daily life. Far from being passive, this process requires active engagement, wherein caregivers balance their emotional involvement with the pragmatic demands of care. Acceptance, in this sense, becomes both a strategy for maintaining emotional resilience and a critical component of lay expertise. It enables caregivers to continue in their roles without becoming overwhelmed by the weight of the illness, while simultaneously fostering a deeper understanding of their loved one's needs.

Alessia's experience exemplifies this adaptive acceptance. Through humor, she transforms her frustration with her mother's memory lapses into a coping mechanism, allowing her to engage with the illness in more manageable emotional terms. Humor, in this case, operates not as denial but as a tool for emotional regulation—an essential aspect of caregiving when faced with the unrelenting progression of cognitive decline. This shift from frustration to acceptance, mediated by humor, illustrates the fluidity of the acceptance process. It is not an endpoint but an evolving strategy that helps caregivers integrate the illness into their lives without succumbing to despair. Such emotional recalibration, far from being a sign of detachment, reflects a sophisticated form of lay expertise, where the caregiver learns to navigate the emotional terrain of chronic illness while maintaining both care and compassion.

Maria's journey toward acceptance underscores another critical dimension of this process: the recognition of the illness's irreversibility. For her, the moment she realized her mother was on a "path with no return" marked the beginning of a new phase in her caregiving role. This acknowledgment of irreversibility is pivotal because it forces caregivers to recalibrate their expectations and approach to care. Maria's subsequent emotional distancing—learning to care without becoming engulfed by grief—illustrates a common but difficult trajectory for caregivers. This emotional distance is not indicative of a diminished relationship but rather a necessary adaptation to protect the caregiver's well-being. Maria's experience reveals that acceptance involves not only the practical aspects of care but also a profound emotional realignment, where caregivers learn to balance love and care with the harsh realities of cognitive decline.

Anna's narrative presents another facet of acceptance, one that focuses on preserving the dignity of the care recipient. Her approach emphasizes the importance of enabling her mother to retain autonomy in whatever ways possible. By focusing on what her mother can still do, rather than dwelling on what she can no longer achieve, Anna embodies a form of acceptance that is deeply rooted in respect for the care recipient's agency. This perspective aligns with a broader ethical framework of caregiving, where the caregiver's role is not merely to provide care but to enable the care recipient to maintain a sense of self, even as cognitive abilities wane. In

Anna's case, acceptance involves a shift in perspective that recognizes the evolving capacities of her mother and adapts caregiving strategies to support those capacities. This form of acceptance reflects a high level of lay expertise, where the caregiver not only adapts to the illness but does so in a way that preserves the dignity and autonomy of the care recipient.

For caregivers like Kaya and Sally, the language of acceptance is closely tied to concepts of mourning and loss. The use of death language—speaking of their loved ones as though they have already been lost—captures the emotional complexity of caregiving for someone with dementia. Alessia describes it as "mourning a loss" even though her parents are still physically present, while Kaya speaks of creating "a good life for a dying woman." These expressions reveal the emotional ambivalence that characterizes the acceptance process: caregivers must come to terms not only with the gradual decline of their loved one but also with the symbolic death of the person they once knew. Acceptance here is not merely about adapting to the illness but also about grappling with the profound sense of loss that accompanies it. In this context, acceptance becomes an emotional reckoning, where caregivers acknowledge the dual realities of life and death, presence and absence, that coexist within the caregiving experience.

In this sense, acceptance within caregiving is a multifaceted process that plays a crucial role in the development of lay expertise. It reflects a caregiver's ability to integrate the illness into their daily life, not as a burden to be overcome but as a reality to be lived with. This acceptance is not a linear progression but an ongoing negotiation between the emotional weight of the illness and the practical demands of care. As caregivers like Alessia, Maria, and Anna demonstrate, acceptance requires both emotional flexibility and practical adaptability. It allows caregivers to continue providing thoughtful, compassionate care while preserving their own well-being, enabling them to navigate the profound challenges of caregiving without being overwhelmed by them.

6.6 The Big Picture: Confidence and Well-Being in Caregiving

An element of this dissertation that has been implicated throughout the preceding sections is the concept of *self-efficacy.* This theme was mentioned briefly in chapter two and more in-depth in chapter three; however, for this work to have found a broader audience and a more succinct understanding of emergent themes of grounded theory analysis from chapters four and five, understanding the nuances of efficacy and more important *perception* need to be explained.

A significant body of research on perception and social support has laid the foundation for this exploration of perceived social support and perceived burden in caregiver experiences (Cornwell and Waite 2009; Waite et al. 2014). This study investigates the relationships between social isolation, caregiver burden, efficacy, and well-being among informal caregivers of individuals with Alzheimer's and related dementias, utilizing social health and support frameworks in a flexible and supportive manner. By considering factors such as age, gender, socioeconomic status, and social networks, this work delves into how perceived isolation—a subjective sense of insufficient social resources (Santini et al. 2020)—and caregiver burden, understood through self-perception and multifaceted strain (Liu et al. 2020), influence caregivers' health outcomes. This approach emphasizes the diversity of caregivers' experiences and stress levels.

Furthermore, the concept of efficacy, both social and self-efficacy, is analyzed to assess its effect on caregivers' capability to manage their roles successfully (Au et al. 2009; Bandura 1977; Cacioppo and Hawkley 2009; Steffen et al. 2002). Finally, by incorporating VanderWeele (2017) 's concept of flourishing and well-being, previously introduced in chapter two, the research underlines the need for supportive policies aimed at enhancing caregivers' quality of life. It emphasizes the importance of targeted interventions and support systems.

Self-Efficacy, Confidence, and Quantitative Findings

The integration of quantitative data on caregiver confidence with the qualitative findings presented in the previous chapter enhances our understanding of the emotional and practical dimensions of caregiving for individuals with Alzheimer's Disease and Related Dementias (ADRD). The quantitative findings serve to empirically substantiate several key themes that emerged from the qualitative analysis, particularly the role of confidence, the importance of social support, and the development of lay expertise among caregivers.

One significant quantitative finding is the strong negative correlation between loneliness and confidence (= -0.354, $p < 0.001$), which supports the qualitative observation that access to robust support systems is critical in alleviating caregiver burden. Caregivers who benefit from strong social networks—whether through family, friends, or formal support groups—are better equipped to manage the emotional and logistical challenges inherent to caregiving. The quantitative data demonstrate that a reduction in loneliness, which often results from enhanced social support, is directly linked to higher levels of caregiver confidence. This connection underscores the need for interventions that focus on reducing caregiver isolation and fostering social connectedness as strategies to bolster confidence and promote caregiver resilience.

Furthermore, the mediating role of confidence in the relationship between loneliness and resignation—accounting for 71% of the total effect—offers a quantifiable link to the qualitative theme of vicarious learning as a pathway to self-efficacy and lay expertise. As highlighted in the qualitative data, caregivers who engage in vicarious learning—by observing others, sharing experiences, and adopting successful coping strategies—are more likely to develop a sense of mastery over their caregiving roles. The quantitative finding that confidence mediates the impact of loneliness on resignation strengthens the argument that building confidence through social support and shared experiences is essential for reducing caregiver burnout and promoting long-term caregiving capacity.

The results of the bootstrap analysis, which indicate a positive indirect effect of confidence on self-reported "excellent" health (ACME = 0.00785, p = 0.026), further align with the argument that lay expertise in caregiving extends beyond practical skill acquisition to include emotional well-being and self-care. Confidence, as a core component of lay expertise, appears to significantly influence caregivers' perceptions of their own health. This reinforces the idea that interventions designed to enhance caregiver confidence not only support emotional well-being but also have tangible benefits for physical health perceptions, thereby highlighting the multifaceted importance of confidence in the caregiving experience.

Additionally, the quantitative data provide a valuable framework for interpreting the transformative processes observed in the qualitative narratives. For example, caregivers like Anna and Maria describe a progression of "changing perspectives" as they adapt to their caregiving roles, transitioning from reactive responses to a more reflective and accepting approach. The quantitative findings suggest that confidence plays a critical role in facilitating this transformation. As caregivers develop confidence through experience, support, and vicarious learning, they become more adept at navigating the emotional complexities of caregiving, which in turn leads to profound shifts in their attitudes and approaches to care.

The data demonstrate that confidence plays a pivotal role in shaping caregiving experiences. Interviews reveal that caregivers with higher levels of confidence find greater fulfillment and are more equipped to handle the emotional burdens of caregiving. For example, some caregivers spoke about feeling more assured in their abilities as they gained experience and support, allowing them to navigate caregiving challenges with greater ease. In contrast, those who lacked confidence often expressed anxiety and a heightened sense of burden. These narratives reflect the quantitative finding that confidence mediates the relationship between loneliness and the likelihood of caregiver resignation. By reinforcing the critical role of confidence in caregiving, these insights underscore the importance of interventions aimed at bolstering caregiver self-efficacy.

Illustrating the Power of Support Systems

Both the qualitative and quantitative data emphasize the essential role of support systems in mitigating caregiver burden. Interviews highlighted how social connectedness, whether through family, friends, or formal support groups, tangibly reduces feelings of isolation and enhances caregivers' sense of competence. Many caregivers described the relief they found in shared caregiving responsibilities or the emotional support offered by their networks. This real-world context corresponds with the quantitative evidence showing a significant association between reduced loneliness and increased confidence. Support systems not only provide practical assistance but also create spaces for emotional validation, helping caregivers feel more capable and less overwhelmed.

Digital Spaces: Expanding the Reach of Support

In addition to in-person support networks, the increasing importance of digital platforms for caregiving became apparent, particularly during the COVID-19 pandemic. Online forums and peer-support communities offered caregivers vital resources when in-person meetings were no longer possible. These digital spaces helped caregivers overcome isolation, providing a venue for sharing experiences, accessing information, and receiving peer support. This aligns with the broader quantitative findings that reduced isolation contributes to greater caregiver confidence. Digital spaces facilitated the development of lay expertise by offering caregivers a place to learn from the experiences of others and engage in vicarious learning, further fostering their sense of self-efficacy.

Support Groups: Fostering Connection, Building Confidence

Support groups emerged as a crucial resource for fostering caregiver confidence and promoting emotional well-being. Caregivers shared how structured environments, such as Gruppo ABC or local peer networks, provided a safe space for exchanging advice, learning new skills, and discussing their caregiving challenges. These shared experiences helped caregivers build their confidence while reducing feelings of loneliness. The quantitative data on the positive correlation between reduced loneliness and increased confidence support these observations, illustrating how the sense of belonging fostered within support groups can significantly enhance caregiver well-being.

Promoting Emotional Well-being and Acceptance

In addition to reducing isolation, support groups play a vital role in helping caregivers process the emotional complexities of their roles. Through group discussions, caregivers explored topics like managing guilt, frustration, and the evolving relationship between caregiver and care recipient. These conversations facilitated emotional coping and promoted acceptance of the illness and its impact, a theme echoed in both the quantitative data and the qualitative interviews. Caregivers who participated in such discussions reported feeling more at peace with their caregiving responsibilities, reflecting the broader findings that emotional well-being is a critical component of successful caregiving.

6.7 Conclusion

In short, here are the most succinct findings that encapsulate the multifaceted experiences of caregivers for individuals with Alzheimer's and related dementias. These key insights highlight the core challenges, the personal transformations, and the support mechanisms that shape caregiving as both a burden and a journey of growth.

1) Caregiving as a Rupture Becoming a caregiver represents a profound disruption in one's life. Although it is often an expected responsibility, the experience is marked by significant emotional pain and adjustment challenges.
2) Caregiving as Personal Growth Caregiving is a journey of continuous personal growth, where caregivers must learn by doing. This learning process, however, involves inevitable mistakes, which can amplify feelings of burden.
3) Support Centers and Burden Reduction The burden of caregiving can be significantly reduced through access to support centers. Caregivers with a strong sense of self-efficacy tend to provide better care, and support centers play a critical role in boosting that perceived self-efficacy.
4) Policy and Systemic Failures From a policy perspective, much more can be done to support caregivers. Specialists must collaborate closely with support centers, using models like Rete Magica (e.g., *case management*). Additionally, rural outreach, especially in the United States, needs to expand. Governments must also address the alarming lack of services and resources for caregivers, especially those unable to secure formal diagnoses for the people they care for. Research shows we know what works, yet the failure to act remains a critical question for future study.
5) Lay Expertise and Reflexivity Lay expertise in caregiving is developed through a caregiver's reflexivity and openness to learning. Caregivers who are proactive in recognizing the possibility of improvement tend to seek assistance before reaching a breaking point, often facilitated by respite care and interactions with other caregivers.
6) Cultivation of Lay Expertise Lay expertise is cultivated through direct caregiving experience, peer-to-peer teaching, and the embodiment of knowledge. It is a process that allows caregivers to better navigate their roles and responsibilities over time and can be actively encouraged or discouraged.
7) The Broader Meaning of Lay Expertise

Lay expertise in caregiving goes beyond practical skills and memory care proficiency. It is a holistic measure of caregiver well-being. Flourishing caregivers are those who seek help, remain open to learning, and prioritize self-care. These qualities, however, are contingent upon the societal support structures in place for caregivers.

In short, lay expertise in caregiving does not equate solely to one becoming an expert in memory care, it is not only a measurement of skill and practical know-how, but it is an overall measurement of caregiver *health.* Expert caregivers reach out for help, are open to learning as much as they can, and take care of themselves. These qualities are dependent on the caregiver context; they are conditional and contingent on society's provision of tools for a caregiver to *flourish.*

The journey of caregiving is often a story of unraveling and resilience—a raw, powerful testament to what it means to love and endure. This chapter has taken us beyond the surface of skill-building and into the depths of human transformation, capturing the heartache and growth embedded in the caregiving experience for those tending to individuals with Alzheimer's Disease and Related Dementias (ADRD).

Caregiving, as revealed in these narratives, is not a deliberate choice but an unplanned plunge into an unforgiving reality—a biographical rupture that tears open the fabric of one's life. The upheaval disrupts identities, redraws relationships, and reshapes the very core of the self. It is in this vulnerability that caregivers either sink beneath the weight or find themselves transformed, binding together fragmented pieces to forge something new.

Within this chaos, lay expertise is not taught; it is embodied, growing like scar tissue over wounds. It arises from nights spent listening to the rhythmic breath of a loved one, from the gut-wrenching moments of realizing how much has already been lost. This expertise is more than just competence; it is emotional resilience, intuition that becomes second nature, and an unwavering ability to keep navigating the bureaucratic and medical labyrinth that ADRD entails.

Yet no caregiver endures this alone. The power of social support - the listening ear, the knowing nod from someone who's walked a similar path emerges as a lifeline. Vicarious learning through others who carry with them the tools and tricks of the trade infuses hope and confidence, a resounding affirmation that "You are not alone." This web of connections sustains the caregiver, not only as individuals but as a community that refuses to let one another be consumed by silence and solitude.

Self-efficacy - that delicate yet transformative belief in one's capacity to face each challenge - merits further qualitative study in its relationship with embodied knowledge. The findings in this chapter reveal that where confidence is nurtured, burden becomes lighter. It doesn't disappear, but shifts - transforming into something that feels sustainable. Acceptance is not a single destination but an ongoing, shifting process, a tightrope walk between grieving what's lost and embracing what remains.

Ultimately, this chapter attempts to show the profoundly human experience of caregiving as a journey of transformation. I hope this work has effectively answered my question - How caregivers for people living with dementia cultivate lay expertise - and posed a number of others. Throughout these findings, a consequential unspoken reality of caregiving experiences is constantly present. That is, the person that these people spend so much time with - expending financial resources and mental and physical health, will pass away, leaving caregivers to refasten splintered plans and identities. These years of service, of providing care to a loved one that will inevitably die, cultivates more than skills and knowledge around pathology and coping mechanisms - it is, as Kleinman (2019) poses, a fundamentally moral education - one which bounds us to our humanity, and forces us to consider mortality, love, and empathy. It pushes us to reflect on ourselves, our roles, and our cultures. It is my hope that through these pages, I have shown, not only the causal relationships of our world, but also its beauty and sadness.

This work calls for empathy and meaningful support - for systems that see beyond the tasks, that recognize the humanity inherent to caregiving experience. It asks we pay attention to their stories; the unspoken moral endeavor behind each day's challenges. Only then can we begin to build a social world that honors both the cared-for and those who care—joining them in the search for missing puzzle pieces, gathering lost fragments, or crafting new ones—so that no one is left to piece it together alone.

Chapter 7

Final Thoughts and Future Directions

7.1 Reastablishing Context and Purpose

Roughly three years ago, I set out to definitively answer the question - “How do caregivers for individuals living with dementia cultivate lay expertise?”. As is the case with most sociological theory and practice, “definitive” is rarely something we as social scientists have the privilege of discovering. I believe that this work is no exception. However, throughout this project, interwoven qualities and elements that delineate, contour and consistute lay expertise have been found.

Through the multi-sited nature of this research, I aimed to highlight the commonalities between two distinct settings. Central to this approach is the focus on lived experiences and caregivers’ voices, drawing connections that reveal a unifying structure around the often ambiguous concept of “knowledge” in caregiving. This aligns with contemporary academic scholarship, which emphasizes the importance of participants’ intersubjective realities, demonstrating the shared dimensions of these deeply personal stories. In the broader context of social sciences, there is a strong emphasis on the significance of “experience,” a shift that can be traced back to the postmodern turn in academia - a departure from the “armchair” academics puffing pipes, theorizing about the world without truly engaging with the people who comprise it. Caregiving, like other areas of study, demands this active engagement. To fully appreciate the complexities of narrative, experience, and care, it is essential to examine these concepts through the interdisciplinary lenses our predecessors have provided; drawing from Anthropology, Sociology, Social Gerontology, and Demography. This work studied caregiving in the United States and Italy, specifically with participants from Emilia-Romagna and the Midwest of the U.S. and this final chapter looks to synthesize its most prominant findings.

7.2 Bridging Concepts and Findings

This research emphasizes how caregiving is deeply influenced by a range of social, cultural, and personal factors, shedding light on the complexities of providing care for individuals living with Alzheimer's and dementia. A critical aspect of this exploration is the influence of social determinants on health outcomes, as discussed in Chapter one, where social structures and inequalities are shown to directly shape both health and caregiving experiences. Drawing from social conflict theory and the work of scholars such as Marx, Virchow, Link, and Phelan, the research highlights how access to resources, financial stability, and the availability of support networks significantly affect caregiver burden and well-being. These social determinants often manifest in the disproportionate load carried by women in caregiving roles, as they are typically expected to assume caregiving duties, reflecting broader gendered inequalities rooted in social structures. This imbalance points to the urgent need for policies that address the specific challenges faced by female caregivers, especially in terms of support systems and financial assistance.

The cultural dimensions of caregiving play an equally pivotal role, as Chapter 2 underscores the ways in which cultural values, norms, and beliefs shape caregiving practices across different societies. Through a cross-cultural comparison between Italy and the United States, the research illustrates how cultural perceptions of caregiving can vary significantly. In Italy, family support is prioritized, and caregiving for elderly relatives is often seen as a natural extension of familial duty. In contrast, the United States tends to associate caregiving more with formal institutions, where external support like nursing homes plays a larger role. The stigma surrounding these facilities in the U.S. is a stark contrast to the more integrated, family-centric approach in Italy. These differences highlight the need for culturally sensitive policies and interventions that take into account the societal context in which caregiving occurs.

In addition to these cultural and social factors, the emotional, physical, and social strains associated with caregiving are central to understanding caregiver burden and burnout, themes explored in both Chapters 1 and 2. Providing care to a loved one with Alzheimer's or dementia is emotionally taxing, often involving significant role overload, family conflicts, and the devastating experience of watching a loved one's cognitive decline. The research provides detailed insights into how these factors contribute to the overall sense of burden that caregivers feel, and why burnout is a frequent outcome. The emotional toll of caregiving is compounded by the practical challenges it brings, leaving many caregivers feeling overwhelmed and isolated.

A key concept that emerges from this discussion is the idea of lay expertise. Drawing from Epstein's (2023) definition of the term, lay expertise refers to the hybrid nature of caregiving knowledge, which blends formal, experiential, embodied, and evidence-based sources. Caregivers are not just passive recipients of medical advice; they actively develop their own forms of expertise through their lived experiences. The research supports this view, showing how caregivers use a variety of knowledge sources to address both practical issues, such as symptom management, and more expressive goals, like preserving the dignity of their loved ones. Caregivers gain expertise through their direct experiences, participation in support groups, and interactions with healthcare professionals. In this sense, they become lay experts, capable of making informed decisions about care strategies based on a deep understanding of their unique caregiving situations.

Crucially, reflection and self-awareness are identified as vital processes in the development of this expertise. The research shows that caregivers who engage in reflective practices are better able to adapt to the challenges they face, manage stress, and maintain their own well-being. Through reflection, they gain a deeper understanding of their own strengths, limitations, and motivations, which in turn allows them to provide more effective and compassionate care. This reflection also fosters resilience, helping caregivers to navigate the emotional and physical demands of their role without succumbing to burnout.

Building on these ideas, Chapters 2 and 5 introduced the concept of flourishing in caregiving, drawing on VanderWeele's (2017) framework. Flourishing is defined not merely as the absence of stress or burden but as a state of well-being that includes happiness, health, purpose, virtue, and strong social relationships. Flourishing caregivers are those who have successfully developed lay expertise and exhibit high levels of self-efficacy—the belief in their ability to effectively manage the challenges of caregiving. These caregivers are empowered to navigate the complexities of their roles, not just by addressing the immediate needs of their loved ones but by finding purpose and meaning in the caregiving experience itself. Self-efficacy plays a crucial role in mediating caregiver burden and promoting well-being. The research reveals that caregivers with higher self-efficacy are more likely to seek support, adapt to challenges, and find satisfaction in their roles. Fostering self-efficacy, therefore, becomes a key target for interventions designed to support caregivers and reduce their overall burden.

The relationship between self-efficacy and flourishing is particularly important. Flourishing caregivers are not only skilled and knowledgeable; they also experience a profound sense of personal growth and fulfillment in their caregiving roles. They manage to maintain their well-being while navigating the often difficult and complex emotional landscape of caregiving. This highlights the need for interventions that go beyond addressing the immediate symptoms of caregiver stress and instead aim to cultivate self-efficacy and foster holistic well-being.

By connecting these theoretical frameworks—social determinants of health, cultural dimensions of caregiving, lay expertise, and flourishing—to empirical findings, the research sought to demonstrate the value of a multi-faceted methodological approach. The interviews and online forum data provide rich, detailed descriptions of caregiving experiences while grounding them in a broader theoretical context. This approach enhances our understanding of caregiving, especially in the context of Alzheimer's and dementia care, by emphasizing the social, cultural, and emotional dimensions of the caregiving journey.

The empirical findings illustrate how caregivers develop expertise through a combination of lived experience, peer learning, and interactions with healthcare professionals. Support groups and online platforms emerge as critical spaces for the exchange of knowledge and emotional support. They provide validation for caregivers' experiences and contribute to their growing sense of expertise. Despite occasional difficulties, interactions with healthcare professionals are also a valuable source of information and guidance, helping caregivers navigate the complexities of Alzheimer's care.

Overall, this research underscores the importance of reflection, self-awareness, and social support in promoting caregiver well-being. Caregivers who feel isolated or unsupported are more likely to experience higher levels of burden and stress. On the other hand, those with access to strong social networks, respite care, and supportive groups are better equipped to manage the emotional and physical demands of caregiving. These findings emphasize the importance of policies and interventions that support caregivers holistically, recognizing both their practical needs and the emotional labor involved in providing care.

In sum, by connecting theoretical frameworks to real-world experiences, this research offers a comprehensive understanding of the caregiving journey. It highlights the challenges caregivers face while also identifying opportunities for empowerment through the development of lay expertise, the cultivation of self-efficacy, and the creation of supportive social environments. The insights gained from this analysis can inform future interventions and policies aimed at reducing caregiver burden, fostering well-being, and ensuring that caregivers can continue to provide effective care for their loved ones.

7.3 Methodology and Findings: A Tapestry of Inquiry

In *Chapter 3*, I outlined a multi-faceted methodological approach that integrated narrative, ethnography, grounded theory, and netnography to explore the intricate ecology of caregiving in the context of Alzheimer's and related dementias. This approach acknowledged the complex, evolving nature of caregiving, understanding that caregivers' identities, the transfer of knowledge within caregiving communities, and the broader sociocultural landscape are interwoven and constantly influencing one another.

Narrative methodology, drawing on the work of Arthur Kleinman, proved essential in capturing the personal stories of caregivers. I sought to recognize the significance of these lived experiences, not only for their emotional weight but also for the insights they provided into caregiving practices. These narratives were not isolated accounts but reflections of broader social processes and cultural norms that shaped how caregiving unfolded in different settings.

Ethnography allowed me to situate these personal narratives within their broader social and cultural contexts. By observing caregivers in both physical support groups and online communities, a rich understanding of the social dynamics, support mechanisms, and the informal knowledge transfer processes that shaped the caregiving experience was effectively gleaned. Ethnography contextualized individual stories within the caregiving community's collective practices.

Grounded theory provided the structured analytical framework necessary to distill key themes from the collected narratives. By employing a systematic approach to coding and categorizing data, I ensured that my analysis remained grounded in the data. This cyclical process of coding, reflection, and analysis enabled me to extract meaningful patterns while staying true to the caregivers' lived realities. In essence, this portion of the project to iterate a pithy maxim that I think more social scientists should take to heart - *the data does not say what the data does not say.*

Recognizing the growing importance of *digital spaces* in caregiving, I applied a *netnographic* or digital ethnographic component to this work, which extended ethnographic principles to online communities. Caregivers increasingly rely on online platforms for information sharing, emotional support, and community building. Netnography allowed me to explore how these platforms facilitated knowledge exchange and shaped caregiving practices, acknowledging the unique characteristics of digital spaces as distinct social arenas. The rationale for this multi-faceted approach lay in its ability to capture the dynamic and fluid nature of caregiving. Traditional research methods, while valuable, often fall short in addressing the interwoven and constantly evolving nature of caregiving practices. I aimed to move beyond static data collection to capture a "dynamic snapshot" of caregiving processes as they unfolded in real-time. This approach was crucial in understanding caregiving as an adaptive, ongoing journey influenced by individual experiences, social interactions, and the changing needs of care recipients. Given the diversity of caregiving practices - shaped by cultural norms, geographic location, and personal experiences - it was necessary to adopt a multi-sited approach. Studying caregiving across different contexts and populations allowed me to capture a spectrum of experiences, recognizing that single-site studies might miss the complexity of caregiving dynamics. By bridging quantitative and qualitative insights, I was able to merge descriptive statistics with in-depth qualitative data. This methodological synthesis allowed me to explore broader social and demographic trends while grounding these findings in the caregivers' lived experiences, creating a fuller understanding of the caregiving landscape.

Again, *Grounded theory* played a crucial role in my analysis of interview transcripts. By systematically identifying and linking key themes, I ensured that the analysis remained closely tied to the participants' experiences. This process enabled the development of *theoretical insights* that were both empirically grounded and relevant to understanding how social processes shaped caregiving. In addition, *situational analysis* extended the grounded theory frameworks by incorporating mapping strategies. This method helped visually represent the complex relationships between individual caregivers, social actors, cultural norms, discursive elements and human/non-human actants to broaden our field of analysis on caregiving processes. Through situational mapping, I explored how individual caregiving experiences were situated within a broader social ecology, acknowledging the power dynamics and cultural influences that shaped these experiences. This *multi-faceted approach*, as outlined in *Chapter 3*, proved highly effective in generating a nuanced understanding of caregiving dynamics. By integrating narrative, ethnography, grounded theory, and netnography, I was able to capture the richness of personal experiences while situating them within larger theoretical and cultural frameworks.

In chapters four and five, I presented my research findings, demonstrating how this methodological framework was applied in practice. My analysis of *netnographic data* from Facebook caregiver support groups revealed distinct patterns in how caregivers utilized these platforms. I identified several types of posts: *informational posts* shared practical advice but often saw low engagement; *engagement posts* used humor or brief interactions to foster community connections; and *cathartic posts*, which provided emotional outlets for venting, attracted the highest engagement. This analysis offered insights into how online spaces contributed to emotional support and knowledge sharing among caregivers and effectively demonstrated a question of contention in caregiving research - that caregivers arguably do in fact create "communities" inasmuch as they shared collective goals, visions and imaginaries albeit fluid and ambiguous. *Fieldwork observations* from support group settings provided further depth, allowing me to document caregiver interactions, group dynamics, and the ways knowledge was shared in physical environments. These observations complemented multiple stages of my research process - that is, they formed the basis for concepts categories are codes through the creation of fieldnotes/jottings that comprised memos, which captured the personal experiences, challenges, and coping mechanisms of individual caregivers. These data points were incorporated into the coding and analysis procedure that was mirrored in interview analysis. From *initial coding* to identify key themes, followed by *axial coding* to refine these themes into a structured framework for analysis. Additionally, *situational mapping* allowed me to visualize the relationships between caregivers, healthcare professionals, and other social actors, revealing the interconnected nature of caregiving experiences.

I also incorporated *secondary data analysis* from datasets like NSOC and SHARE, which provided a quantitative context for the qualitative findings. This analysis explored measures of social support, caregiver burden, and health outcomes, adding demographic depth to the themes identified in the qualitative data. In *Chapter 5*, I moved beyond presenting results to offer a heightened level of "abstraction" (e.g., interpretation) of the findings. I explored the concept of *embodied knowledge*, emphasizing how caregivers developed an intuitive understanding of care through lived experiences, emotional bonds, and an evolving sense of self. This *embodied knowledge* went beyond technical skills to encompass the emotional intelligence and attunement required in caregiving.

I also examined how *situated narratives* shaped the caregiving experience, acknowledging the cultural and social contexts that influenced each caregiver's journey. The process of *role acquisition* - how caregivers navigated and redefined their roles within their families and communities—emerged as a significant theme, as caregivers balanced societal expectations with the specific demands of their caregiving situations. The findings underscored the importance of *knowledge and know-how* in caregiving, recognizing that caregivers draw from various forms of knowledge, including *embodied, experiential, and vicarious learning.* The *strategies* caregivers employed to cultivate expertise—such as seeking information, reflecting on experiences, building support networks, and advocating for their loved ones—were crucial to their ability to provide effective care while maintaining their own well-being.

The findings from this multi-faceted approach revealed several key insights. First, it captured the *nuances of caregiver experiences*, providing a deep understanding of the emotional, psychological, and social challenges faced. It also identified *common patterns and themes* across diverse caregiver populations, highlighting shared aspects of the caregiving journey. By situating these individual narratives within broader social and cultural contexts, I was able to *contextualize* caregiving experiences and examine the influence of factors such as family dynamics, access to resources, and societal perceptions of aging and dementia. Finally, this approach yielded the theoretical insights into how lay expertise developed which were elaborated on in chapter six, how caregivers acquired and adapted to their roles, and how caregiving impacted individual well-being.

In *Chapter 4* and *Chapter 5*, I provided a detailed analysis of the cross-cultural variations in caregiving practices between Italy and the United States. A key finding was the contrasting *discursive frameworks surrounding care* in both contexts. In Italy, caregiving is deeply embedded in family structures and cultural norms that prioritize familial responsibility, while in the U.S., caregiving is often shaped by institutional frameworks and external support systems such as nursing homes. This difference in cultural perceptions significantly affects how care is provided, perceived, and supported in each context. From my *grounded theory analysis*, two core categories emerged: *Constellation of Burdens* and *Building Lay Expertise.*

These categories encapsulate the diverse challenges that caregivers face and the ways in which they acquire knowledge and skills over time. The *Constellation of Burdens* refers to the overlapping emotional, physical, and social burdens that caregivers endure, which are shaped by cultural, social, and economic factors. *Building Lay Expertise*, on the other hand, highlights the processes through which caregivers develop a form of practical knowledge that is both intuitive and experience-based, allowing them to effectively manage their caregiving responsibilities.

The data also revealed key insights into the challenges and strategies caregivers face and utilize. Strategies often involved reliance on both formal support systems and informal networks, with resilience being built through the caregiver's ability to reflect, adapt, and find meaning in their role. *Pathways to lay expertise* were forged through hands-on experience, peer-to-peer learning in support groups, and interaction with healthcare professionals, all of which contributed to a caregiver's evolving understanding and mastery of their role. In *Chapter 6*, I introduced the the concept of *embodied knowledge*, which reinforced the conceptualization of lay expertise as something more than the acquisition of technical skills. *Embodied knowledge* emphasizes the *lived experience*, and *adaptive capacity* of caregivers, which enable them to respond effectively to their care recipient's evolving needs. This concept underscores the importance of intuition and emotional attunement in caregiving, traits that are honed through daily engagement with the care recipient. Key sub-themes emerged through my analysis of *embodied knowledge*, which I reiterate below.

7.3.1 Situated Narratives of Care

Caregiving narratives are always embedded in specific *social and temporal contexts*. Using positional mapping, I visualized the *complexities of caregiving ecosystems*, where caregivers constantly interact with both human and non-human elements (such as healthcare systems, cultural expectations, and even the physical environments they operate within). Time was a critical factor in shaping the caregiving experience, influencing how caregivers developed lay expertise over time and how they reinterpreted their past experiences to create continuity and meaning within their evolving roles.

7.3.2 Knowledge and Know-How

Building on Epstein's (2023) work, I revisited the *hybrid nature of lay expertise* in caregiving. Caregivers draw on both formal knowledge (gained from healthcare professionals) and *experiential knowledge* (developed through hands-on caregiving) to achieve *pragmatic goals* such as symptom management, as well as *expressive goals* like preserving the dignity and emotional well-being of the care recipient. This balance between practical action and emotional presence is key to understanding caregiving as a dynamic and multi-dimensional role. The concept of *"insufficiency vs. role mastery"* emerged as a useful framework for assessing how well caregivers are able to manage the complexities of their roles, with insufficiency representing moments of doubt and struggle, while mastery signified the development of confidence and skill.

7.3.3 Pathways to Lay Expertise

The development of lay expertise was often facilitated through *peer-to-peer learning*, especially in support groups where caregivers shared experiences and strategies. Interactions with *credentialed experts* also played a role, although these interactions were sometimes fraught with challenges, particularly around navigating the healthcare system. *Self-reflection* was another critical pathway, allowing caregivers to assess their own growth, recognize their limitations, and develop new approaches to care. Specific examples from my data illustrated how caregivers actively engaged in these processes, demonstrating resilience and adaptability.

7.3.4 Generational Differences in Caregiving

Younger adults assuming caregiving roles faced unique challenges, especially regarding the impact of caregiving on *career development* and *identity formation*. Many of these caregivers struggled to balance their professional ambitions with the demands of caregiving, often experiencing isolation and frustration. My data provided clear examples of how these challenges manifested, with younger caregivers expressing a sense of sacrifice and delayed personal growth due to their caregiving responsibilities.

7.3.5 Redefining "Good" Caregiving

Caregivers frequently *redefined what it meant to be a "good" caregiver* in their own terms, moving beyond traditional measures of success such as medical competence. Instead, they emphasized *attentiveness*, *emotional presence*, and the *preservation of dignity* for their loved ones as key indicators of good caregiving. This shift in perspective called for an expansion of conventional frameworks that measure caregiving mastery, advocating for a broader understanding that includes *well-being* and *flourishing*, both for the caregiver and the care recipient.

In *Chapter 6*, I connected my findings to the broader social and policy context, emphasizing the need for more comprehensive support for caregivers, particularly those caring for individuals with Alzheimer's and related dementias (ADRD). This discussion focused on several key issues:

7.3.6 Self-Efficacy and Perceived Health

The relationship between *self-efficacy* — the caregiver's belief in their ability to manage caregiving tasks—and *perceived health* emerged as a significant predictor of caregiving outcomes. Caregivers with higher self-efficacy were more likely to experience positive health outcomes and lower levels of stress. By drawing on quantitative data from the *NSOC and SHARE studies*, I was able to support this interpretation, demonstrating that self-efficacy plays a central role in moderating caregiver burden.

7.3.7 Social Ties and Health Outcomes

Another key finding was the importance of *social support and connectedness* for caregiver well-being. Social ties, both within families and in broader community settings, mitigated caregiver stress and improved mental health outcomes. I used data from the *NSHAP study* and the work of Cornwell and Waite (2009) to further highlight how strong social networks could alleviate some of the burdens of caregiving, underscoring the necessity of fostering these networks through policy initiatives.

7.3.8 Global Health Initiatives and Gender Divide

The global health implications of ADRD were also discussed, particularly the growing demands on *informal caregivers* as populations age. The *gendered nature of caregiving* emerged as a critical issue, with women disproportionately bearing the burden of care. I advocated for policies that addressed this imbalance, recognizing the urgent need for more equitable distribution of caregiving responsibilities and better support systems for female caregivers.

In conclusion, by linking these broader social and policy discussions back to my specific findings from interviews, digital spaces, and support groups, I was able to illustrate how caregiving for individuals with ADRD is not just a personal or family matter but a broader societal issue requiring systemic change. The need for *greater support, both formal and informal*, is critical, and my research contributes to the ongoing conversation about how best to empower and sustain caregivers as they navigate these challenging roles.

7.4 Synthesisis and Foresight

In this dissertation, I explored the multifaceted nature of lay expertise in dementia caregiving, utilizing a combination of qualitative and quantitative data sources. Seven key insights emerged from this research:

1) *caregiving often represents a rupture in a caregiver's life*, marking

a profound disruption. While familial obligation can make this transition seem inevitable, the reality of assuming a caregiving role is invariably accompanied by significant emotional distress and challenges in adapting to new responsibilities.

2) caregiving is also a journey of *personal growth.* Caregivers are thrust into new roles and must learn through hands-on experience, often making mistakes along the way. These errors can exacerbate feelings of inadequacy, contributing to a heightened sense of burden.

3) *support centers* play a crucial role in alleviating the emotional and logistical burdens of caregiving. Caregivers who engage actively with these centers often experience an increase in their sense of self-efficacy, which in turn leads to the provision of higher quality care. Support centers provide opportunities for knowledge sharing, emotional validation, and practical guidance, all of which contribute to reducing caregiver stress.

4) my research uncovered *significant policy and systemic failures*, particularly in rural areas where caregivers struggle to secure formal diagnoses for their loved ones and access necessary resources. There is an urgent need for governments and policymakers to address these gaps by implementing proven support programs on a broader scale.

5) the development of *lay expertise* in caregiving is closely tied to a caregiver's ability to be reflexive and open to learning. Those who recognize their limitations and seek assistance before reaching a breaking point tend to cultivate expertise more effectively. This often includes utilizing respite care and forming meaningful connections with fellow caregivers, which facilitate the exchange of knowledge and emotional support.

6) the *cultivation of lay expertise* is a dynamic process that emerges from lived caregiving experiences, peer-to-peer learning, and the embodiment of knowledge gained through trial and error. Over time, caregivers refine their skills and become more adept at navigating the evolving demands of their roles.

7) Lastly, lay expertise in caregiving goes beyond practical knowledge of dementia care. It is a *holistic measure of well-being*, encompassing emotional resilience, adaptability, and the ability to maintain a sense of self amidst the challenges of caregiving. Flourishing caregivers are those who actively seek support, remain open to learning, and prioritize self-care. However,

> the extent to which they can cultivate these qualities is heavily influenced by the societal structures and resources available to them.

These findings have practical implications for *policy, practice, and future research* on dementia caregiving. From a *policy perspective*, increased funding for support services is essential, particularly in underserved areas. Access to affordable, flexible respite care options must be expanded, and caregiving should be recognized as a critical public health issue. Moreover, support centers should be integrated into healthcare systems to offer coordinated, accessible services for caregivers. In *practice*, there is a need to empower caregivers through education and training, equipping them with the knowledge and skills necessary for effective caregiving. Peer support networks, both online and in-person, should be strengthened to reduce social isolation and foster emotional and practical support. Culturally sensitive approaches are also important, ensuring that caregiving programs meet the diverse needs of different caregiver populations. In terms of *future research*, longitudinal studies should investigate the long-term impacts of caregiving on individual well-being and explore the factors that contribute to the development and maintenance of lay expertise. Additionally, in-depth studies of cultural influences on caregiving will enrich our understanding of how different contexts shape the caregiving experience. Research into caregiver identity and well-being, particularly how caregiving transforms one's sense of self and personal fulfillment, should also be prioritized. The findings of this dissertation resonate deeply with Arthur Kleinman's (2019) notion of caregiving as a form of "moral education." The act of caring for a loved one with dementia, in its profound challenges and poignant moments of connection, reveals the depth of human compassion and resilience. It is a journey that demands not only practical skills but also an expanded capacity for empathy, patience, and understanding. Through the day-to-day labor of love, caregivers grapple with profound ethical questions surrounding autonomy, dignity, and the meaning of personhood.

The caregiving experience is not easily encapsulated in neat conclusions nor messy dissertations. It is a tapestry woven with threads of love, loss, frustration, and growth. This research has sought to illuminate the beauty and sadness that characterize this profound human endeavor, revealing the intricate ways in which caregivers cultivate expertise, navigate challenging circumstances, and find meaning amidst the complexities of caring for those they love. It is a journey that ultimately teaches us not only about disease or illness but about an enduring power of connection and the vital role of care in shaping our shared humanity.

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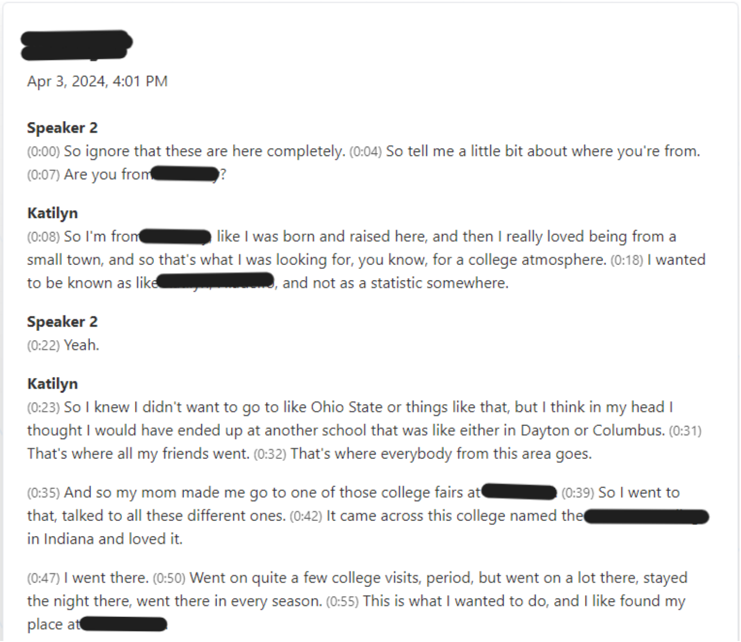
Appendix



[redacted]

Apr 3, 2024, 4:01 PM

Speaker 2

(0:00) So ignore that these are here completely. (0:04) So tell me a little bit about where you're from. (0:07) Are you from [redacted]?

Katilyn

(0:08) So I'm from [redacted] like I was born and raised here, and then I really loved being from a small town, and so that's what I was looking for, you know, for a college atmosphere. (0:18) I wanted to be known as like [redacted], and not as a statistic somewhere.

Speaker 2

(0:22) Yeah.

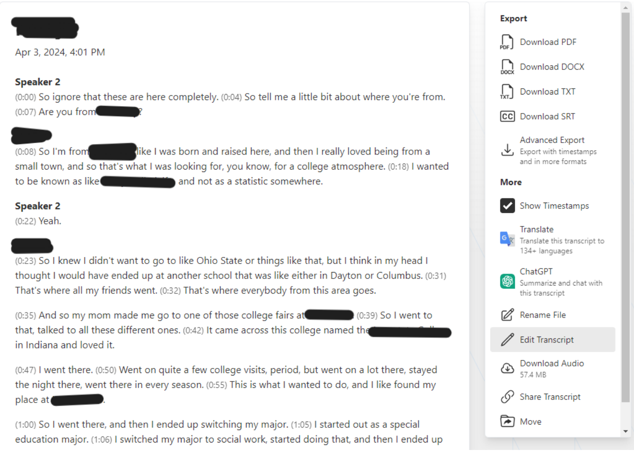
Katilyn

(0:23) So I knew I didn't want to go to like Ohio State or things like that, but I think in my head I thought I would have ended up at another school that was like either in Dayton or Columbus. (0:31) That's where all my friends went. (0:32) That's where everybody from this area goes.

(0:35) And so my mom made me go to one of those college fairs at [redacted] (0:39) So I went to that, talked to all these different ones. (0:42) It came across this college named the [redacted] in Indiana and loved it.

(0:47) I went there. (0:50) Went on quite a few college visits, period, but went on a lot there, stayed the night there, went there in every season. (0:55) This is what I wanted to do, and I like found my place at [redacted]

Figure 7.1: Turboscribe Interface 1



[redacted]

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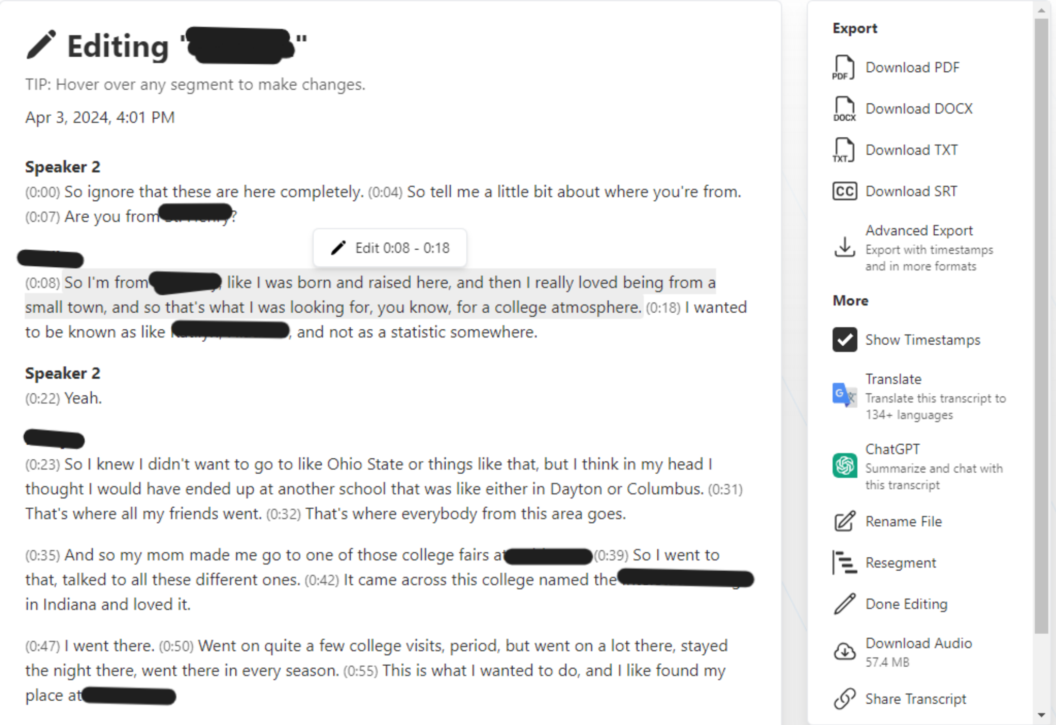
(0:23) So I knew I didn't want to go to like Ohio State or things like that, but I think in my head I thought I would have ended up at another school that was like either in Dayton or Columbus. (0:31) That's where all my friends went. (0:32) That's where everybody from this area goes.

(0:35) And so my mom made me go to one of those college fairs at [redacted] (0:39) So I went to that, talked to all these different ones. (0:42) It came across this college named the [redacted] in Indiana and loved it.

(0:47) I went there. (0:50) Went on quite a few college visits, period, but went on a lot there, stayed the night there, went there in every season. (0:55) This is what I wanted to do, and I like found my place at [redacted].

(1:00) So I went there, and then I ended up switching my major. (1:05) I started out as a special education major. (1:06) I switched my major to social work, started doing that, and then I ended up

Figure 7.2: Turboscribe Interface 2



Editing "[redacted]"

TIP: Hover over any segment to make changes.

Apr 3, 2024, 4:01 PM

Speaker 2

(0:00) So ignore that these are here completely. (0:04) So tell me a little bit about where you're from. (0:07) Are you from [redacted]?

[redacted]

(0:08) So I'm from [redacted] like I was born and raised here, and then I really loved being from a small town, and so that's what I was looking for, you know, for a college atmosphere. (0:18) I wanted to be known as like [redacted], and not as a statistic somewhere.

Speaker 2

(0:22) Yeah.

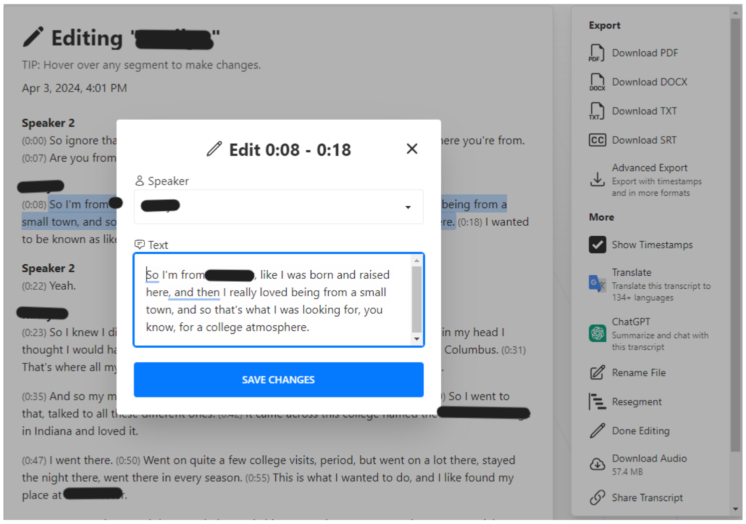
[redacted]

(0:23) So I knew I didn't want to go to like Ohio State or things like that, but I think in my head I thought I would have ended up at another school that was like either in Dayton or Columbus. (0:31) That's where all my friends went. (0:32) That's where everybody from this area goes.

(0:35) And so my mom made me go to one of those college fairs at [redacted] (0:39) So I went to that, talked to all these different ones. (0:42) It came across this college named the [redacted] in Indiana and loved it.

(0:47) I went there. (0:50) Went on quite a few college visits, period, but went on a lot there, stayed the night there, went there in every season. (0:55) This is what I wanted to do, and I like found my place at [redacted]

Figure 7.3: Turboscribe Interface 3



Editing '[redacted]"

TIP: Hover over any segment to make changes.

Apr 3, 2024, 4:01 PM

Speaker 2
(0:00) So ignore tha … ere you're from.
(0:07) Are you from

[redacted]
(0:08) So I'm from [redacted] … being from a
small town, and so … re. (0:18) I wanted
to be known as lik

Speaker 2
(0:22) Yeah.

[redacted]
(0:23) So I knew I di … in my head I
thought I would ha … Columbus. (0:31)
That's where all my … .

(0:35) And so my m …) So I went to
that, talked to all th… [redacted]
in Indiana and loved it.

(0:47) I went there. (0:50) Went on quite a few college visits, period, but went on a lot there, stayed the night there, went there in every season. (0:55) This is what I wanted to do, and I like found my place at [redacted].

Edit 0:08 - 0:18

Speaker: [redacted]

Text:

So I'm from [redacted], like I was born and raised here, and then I really loved being from a small town, and so that's what I was looking for, you know, for a college atmosphere.