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**Looking After *Abuelos*:**  
**An Ethnography of Dementia**  
**Care in an Andalusian Town**

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**Doctoral Dissertation by Chloë Place**

ESRC Funded Doctoral Research Project  
Supervised by Dr Rebecca Prentice and Dr David Orr  
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Submitted in May 2022

I hereby declare that this thesis has not been and will not be, submitted in whole or in part to another University for the award of any other degree.

Signature:

This thesis is dedicated to the memory of Ailsa and Paquita, two *abuelas* whom I could never have completed this project without...

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## Thesis Summary

This thesis explores the lived experiences of people with dementia and their care-givers in Andalusia, Spain. An ageing world population has led to rising dementia rates and a global crisis narrative around dementia. Increasingly western countries are turning to long-term care institutions to manage dementia care. However, despite Spain's international status as a 'western' country, holding one of the world's highest life expectancies, with rising dementia rates, the majority of people with dementia in Spain are cared for at home by family. Andalusia, a region known for its strong kinship networks, thus provides a valuable context to explore dementia care, as despite its 'western' status, people are adapting care-giving into long-established patterns of family life.

This research delves into dementia, personhood, kinship and care through data drawn from fourteen months of ethnographic fieldwork in a rural Andalusian town, using a methodological approach informed by occupational therapy and anthropology. It uncovers how intergenerational kinship networks in Andalusia remain central to a deeply interdependent personhood that shapes local dementia care strategies. Local attitudes towards dementia care are analysed as shifting alongside social transformations, with people increasingly demanding state-funded formal care. The gendered nature of dementia care in Andalusia is shown to prevail, and the role of the middle-aged woman as matriarch of kinship care is identified. The thesis also explores spiritual aspects of dementia care through analysis of the town's Virgin Mary saints' statues and *fiestas*. In revealing how local collective rituals are incorporated into dementia care this research shows the need for a shift from individualist, person-centred dementia care approaches towards explorations of dementia care as profoundly 'community-centred'. It also exposes the complex power relations underpinning formal dementia care by opening the doors to local care institutions. The thesis demonstrates how, as dementia care formalises in Andalusia, people strive to (re)create kinship and solidarity to find meaningful connections through a profoundly community-centred care.

Approaching care as a relational need, co-created through social interactions formed within specific contexts, enables recognition of care's cultural diversity and the need to consider not just the person but the community and culture that shape dementia care. This work helps deconstruct prevailing dichotomies within care research and unlocks learning between occupational therapy and anthropology to show the benefits of invoking a caring participant-observation approach. As we continue moving through the Covid-19 pandemic and attempt to navigate a socially-distanced world, it is even more vital that we understand human interdependency, and recognise the value of community-centred dementia care.



## Introduction: Dementia, Personhood, Kinship and Care in Andalusia

This introductory chapter raises the critical research questions this thesis grapples with by situating it within existing debates. It explains why Andalusia, a context mediating between long-established kinship care practices and the influx of formal dementia care forms, was chosen as a valuable site to investigate dementia care. This leads into presentation of the key research questions which explore dementia, personhood, kinship and care. It then outlines existing care dichotomies which frame dementia care research, also exploring how these works have attempted to overcome such oppositions. These dichotomies of care reveal the need for ethnographic exploration of the *lived experiences* of dementia care, breaking down reductive dialectic understandings to display the contradictory, lived realities of dementia care. I outline my positionality, as both an anthropologist and occupational therapist with experience in dementia care, bringing an inter-disciplinary angle to this ethnographic investigation. I reveal the similarities and differences of these disciplines and explain my argument that the two can be complementary. This is followed by a literature review to uncover existing work around personhood, dementia, kinship and care, that also outlines the long-debated 'west versus the rest' binary. It also includes a review of 'belonging', a concept that emerged as important to dementia care during data collection, and proves to be integral to the central argument of this thesis that explains dementia care as profoundly *community-centred*. This introduction ends with an overview of the ethnographic chapters of the thesis.

Streams of light filter through the stained-glass windows of *Pueblo's* care home, sending a scattering of colourful patches across the tables where its elderly residents are seated. The residents, known locally as *abuelos* [grandparents], are hunched over pieces of paper, clutching at pencils.

A clack rings around the hall, as Isabel, an *abuela*<sup>1</sup>, drops her pencil onto the table and raises her hand.

'Iris,' she calls to the care home's occupational therapist, who's balancing precariously on a ladder, pinning a string of bunting decorated with images of one of the town's patron Virgin Mary statues. 'How long until she arrives?'

Iris, steps down from the ladder and looks at her watch.

'Another forty-five minutes, Isabel. Be patient!'

The *abuelos* are participating in this morning's 'cognitive exercises', completing worksheets containing wordsearches, colouring-in, and fill-in-the-gap number and word tasks, with varying levels of enthusiasm. One *abuelo's* head lolls sharply backwards, on the cusp of sleep. Another clasps her pencil tightly but stares vacantly ahead. Some scrunch their faces in determined concentration.

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<sup>1</sup> '*Abuela*' is the female form of the Spanish word '*abuelo*', translating into English as 'grandmother'. '*Abuelo*' translates into English as 'grandfather', or can refer to the neutral/generic form of the word, i.e. 'grandparent'.

The excited buzz feels different from the regular morning groups. Isabel, who I'm sitting beside, pokes me.

'Not long to go now!' she whispers, 'Pilar [the Virgin Mary statue] never looks prettier than at this time of year.'

'It's a beautiful procession' adds Josefa, another *abuela*, looking up from her worksheet. 'She comes right up to see us.'

After another twenty minutes, more worksheets lie abandoned, whilst a chattering hubbub rises.

A group of carers enter the hall and Iris claps and calls, 'OK, stop there. Let's go! We don't want to miss our Pilar!'

Iris collects the worksheets as the carers escort *abuelos* out, easing stiff bodies up from the tables. The more mobile *abuelos* push the wheelchairs of those unable to walk. Shaky legs cross the hall, supported by frames and sticks. As Isabel moves her frame, the brass crucifix that hangs from a chain wrapped around one of the handles clangs against the metal bars.

In the corridor, a queue of *abuelos*, staff and relatives forms, chatting enthusiastically as they await the elevator. The distant sound of music can now be heard.

'It's coming!' someone shouts.

I reach the front of the queue, the doors open and I help Isabel manoeuvre her frame into the elevator, with Marta, a relative, pushing her elderly mother-in-law, Auxi, in a wheelchair behind. It's a tight squeeze. Auxi has advanced dementia and is unable to speak, but smiles. Isabel recounts what happens at this special visitation of the Virgin Pilar, and asks if I've yet had the honour to meet her or see any other processions.

'Yes, I've seen Pilar in the chapel' I respond, 'and I was here for the Spring *fiestas* too.'

'We're lucky to have so many *fiestas*' Isabel nods, 'but Pilar's my favourite.'

The elevator doors slide open and we cross the atrium's patio, with its colourful tiled walls, decorated with more of the Virgin adorned bunting. We arrive at reception to find the front doors propped open and a crowd gathering outside.

Women, men and children spill across the pavement, chattering, munching on sunflower seeds and waving flags. Staff from the care home stand alongside a group of *abuelos*, perched on chairs placed in front of the building, facing onto the road where the procession approaches.

We weave our way to the pavement's edge and hear the heavy drumbeat, blasting brass music and thumping of footsteps drawing closer.

I catch sight of the procession marching down the road's centre, with people dressed in decorative religious costumes. Priests in purple cloaks with ornate lapels swing brass thuribles, sending swirls of strongly-scented frankincense floating into the watching crowd. A group of women march behind in sombre black dresses decked with lacey veils, carrying candles. Men in brightly-coloured blazers holding up heavy-looking crucifixes march behind.

The procession draws closer until we catch sight of the huge wooden beams of the *paso* [float], supported on the shoulders of men dressed in tunics, sweating from the force of the heavy beams. Towering above them is the ornately decorated *paso* with the Virgin Pilar resting on top, her long lacey trail flowing behind her. As the Virgin comes into view Isabel grabs my hand, her face creased with emotion and she joins the crowd's shouts of '*¡Guapa! ¡Guapa! ¡Guapa!*' [Beautiful!]. Auxi signs the cross as the Virgin passes.

Pilar arrives in front of the care home doors and suddenly there is a shout and the marching halts. Another shout and a huge swish sounds as the tunicked men in unison turn the enormous *paso* so Pilar faces directly towards the care home. The music changes and the crowd bursts into song. Song-sheets are passed around, and I grab one to join in, but most people know the words by heart. Isabel sings loudly and Auxi sways with the melody of the crowd.

Remembering the Virgin Pilar procession's stop at the care home situated in *Pueblo*, the small Andalusian town where I conducted fourteen-months of ethnographic fieldwork, I reflect on how this scene contradicts many enduring assumptions around dementia and eldercare. Care homes are frequently depicted as segregated institutions, yet this special visitation of *Pueblo's* honoured Virgin Mary statue, demonstrates how this institution remains an integral part of this community and deserving of their patron saint's blessing. Care-givers are commonly understood as either relatives or formal carers supporting dependent care-receivers, yet observing *abuelos* actively help one another suggests otherwise. People with advanced dementia are depicted as unaware of the meanings of people and places surrounding them, yet watching Auxi enthusiastically react to the statue's arrival contradicts this. Dementia is explained through international medical epistemology as a cognitive disease to be resisted through psychometric exercises upheld as well-researched tools. Yet the glazed expressions of *abuelos* filling in lengthy cognitive worksheets, leaves me questioning the efficacy of such tools, particularly when compared to the excitement sparked by the arrival of the Virgin statue to the care home. Europeans, assumed to possess individualised personhood, frame dementia care through person-centred approaches, but observing care practices in *Pueblo* that are constructed through community, makes me question whether individualist assumptions capture the complexities of people's lived experiences of dementia care within cultural contexts. This ethnography provides a window into the everyday lives of people with dementia and those caring for them in an Andalusian town, uncovering how, when faced with interactions muddled by forgetfulness and confusion, people reshape their everyday cultural practices, community forms, and fundamental understandings of kinship, care and personhood to seek meaningful connection to those with dementia.

This introduction will initially explain why Andalusia provides a valuable context to explore dementia care, leading into key research questions. It then describes existing care dichotomies which frame dementia care research and investigates how previous works have attempted to overcome these. Presentation of prevailing dichotomies highlights the need for exploration into the *lived experiences* of dementia care, deconstructing reductive conceptualisations to depict the contradictory, lived realities of dementia care. I outline how my positionality, as an anthropologist and occupational therapist, provides a beneficial, interdisciplinary approach. This is followed by a literature review unpacking existing understandings of personhood, dementia, kinship and care. It also investigates 'the west versus the rest' binary that has been long-debated in anthropological discussions around personhood, but that continues to emerge ethnographically in medical and social framings of dementia and its care. I also include a literature review investigating 'belonging', a

concept that emerged organically through data collection as playing a critical role in dementia care in this context. Finally, I give an overview of the ethnographic chapters that follow.

## Context and Research Questions

Spain boasts the highest life expectancy of European Union member-states and rising dementia rates (Statista, 2022; OECD, 2017). European countries are increasingly turning to care institutions to look after people with dementia (Verbeek et al, 2015). In Spain however, despite this trend, the majority of people with dementia diagnoses live at home with family (Rivera et al, 2008; Ruiz-Adame and Jiménez, 2017). Eldercare in Spain, even of those with neurodegenerative diseases like dementia, has traditionally been considered a family responsibility, reflecting Mediterranean kinship values, and, until recently, there has been a reluctance to use formal care services (Lillo and Riquelme, 2018). Andalusia, a distinct autonomous community with a history of socioeconomic marginalisation from Spain's central state (Pratt, 2003; Cazorla, 2010), is well-known for its strong family values and close-knit kinship networks which give core care provision to dependent older adults (Tobío and Cordon, 2013; Ruiz-Adame and Jiménez, 2017). Andalusia thus provides a critical site to explore global debates on how kinship, care, dementia and personhood are constructed and experienced.

Andalusia was first brought to anthropological attention with Pitt-Rivers' [1954] (1971) ethnography, conducted in a rural *pueblo* [small town/village] in Andalusia between 1949 and 1952. He identified a 'sacred duty' existing whereby younger kin were obliged to care for ageing parents. Social transformations since Spain's democratic transition in the late 1970s shifted approaches to kinship eldercare, and Collier's (1997) ethnography of an Andalusian *pueblo* explored these fluctuations. Visiting the *pueblo* during the 1960s and again in the 1980s, she noted how generational conflicts resulted from transformations in traditional eldercare ideals. Many children from the *pueblo* had moved as adults to urban residences to gain economic independence. Although they still wanted to care for their elderly parents, they did not wish to return to the *pueblo* and felt their elderly parents should move into their new urban homes. Elderly parents, having cared for their own parents in the *pueblo*, expected this same dedicated home care to be returned and thus generational conflicts ensued.

This thesis continues anthropological investigations of Andalusian kinship, through exploring dementia care and how this shapes, and is shaped by, local understandings of personhood, dependency and relatedness. Social changes since these contributions mean that increasingly Andalusians are seeking formal care beyond kinship networks. These changes include but are not limited to: Andalusia's ageing population and rising dementia rates; economic insecurity in younger generations since the 2008-crisis; migration of affluent Northern Europeans to Andalusia's *costa del sol* generating an increase in luxury care homes; and the influx of global discourses around women's

and carers' rights. In exploring how families continue to (re)negotiate dementia care, this ethnography reveals the shifting meanings of kinship, care, dementia and personhood which adjust alongside social change. I also open the doors to *Pueblo's* care institutions, and investigate local formal homecare services, to understand how people with dementia, their family, carers, friends and the community around them negotiate newer forms of dementia care, incorporating these into long-established Mediterranean family care approaches.

Dependency caused by dementia challenges western liberal values centring around the autonomous *independent* individual, re-formulating personhood and forcing us 'to recognize ourselves and others as fundamental dependent beings' (Gjødtsbøl and Svendsen, 2018, p. 104). The way dementia care occurs therefore raises critical anthropological questions around the nature of what it means to be human. Dementia care has been gaining increasing attention from social anthropologists whose ethnographies investigate dementia care across contexts to reveal wider meanings around relatedness, care and personhood.

Anthropological explorations of personhood, however, have been rooted in an 'overly dichotomized view of East and West, where East represents 'relational' persons and the West 'individuals'' (Lamb, 1997, p. 281). Modern anthropology attempts to deconstruct this historical binary. Spain therefore provides an intriguing context to explore dementia care, as despite its status, internationally reified as a 'western', industrialised country, rooted within advanced processes of economy, politics, media and technology, people are engaging in long-established patterns of kinship care, and creatively reformulating these as newer dementia care forms are incorporated into day-to-day cultural practices. This ethnography therefore spills into the 'divide between the individualist west and the social relational rest' (Bloch, 2011, para. 13), using dementia care to reveal the inconsistent and complicated nature of what it means to be human wherever one lives.

I thus take Andalusia as a useful ethnographic site to explore dementia care experience, to reveal critical insights into kinship and relatedness, morality and ethics, community and belonging, and understandings of dementia and personhood, contributing to both anthropological and public health debates. I conducted fourteen-months of fieldwork exploring the lived experiences of people with dementia and their care-givers in an Andalusian town, investigating the following research questions:

How are people in Andalusia experiencing dementia and its care, and in what ways is dementia care re-shaping cultural practices and understandings of kinship, care and personhood?

- What strategies of dementia care are emerging through kinship relations in Andalusia, and why?
- How is personhood constructed through dementia care practices in Andalusia?
- How are public healthcare practices around dementia care experienced in Andalusia?

## Dichotomies of Care

Assumptions surrounding care idealise home-based over institutional care. Before fieldwork in *Pueblo*, I had a somewhat romanticised image of Andalusia. I had already spent significant time in the region, having been with my partner from Almería, a small city in Eastern Andalusia for five years. During this time, I had visited his family on many occasions and spent a year living in Granada. I had been struck by the differences in people's approaches to ageing, dementia and care, compared to what I had experienced working as an occupational therapist to people with dementia in London. Working in Granada as a childminder/English teacher for various families, I encountered many intergenerational households that engaged in rotational care patterns to ensure frail elderly relatives, or those with age-related health conditions, like dementia, avoided institutional care.

Researching for my PhD application, I found rates of elderly people in care homes in Spain were significantly lower than other European countries (Ruiz-Adame and Jiménez, 2017) and a dominant care culture critical of those who did not care for their elderly relatives themselves (Lillo and Riquelme, 2018). Those who did rely on care homes reported feelings of family 'humiliation' (Rodríguez-Martín et al, 2014). However, care homes and formal care for older people were increasing, alongside Spain's ageing population and women's increasing labour-market participation (Ruiz-Adame and Jiménez, 2017). As the psychologist at *Pueblo's* care home commented, 'We're in the transition', as older people and families in Andalusia adjusted to the shift from kin-based to formal care provision.

Across the globe, care homes, particularly in places where kinship eldercare has long-standing traditions, have been widely imagined negatively. Brijnath, conducting an ethnography of dementia care in India, found local people painted a picture of care homes as places where 'people are dumped' and relatives 'abandoned' (Brijnath 2011, pp. 700-709). Leinaweaver's (2013) ethnography in Peru found elderly relatives' entrance into institutional care was constructed as family failure. In Denmark, Gjødsbøl, Koch and Svendsen explored how nursing homes were understood as 'conduits for societal disposal of people with dementia' and associated with 'death and decay' (Gjødsbøl, Koch and Svendsen, 2017, p. 117). Meanwhile, Davies' (2017) ethnography of

a UK care home found narratives of loss dominated residents' descriptions of their move into the care home, and that institutional life led to social marginalisation.

Yet life in *Pueblo* challenged characterisations of institutional care as associated with social abandonment and loss. Instead, I observed how *Pueblo's* care institutions remained part of its wider community. This destabilises the dichotomy that divides home/community from institutional care. The visitation of the Virgin Mary statue to the care home, and residents' excitement and participation in this event, provides an example of how *Pueblo's* care institutions were deliberately incorporated into the collective rituals integral to community life. I outline how *Pueblo's* care home, located centrally, was rarely free from visiting family and friends. Moreover, both the care home and day centre participated actively in a variety of community events that constructed *Pueblo's* legacy as a town well-known for its vibrant *fiestas*, enabling collective social bonding, sense of belonging, and feelings of *communitas* in people with dementia living within these care institutions. This is not, however, to oversimplify people's perceptions of institutional care as entirely positive, and I still observed significant stigma existing around institutional eldercare. This resulted in families going to extreme lengths to develop complicated strategies of kinship care to avoid elderly relatives requiring institutional care, such as rotational care systems across multiple households that kept eldercare within extended kinship networks.

Research outside of anthropology has highlighted the need for recognition of community influences on dementia care. Barlett and O'Connor (2010) advocate recognition of people with dementia as 'citizens' to emphasise community membership. Quirk, Lelliotta and Seale's (2006) ethnographic research on psychiatric wards found that, unlike Goffman's analysis of care institutions as 'total', modern-day institutions are 'permeable' with patients maintaining contact with the outside world. I carry this into dementia care by revealing how *Pueblo's* care institutions were not only 'permeable', but formed a fundamental *part* of its wider community. My ethnography thus works against reductive understandings of dementia care as either occurring at home or within isolated care institutions, and instead works towards more nuanced anthropological understandings of care that recognise the critical role of collective sociality in dementia care both outside and within care institutions.

This contrast of home/community against institutional care builds understandings of care-givers as either informal, insider, unpaid kin or formal, outsider, paid carers. Such conservative understandings of care are misleading; as Duclos and Sánchez-Criado critiqued, care systems 'are not singular...but vexed, multiple, and often contradictory' (Duclos and Sánchez-Criado, 2019, p. 162). Through participating in the lives of formal carers and family care-givers in *Pueblo* this reductive



separation was shown as misleading. Many so-called 'informal' family care-givers were caring for elderly relatives to afford themselves economic stability or housing in a region of high unemployment and limited welfare, whilst many formal carers I spoke to described kin-like connections with the people they looked after. The association of care-giving with a dutiful kinship role however, often led to professional carers being expected to meet exaggerated care demands that went beyond the low economic provisions their jobs provided. This ethnography, by exploring the everyday lived experiences of care-givers, reveals the messy and contradictory nature of who is care-giver and how care-giving is experienced.

The term care-giving presents further difficulties. Care-giving is frequently presented in opposition to care-receiving, and thus care is constructed as actively performed by a care-giver towards a passive care-receiver. As Warren and Sakellariou critiqued, caring relationships are understood as 'unidirectional', leading to understandings of care as a 'burden' to the care-giver (Warren and Sakellariou, 2020, p. 3). Conceptualisations of active versus passive care relationships are strengthened by dominant discourses prevailing in western contexts that construct elderly people, particularly those with dementia, as incapable of production and thus devalued by capitalist society (Federici, 2012). Yet, elderly care-receivers, including those with dementia, continue participating in their relationships and communities in diverse ways. I reveal how people with dementia continue to actively participate in others' lives: supporting kin economically; participating in community events; providing compassionate care towards others; emotionally bonding and engaging in cultural exchanges between care-givers. This ethnography thus takes Barlett and O'Connor's repositioning of people with dementia as 'active agents' rather than 'passive recipients of care' (Barlett and O'Connor, 2010, pp. 4-5) into an anthropological understanding, whereby people with dementia are understood as actively constructing their own social worlds through their everyday practices within cultural contexts. Participating actively in community through kinship bonds, mutual support, participation in collective events, *abuelos* with dementia remain deeply embedded into the social fabric of community. This again emphasises the necessity to approach care as a relational, co-created need, developed through social relations within specific contexts. Throughout this thesis I thus emphasise the need to recognise care as 'community-centred', shifting dementia care debates into an anthropological focus that recognises the social diversity of care and the importance of the community and culture that shape it.

Notions of people with dementia as passive care-recipients combine with imaginings of cognitive disorder that contradict western conceptualisations of personhood, defined as cognitively functioning and independent individuals. People with dementia are presented as cognitively malfunctioning non-persons, depending on the cognitively functioning majority. Ethnographic

research has however, begun unravelling this misconception. Kontos' (2005) ethnography of a Canadian care home revealed the deeply embodied ways people with dementia express personhood. This contradicts medicalised understandings of dementia that frame people with dementia's behaviours as disease symptoms. In chapter seven, I describe how *Pueblo's* day centre staff sought agricultural knowledge from *abuelos* with dementia, who recounted environmentally-specific information that came from years of working on *Pueblo's* olive plantations, delving into long-term memories that remained intact. This research thus continues destabilising the dichotomy between cognitively malfunctioning and cognitively functioning persons, to explore the diversity of interactions, knowledge, and practices that people with dementia engage in alongside disease progression to diversify western understandings of personhood as demanding high-functioning cognition.

Embedded into understandings of personhood as dependent on high-functioning cognition is a vision of people as independent self-caring beings. Previously dominant gerontological theories emphasised older age as a time for reflection on previous life-stage achievements to gain integrity and preparation for death (Erikson, Erikson and Kivnick, 1987). However, acceptance of older age decline in western contexts shifted into resistance of ageing and dependence. Lamb (2000; 2014; 2017) through her ethnographic explorations of ageing in North America identified a paradigm of 'successful ageing', whereby individuals are expected to work hard to stay healthy, through engaging in disciplined exercise, healthy eating and lifestyles, to maintain independence in older age and avoid becoming dependent on others or the state. She critiqued this paradigm as condemning people to failure as it denies the inevitability of ageing, decline, dependence and ultimately death. She compares this approach to ageing with understandings in India which emphasise acceptance of older age and dependence on younger kin as a welcome, spiritually-valuable time in which people prepare for the afterlife. Participating in the daily lives of people with dementia and care-givers in *Pueblo*, it became clear that the Euro-American healthcare establishment's successful ageing paradigm was present in understandings of eldercare. However, it came into frequent 'disjunctures' (Appadurai, 1990) as it clashed with people's place-specific understandings of ageing and dependence as having always been managed through supportive interdependent kinship networks.

Lamb however recognised issues in contrasting western and non-western approaches to ageing and care as inadvertently generating dichotomising narratives around personhood which understand the west as individualistic versus 'the rest' as interdependent and enmeshed in kinship networks, when in reality personhood is 'complex and multifaceted' (Lamb, 1997, p. 281). Human dependence has been recognised by anthropological research as a fundamental reality across contexts (Ferguson, 2013). Exploring dementia care through people's everyday lived experiences in

Andalusia, a European setting that is known for its interdependent kinship networks, highlights the human vulnerabilities and dependencies that define us as social beings. This thesis thus contributes towards more nuanced understandings of personhood that deconstruct reductionist dichotomies separating ‘the west from the rest’.

Care narratives separating ‘the west from the rest’ lead into visualisations of tradition against modernity. Cohen’s (1998) ethnography exploring dementia in India highlighted local understandings of modernity as a ‘wicked spectre’ causing families to neglect their sacred duties to care for elders, resulting in ‘bad’ old age. Brijnath (2014) conducted an ethnography in India two decades later and found people had absorbed modernity’s biomedical language around dementia but had indigenised it through local understandings that understood kinship care as influencing one’s experience of dementia symptoms. In *Pueblo*, traditional imaginings of the Mediterranean family, which romanticised entirely kin-provided eldercare, had shifted. Although I observed a strong sense of duty to care for elder kin, this had reformulated. Families could now cite idealised kinship eldercare as including some formal care, as professional care was understood, through medical frameworks, as offering specialist dementia interventions which families were not necessarily trained in. Lamb highlighted how shifts from family to formal care are not necessarily signs of modernity or ‘progress’ but carry ‘profoundly different meanings across cultural, political-economic and historical contexts’ (Lamb, 2013, p. 78). As demonstrated in this chapter’s opening vignette, in *Pueblo*, traditional cultural rituals were incorporated into newer forms of institutional eldercare. Such long-established rituals stimulated deeper engagement by *abuelos* than the medicalised cognitive worksheets that subscribed to successful ageing paradigms. This ethnography thus deconstructs understandings of traditional versus modern dementia care to reveal the place-specific yet international, new yet old versions of dementia care within a specific cultural context.

Care is central to everyday human experience, yet this is not reflected in the academic attention it has received. Duclos and Sánchez-Criado critiqued how care has been approached as a ‘tedious practical necessity’ rather than an intellectually stimulating topic, which has resulted in much research on care conforming to a ‘conservativism’ that seeks ‘wholeness, conformity, and civility’ (Duclos and Sánchez-Criado, 2019, p. 155). This has influenced the development of the reductive care dichotomies I discuss above. There is thus a need for critical explorations into the diversity of care experiences, to reveal its complexly messy reality.

Medicalised framings viewing dementia as a disease – a cognitively malfunctioning brain in need of fixing – have gained funding for biomedical research. However, this focus on fixing malfunction has overshadowed research into care experience, deemed as less important than

research seeking a cure. I follow Ballenger's (2017) call for research beyond biomedicine to explore experiences of people living with and caring for dementia to reveal alternative understandings. This ethnography, through everyday participant-observation into people's *lived experiences* of dementia care within a small Andalusian town, across homes and institutions, enables me to develop critical insights into dementia, care, kinship and personhood that resist oversimplification. This investigation thus goes beyond narrow conceptualisations prevailing in existing research to disentangle care from reductive, clinical and medicalising understandings; to breathe life into dementia care.

## **Positionality**

My positionality, as an anthropologist and occupational therapist, provides an inter-disciplinary perspective. Occupational therapy and the occupational science discipline understand 'occupation' as 'experiences of humans which necessitate active engagement, have purpose and meaning, and are contextualized' (Molineux, 2017, p. 19). Occupational therapists work with people with disabilities, mental health conditions and physical illnesses to foster engagement in meaningful occupation (NHS, 2020). Occupational science is a relatively new academic discipline, founded in 1989, researching human occupation to contribute to occupational therapy's knowledge-base (Yerxa, 1990). Occupational therapy and science thus share interests with anthropology as they centre on people's everyday practices, and how these are made meaningful.

Working as an OT (occupational therapist) in UK healthcare settings, however, I was frustrated by the lack of reflection into wider societal issues behind healthcare experiences. My feelings resonate with Yahalom's who, working as a psychologist, critiqued how the 'humanity of care' was subsumed under clinical symptomology (Yahalom, 2019, p. 5). Despite occupational therapy's claims to be holistic and open to the diverse ways people create meaning through occupation, I found the profession focused on narrow conceptualisations of health and wellbeing that neglected the socio-political meanings behind occupation. Pollard and Sakellariou (2014) critiqued occupational therapy's focus on medical objectives for obscuring wider societal, economic and power structures that restrict occupational engagement. Whereas social anthropology, a discipline concerned with existential questions around 'what it entails to be human in the world' (Eriksen, [1995] 2015, p. 7), delves into deeper, more critical explorations around the nature of how meaning is formed and given shape through social practices, which are underscored through power structures. A social anthropological approach, exploring how diverse subjectivities are constructed through specific contexts, thus enables a more critical investigation of people's lived experiences of dementia care.

Furthermore, I found occupational therapy's focus on 'person-centred care', rooted in an understanding of personhood as individualistic, problematic, particularly with dementia. The person-centred care movement advocated by Kitwood critiqued biomedical conceptualisations of dementia as dehumanising. He advocated for a 'person-centred care' whereby 'the human being is taken as a person rather than an object' (Kitwood, 1997, p. 12). His work had far-reaching effects in dementia care and person-centred care has been widely adopted into healthcare professionals' practices. Occupational therapy's interpretation of person-centred care in ageing has focused on maintaining individuality and independence in later life (Creek, 2010). This emphasis on independence, however, seems to reflect the denial of decline and dependence identified by Lamb (2014) in her critique of the successful aging paradigm. This approach emerged from specific socio-historic circumstances, the development of contemporary neoliberal ideals of individual freedom and self-governance against a demographically ageing population constructed as a burden. Health itself is increasingly understood as 'an achieved rather than an ascribed status...each individual is expected to 'work hard' at being strong, fit and healthy' (Scheper-Hughes and Lock, 1987, p. 25). Metzl (2010) critiqued how 'health' is used to make moral judgements, blaming poor health on individual lifestyle choices and thus masking the structural inequalities shaping health. Working as an occupational therapist to people with dementia, such individualist understandings of health, personhood and independence felt futile and inappropriate. This valuing of independence generates hierarchies of good and bad ageing that must be critiqued. I thus take a critical, anthropological approach to investigating subjective lived experiences to enable diverse understandings of dementia, kinship, care and personhood to be explored.

Anthropology meanwhile, can be critiqued for deconstructivity resulting in a lack of concrete applications, whereas occupational therapy, rooted in therapeutic outcomes, is inherently suited to producing practical results. Occupational science distinguishes itself from other social sciences by claiming to be working towards findings that empower the occupationally restricted (Zemke and Clark, 1996). As Frank, Block and Zemke argued, occupational therapy's groundings in 'doing', 'activity', 'engagement', 'performance' and 'participation' can be 'liberating for a text-bound anthropology' (Frank, Block and Zemke, 2008, pp. 3-4). My training as an occupational therapist, attuned to problem-solving, thus facilitates research that leads into the fruition of practical applications, rather than floating into the dislocated vortex of anthropological debate.

However, differences between occupational therapy and anthropology are, I argue, outweighed by their shared goals. Studying anthropology as an undergraduate, Ortner's quote explaining anthropology as the study of 'real people doing real things' (Ortner 1996, p. 2) became the unofficial soundbite to our degree. Occupational therapy and science are focused on the study of

humans occupying themselves and thus ultimately share anthropology's objective of exploring *people doing things*. Perkinson and Briller (2015) emphasised the disciplines' similarities, which both recognise the need to understand meanings within contexts.

Spencer, Krefting and Mattingly (1993) highlighted similarities between ethnographic methodology and assessment processes in occupational therapy. Working as an OT on an older adults' psychiatric ward, my job included conducting home assessments in which I accompanied patients home to evaluate their engagement in everyday activities, like making themselves a cup of tea, to assess if they were ready for discharge. This process felt like an intensely compressed ethnography, as I had to rapidly explore patients' everyday lives through fitting myself into them. For example, despite being a long-term vegetarian, during OT home assessments I would eat ham sandwiches which patients had prepared for me, to fit into the natural reality of their daily lives, in much the same way as years later in *Pueblo* I found myself chewing on chorizo with informant families who invited me into their homes within participant-observation. The disciplines thus share methodology and interests. Being trained as an anthropologist and OT enables me to produce a richly inter-disciplinary ethnographic exploration of dementia care.

Prior to this research, I was already familiar with Andalusia, from having a long-term partner from the region and having spent extended periods living/visiting there. I had learnt Spanish and was accustomed to the local dialect. Before moving to *Pueblo*, I spent three-months living in Almería with my partner, Antonio's family, during which I contacted day centres and conducted scoping trips searching for a field site. Having stayed with Antonio's family as a 'pseudo-family member' gave me somewhat more intimate background knowledge of Andalusian family life. Sadly, Antonio's paternal grandmother, Paquita, became seriously ill during this period and was admitted to hospital, where she was diagnosed for the first time with dementia and passed away shortly after. I describe my experiences during this difficult period in chapter two, when discussing the mixture of personal and academic factors that influenced me in choosing a field site. Spending time with Paquita, observing how she participated in family life and was cared for by her adult children, was partly what inspired me to research dementia care in Andalusia. This personal connection to place and topic gives me a positionality that I believe helps me understand informants' experiences.

I had however, only lived in Andalusian cities before moving to *Pueblo*, so it was still an adjustment moving to a relatively small rural town. Arriving in *Pueblo*, I was accompanied by Antonio for the first eight-months of fieldwork, before he moved to Málaga for work. Neighbours automatically referred to Antonio as my *marido* (husband), presumably because we lived together, and I believe that perceiving me as in an established relationship with someone from Andalusia may

have meant people felt I was less of an outsider than I would have been had I moved to *Pueblo* alone.

I remain extremely conscious, however, that such personal factors do not give me authority to speak knowingly about 'Andalusian culture', as though it were an identifiable entity, which I am somehow closer to. I instead approach 'culture' as something experienced subjectively by diverse individuals who continuously co-construct it. It is particularly important that I remain conscious of my 'outsider' status to an abstract cultural process, given the historic 'othering' (Said, 1978) of Andalusian culture by Anglo-anthropologists. Andalusian anthropologists have critiqued Anglo-anthropologists in Andalusia, including Pitt-Rivers [1954] (1971) and Collier (1997), for exoticising Andalusian culture (Roca and Martín-Díaz, 2016). I therefore must be cautious of my personal ties to the region not causing me to romanticise 'Andalusian culture' as though it were a tangible entity. Instead, I attempt to describe the views of those I encountered during fieldwork as representatively as I can, whilst accepting this inherently occurs through my own subjectivity.

Final aspects of my positionality worth highlighting were my age and gender. Dementia care is a sensitive topic that can delve into people's intimacies and cross personal boundaries. I feel that approaching people as a woman with experience of dementia care as a healthcare professional facilitated trust. The majority of care-givers and *abuelos* I encountered were women themselves and I believe our shared gender played a role in developing intimacy and trust. My age, at 30/31-years-old during fieldwork, may have meant *abuelos* were inclined to perceive me as a care worker. However, this may have also masked my researcher role, an issue I explore in chapter two. I believe my age and gender meant care-givers generally approached me comfortably, as I fitted within the perceived age and gender of a care worker, and this facilitated trusting intimate relationships to develop which allowed for deeper, more sensitive portrayals of people's lived experiences.

## **Literature Review**

### *Personhood and its Historical Development in Anthropology*

This thesis explores the ways that dementia care practices influence how personhood is constructed in Andalusia. It is critical that I thus provide an abbreviated history of the concept of personhood in anthropology to understand the key debates in the literature, as well as the current state of the field. I end this presentation of the historical development of personhood in anthropology by providing my own definition of the concept, to make clear how this research can contribute to ongoing debates.

Mauss is widely considered to have had the earliest significant influence on the anthropological study of personhood. Mauss' [1938] (1985) presentation, entitled 'A category of the human mind: the notion of person; the notion of self' sparked anthropological interest in the topic (Appell-Warren, 2014; Degnen, 2018). Mauss took an evolutionary approach to analyse the concept of the person, explaining types of person as developing through three stages. He began by explaining what he claimed to be the most primitive, tribal persons, which he named '*personnage*', and explained as understanding persons solely through their 'roles' in society. The next progression he labelled '*persona*', which he claimed could be found in ancient societies, and recognised persons as having 'rights' as individuals. The final, most advanced version of the person, Mauss claimed, was the '*personne*', found in western Christian societies, which he explained as possessing a 'moral strength' which elevates it to the highest status of person (Mauss, [1938] 1985, p. 22). Although no current anthropologist would support this undoubtedly ethnocentric, evolutionary perspective, Appell-Warren (2014) has highlighted how recent anthropologists continue to stake simplistic claims of non-western personhood being 'relational', and western personhood being 'individual'. She critiqued this as 'a claim that is strikingly similar to the claims of the early anthropologists', such as Mauss (Appell-Warren, 2014, p. 36). Mauss' description of these culturally varying versions of the concept of the person thus may have planted the seed for an anthropology of personhood that became caught up in an over-simplistic, ethnocentric understanding of western versus non-western forms of personhood.

Mauss' work inspired a multitude of subsequent further analyses of the concept of the person from other authors that approached analysis through a similar evolutionary perspective (see Leenhardt, [1947] 1979; Hallowell, 1969). However, to allow space to focus on personhood in dementia and in Andalusia, I now move on to explore the next critical shift that occurred in anthropology's historical investigation of the person. This was when cross-cultural analyses on variations of the concept of 'the person', shifted towards analyses of the concept of 'personhood', a term which appears to have been first used in Geertz's [1966] (1973) work. Appell-Warren (2014) explained that Geertz did not believe himself to be the first anthropologist to invoke the use of the term 'personhood', but that she was unable to find any earlier use of the term in anthropological works, despite conducting extensive reviewing of the literature. In this work, Geertz made multiple references to 'personhood' and 'Balinese formulations of personhood' (Geertz, [1966] 1973, p. 390). He continued the western versus non-western crux of the personhood debate, by highlighting the fundamental Balinese conception of personhood as being 'depersonalizing' when compared to western understandings (ibid., p. 391).



Although Geertz appears to have been the first to use the term, the first extensive anthropological exploration of personhood came from Fortes' work, originally published in 1971, amongst the Tallensi in west Africa (Appell-Warren, 2014). Fortes was attentive to Mauss' work on the person, but was one of the first anthropologists to argue against his original conceptualisation (Degnen, 2018). Fortes asked the question 'If personhood is socially generated and culturally defined, how then is it experienced by its bearer, the individual?' (Fortes, [1971] 2009, p. 250). This led him to theorise two components of personhood, the 'objective side', which 'society endows a person' and the 'subjective side', which explains 'how the individual, as actor, knows himself to be' (ibid., p. 251). This marked a clear shift from Mauss' original conceptualisation, as Fortes was arguing that, amongst the Tallensi, a non-western society, people possessed a conscious perception of themselves as people, and of their status, and deliberately acted on this. Fortes was thus able to explain agency through personhood, as he recognised individuals as not passively bearing personhood but appropriating the governing norms of its expression onto themselves. This understanding of conscious, agentic individuals outside of western contexts helped advance previous ethnocentric discussions of the person that accredited such qualities as only applicable to western forms of personhood.

Fortes also pushed forward the personhood debate by his argument that 'full personhood is only attained by degrees over the whole course of life' (Fortes, [1971] 2009, p. 261). He explained how, amongst the west African Tallensi, rites of passage served to publicly mark the change in one's status and level of personhood. Fortes argued that, amongst the Tallensi, it was not until a person's parents' died that one could be granted the highest level of full personhood. Fortes also explored how personhood was influenced by cognitive status, but not taken away, stating 'a madman is not a non-person' but a 'fragmented, and marginal person' (ibid., p. 277). He discussed how the very old or senile still maintained personhood, and although they might be treated differently, because they had attained a certain degree of personhood, their status could not be taken away during their lifetime. Fortes' discussions are helpful in thinking about how personhood is influenced by both cognitive changes and age. Although Fortes argued the Tallensi did not understand older people or people with cognitive impairment as being deprived of personhood, he did recognise how the type and status of personhood changes across the life course.

Despite insights from Fortes pushing towards a more universal understanding of all individuals having a conscious, agentic personhood, in the late 1980s and early 1990s researchers 'began to question the cross-cultural validity of the concept of the "individual"' (Appell-Warren, 2014). Strathern's (1988) monumental ethnography in Melanesia had a huge influence on anthropological debates of personhood through her development of the concept of the 'dividual'.

Strathern explained how people in Melanesia, rather than being solely individuals, were ‘dividually’ built. She explained how persons are ‘constructed as the plural and composite site of the relationships that produced them’ (Strathern, 1988, p. 13). Contrasting with conceptualisations of the western person as an autonomous individual, who is free from dependency on social relations, through the notion of ‘dividual’, ‘the person is *made through* social relations’ (Degnen, 2018, p. 8). Degnen (2018), in her extensive investigation of anthropological discussions of personhood, emphasised the critical influence these concepts of the individual and dividual have had on anthropological debates on personhood. The individual/dividual theorisation may have restrengthened ‘the west versus the rest’ dichotomy in personhood debates in anthropology, which I discuss in more detail in a later subsection of this literature review.

Research investigating personhood in the 1990s shifted on to detailed explorations of individual categories of analysis, rather than overarching discussions of personhood as a whole in a particular culture (Appell-Warren, 2014). One of these categories of analysis that generated much discussion, Appell-Warren explained, was ‘disability’ and its influence on personhood. One study on disability and personhood from this period, was Nicolaisen’s (1995) ethnographic work on disability and personhood among the Punan Bah of Central Borneo. She found that amongst the Punan Bah personhood was not taken away by physical or mental impairment, and that even people who became severely affected by mental illness were ‘not disqualified as persons’ (Nicolaisen, 1995, p. 53). The Punan Bah sense of personhood, Nicolaisen explained, was intricately connected with society and with an understanding of themselves as mortal beings who exist as living incarnations of their ancestors. She described a ‘moral obligation’ felt by kin to care for people with physical or mental impairment, understood as part of this social entity, to ensure the person was not deprived of the social relationships that were necessary for adult personhood. These ethnographic insights, despite being taken from a geographically very distant place to Andalusia, still resonate with some of the later insights I will discuss in this thesis. In *Pueblo*, family members described a moral duty to care for loved ones with dementia, and I observed how they engaged in care-giving practices towards relatives with dementia to enable the fulfilment of an interdependent personhood.

More recent anthropological investigations of personhood have continued to move away from overgeneralising static understandings of personhood, towards recognising the changing, flux-like nature of personhood. Appuhamilage’s (2017) work attests to the fluidity of boundaries that define people’s sense of personhood. She explored how personhood was conceived and enacted through her ethnographic work in a rural community in Sri Lanka. She argued against the reductive individual/dividual binary of autonomous versus collective personhood to recognise the commonalities and ambiguities within these polarising constructions of personhood. A better way

to understand the nuances of personhood, she suggested, is to investigate the multifaceted ways of being that coexist in persons. Possessing this ambiguity enables people 'to play with different intersubjective and intrasubjective modes of being' (Appuhamilage, 2017, p. 15) which allows people to shift and mould their own personhood to adapt across differing contexts, and connect to individual and collective desires.

Recognising how personhood can shift as people grow older, Robbins' (2009; 2019) ethnographic work amongst people with Alzheimer's disease in Poland, highlighted this fluidity in personhood. She observed how older people who had experienced a physical or cognitive impairment through illness, in coming to a rehabilitation centre and engaging with healthcare staff and other patients, came to accept and adapt to their newly-acquired physical limitations. She observed how older people were able to adopt new forms of personhood based on self-acceptance, rather than self-fulfilment. Her work suggests that individuals can consciously transform personhood in later life, and is useful to consider in relation to my observations in *Pueblo*. In drawing out the everyday lived experiences of both older and younger people in *Pueblo*, both giving and receiving care, I follow this more recent turn in anthropological debates on personhood that recognises the flux-like nature of personhood that shifts and changes over people's lifetimes.

In this thesis I am ethnographically exploring the ways that dementia care practices influence how personhood is constructed in Andalusia. Taking into account historical and contemporary developments of personhood in anthropology, it is still critical that I lay out what I mean by personhood as an anthropological category. Appell-Warren's (2014) extensive reviewing of the literature around personhood revealed that the frequency of the use of the term 'personhood' had increased. However, she found there was still a lack of consensus over the exact meaning and definition of personhood. She advocated that, given its increasing prevalence, it is critical that anthropology establishes 'a clear, concise and common understanding of how personhood should be defined, understood and used' (Appell-Warren, 2014, p. 88). Appell-Warren thus offered a detailed suggested universal definition of personhood. In summary, Appell-Warren's definition explained personhood as the attainment of certain physiological, psychological and social competencies, which are defined by a given culture. She crucially also explained how the attainment of differing levels of personhood are marked throughout the life cycle by rituals and rites of passage (for full definition see Appell-Warren, 2014, p. 105-106).

Degen's (2018) work reviewed a wide-range of anthropological literature, and drew on her own ethnographic fieldwork with older adults in Northern England, to build a thorough analysis of the concept of personhood. Degen also emphasised the importance of recognising personhood as *processual*, in that it 'shifts and moves across the life course within and between various cultural

settings' (Degnen, 2018, p. 22). It is important that I thus recognise the *shifting* nature of personhood, and how it varies, both across different cultures, as well as across differing stages of the life course. Degnen's (2018) work is particularly relevant to this thesis as she explored how personhood is reshaped, and even threatened, through ageing and the occurrence of cognitive conditions, such as dementia. Through her analysis, Degnen demonstrated how personhood is not a given, but rather 'something that needs always to be worked at, maintained, shored up, protected' (Degnen, 2018, p. 186). Personhood, Degnen explained, is thus not an inherently existing entity, but a concept that 'is brought into being via reciprocal fields of social relations and interactions' (Degnen, 2018, p. 178).

I am guided by these contemporary understandings of the concept of personhood to reach my own definition. In this definition, I therefore emphasise both the cross-cultural and life cycle shifts that shape personhood. I also follow Degnen's (2018) suggestion that personhood attributes a moral value that non-persons are excluded from. I thus state below my definition of personhood, as it applies to anthropology:

Personhood is a concept that specifies who, or what, within any given culture, is collectively experienced as a being with moral value, and is continually (re)produced and (re)shaped through social interactions and relationships.

### *Person, Self and Identity*

I have detailed above an abbreviated history of the anthropological development of the concept of personhood and outlined key debates that have relevance to this thesis. Before discussing in more depth the 'west versus the rest' debate around personhood which this thesis inherently encounters, it is important I establish the differences between the much-conflated terms of 'person', 'self' and 'identity' to ensure clarity throughout this thesis. Appell-Warren (2014) described how Poole (1982) understood personhood to be the outer layer of an onion which contains the inner layers of person, self and identity. It can be helpful to understand personhood then, as the overarching concept that holds these interrelated conceptual components together.

Degnen (2018) conducted extensive reviewing of the anthropological literature on personhood and highlighted how personhood and its related terms are frequently conflated. Harris' (1989) work also raised this issue and assumed the objective of clearly distinguishing between the much-conflated terms of 'individual', 'self' and 'person'. She argued for a pressing urgency to deal with 'what is a confusion of concepts, not merely terminology' (Harris, 1989, p. 609). She suggested that in clarifying these conceptual distinctions, anthropologists would be able to make better

contributions towards cross-disciplinary debates around personhood. I thus now attempt to establish the differences between commonly conflated terms relating to personhood.

An 'individual' was defined by Harris as 'a human being considered as a single member of the human kind' (Harris, 1989, p. 600). Harris explained however, that not all 'individuals' possess the higher status of being 'full persons' or 'agents-in-society' (ibid.). She suggested that to determine whether an entity is an individual or a person in any given society one must look to ideals of 'normal' characteristics (ibid.). I thus understand an individual to be a singular living entity of one member of humankind. An individual may, or may not, fit into the normalised characteristics determined by their given society that raises that individual to the standing of a 'person'.

For an individual to be granted the standing of a 'person' Harris (1989) referred to this individual as needing to be an agent who is able to take action towards a purposively directed goal, and to have a certain standing within society's social order. Through understanding persons as 'agents-in-society' we can raise awareness to social relationship systems, wherein people perform actions and respond to one another's actions (Harris, 1989, p. 603). Harris also recognised that not all persons need necessarily be human beings. Hallowell's (1969) work, drawn from his ethnographic findings researching amongst the Native American Indian Ojibwa people, investigated the Ojibwa's metaphysical concepts around the nature of humans and supernatural beings. Through this exploration, Hallowell highlighted how the category of 'person', 'is by no means limited to *human* beings' (Hallowell, 1969, p. 51). Hallowell discussed how supernatural beings could be recognised as 'persons' and that therefore person is 'not...synonymous with human being but transcends it' (ibid., p. 51). This is important to highlight, as in chapter five, I explore the multitude of ways through which social relations towards *Pueblo's* Virgin Mary statues raised their standing from that of inanimate objects to that of persons. The statues even came to be recognised as kin, with whom *abuelos* could relate to, harness comfort from, and through which dementia care practices could be orientated around. I thus understand a person to be an agent with a certain standing in a social order within a given context, but whom may or may not be human.

The 'self' is conceived by Harris as 'the human being as a locus of experience, including experience of that human's own someoneness' (Harris, 1989, p. 601). This reflexive, awareness of one's own existence and 'someoneness' positions the concept of the 'self' as rooted in subjectivity. Poole (1982) explained the concept of 'self' through recognising the distinction between the objective side of personhood, which is placed on an individual by society, and the subjective side of personhood, which considers how an individual experiences what is imposed on them by society. As Appell-Warren (2014) highlighted, this was an important distinction from Fortes' [1971] (2009)

separation of the objective and subjective sides of personhood, as Poole was labelling this subjective side of personhood 'the self'.

Cohen's (1994) work explored the concept of the self in anthropology. He was critical of social anthropology for only implicitly incorporating the self into its discourse. He attempted to address this neglected attentiveness to self through clearly distinguishing 'selfhood' from 'personhood'. Personhood he explained as 'the definition of me as a social entity which society imposes' (Cohen, 1994, p. 57), which appears to fit with the objective side of personhood explained by both Poole (1982) and Fortes [1971] (2009). Cohen contrasted this objective notion of personhood explicitly with 'selfhood' as 'the substance of 'me' of which I am aware' (Cohen, 1994, p. 56-57). This inner, deeply rooted sense of self is thus arguably complicated, or impossible, to read in others. The 'self' is thus understood as a deeply subjective, inner sense of consciousness of one's own existence and, to borrow from Harris, one's own 'someoneness' (Harris, 1989, p. 601).

'Identity' is another concept commonly conflated with personhood, that brings up multiple ambiguities. Finke, Sökefeld and Callan (2018) investigated the use of the concept of identity in anthropology and highlighted how it is frequently confused with self, personhood and individual. They argued that identity is largely used to classify people into socially constructed categories. The word 'identity', they explained, is rooted in the Latin term '*idem*', which means same/sameness. Identity is thus on the one hand about 'sameness with oneself...those characteristics defining the uniqueness of one individual', whilst also referring to 'sameness with particular others, which, in turn, implies differences with other others' (Finke, Sökefeld and Callan, 2018, p. 2). Identity is thus associated with a sense of belonging to a group or wider collective, with whom one shares a commonality. I emphasise this by referring to a sense of 'collective identity'. At times in this thesis, I refer to the national collective identity of Spain, the regional collective identity of Andalusia and the municipal collective identity of *Pueblo*. I explore how certain practices draw on these collective identities to generate a shared sense of belonging, whereby people feel connected within these particular groups.

One of the key criticisms of 'identity' as a concept however, is that it can be reductive in defining people entirely through these limited socially constructed categories (May, 2013). Identity categories include such groups as gender, ethnicity and class. This is why the term 'intersectionality' emerged as a way of explaining how 'various aspects of identity cannot be singled out and analyzed in isolation' (Finke, Sökefeld and Callan, 2018, p. 4). Intersectionality enables the understanding of the overlapping relations of differing aspects of identity. May raised a crucial point in analysing the concept of identity, in stating that it is important 'not to reduce people to the categories that social scientists use' (May,

2013, p. 7). I agree with May and thus follow instead her advocacy of the use of the concept 'belonging' over identity. May critiqued how even the term 'intersectionality' still relies on the narrow identity categories defined by social scientists, albeit allowing for identification of the overlapping nature of multiple aspects of identity. Through using the concept of 'belonging' instead of identity, one can examine 'people with multiple solidarities and hybrid identities' that are found 'through their sense of belonging' (May, 2013, p. 8), rather than reducing people to a homogenous group, such as 'female', or 'working-class'. Belonging also fits with the argument I make in this thesis around the interdependency of personhood in Andalusia, as unlike 'identity' which 'begins from the separate, autonomous individual, 'belonging' focuses on what connects people to one another' (May, 2013, p. 9). It is however, important to understand what I mean by identity, to separate it out from other interrelated, but conflated, concepts surrounding personhood. Thus, although throughout this thesis I follow May's (2013) advocacy of analysing through 'belonging', identity remains a useful way of distinguishing a certain person/group by positioning them into a specific socially constructed category, which establishes them as distinct from others.

### *'The West Versus the Rest' Tension*

A tension that anthropological debates around personhood have grappled with over time has been the overly polarising division between 'western' versus 'non-western' forms of personhood. This binary is rooted in the ethnocentric, evolutionary approach of anthropologists' historical development of the term personhood (Appell-Warren, 2014). Geertz's conceptualisation of western personhood, developed during his ethnographic fieldwork in Bali, illustrates the foundational understanding of this exaggerated version of western personhood:

'The Western conception of the person as a bounded, unique, more or less integrated motivational and cognitive universe, a dynamic center of awareness, emotion, judgment and action organized into a distinctive whole and set contrastively both against other such wholes and against its social and natural background is, however incorrigible it may seem to us, a rather peculiar idea within the context of the world's cultures' (Geertz, [1973] 2006, p. 31).

The emphasis is that western personhood is fundamentally constructed around a profoundly autonomous, self-reliant and individualistic sense of being in the world. This notion of the western

bounded 'individual' in literature exploring personhood in anthropology has been frequently and typically contrasted against the 'dividual' (Degnen, 2018).

The conceptualisation of the 'dividual' arose in the late 1970s as researchers began cross-cultural investigations of the question of the person (Degnen, 2018). By the late 1980s and early 1990s researchers, particularly those working in Oceania, started replacing the use of the term 'individuals' with the concept 'dividuals' (Appell-Warren, 2014). As mentioned, the 'dividual' explained persons as composite beings created through social relations, and came to prominence from Strathern's (1988) ethnographic work in Melanesia. Degnen (2018) through extensively reviewing anthropological literature on personhood, emphasised the lasting impact this binary has had on anthropological debates on personhood. She uncovered how it led to an 'over-commitment to a sharp binary between dividuals and individuals' (Degnen, 2018, p. 11). This binary portrayed a caricatured, exaggerated version of a non-western relational kind of personhood that was continually contrasted against a profoundly individualistic, autonomous understanding of western personhood. Smith in his (2012) paper reviewing personhood debates in relation to the individual/dividual binary, highlighted how ethnographies during the 1980s, around the time of Strathern's (1988) work, tended to compare against idealised conceptions of persons that focused on differences and ignored commonalities. Appell-Warren also investigated this problematic dichotomy, critiquing how claims of Melanesian people as being 'dividuals' who are incapable of understanding individuality, fell into 'the same traps of the ethnocentric and evolutionary analysis that plagued the anthropologists who have long viewed "individuality" as a Western prerogative' (Appell-Warren, 2014, p. 67). This binary of individual/dividual thus appeared to restrengthen 'the west versus the rest' dichotomy within anthropological debates on personhood during this period.

Hollan's work (1992) which cross-culturally explored differences in the self, argued that this sharp contrast between western and non-western selves was based on over-simplified, idealised conceptualisations that neglected to compare descriptive accounts of subjective experience. He demonstrated the ill-founded nature of this division through portraying evidence from research of an independent, autonomous sense of self amongst the Toraja of Indonesia, who had been interpreted in anthropological literature to be 'sociocentric'. He also described the existence of interdependent, relational selves amongst Americans in the United States, despite having been frequently claimed as only 'egocentric'. He critiqued how such cultural models of selves led to a 'simplified and often idealized conception of objects and processes' which resulted in the 'blooming, buzzing complexity of phenomena' being ignored (Hollan, 1992, p. 285). Hollan advocated avoiding focusing on the broad contrasts between western and non-western selves, and instead to examine



the differing aspects of both egocentrism and sociocentrism that occur within both western and non-western contexts.

Kusserow's (1999) reflective piece, later highlighted how, although anthropologists had already begun attempting to unravel this dichotomy through investigations of non-western contexts where people were shown to have more independent conceptualisations of the self, the reverse gathering of evidence had not happened. She critiqued how anthropologists needed to provide contradictions to oversimplified understandings of western conceptualisations of the self which had not been adequately explored. She fervently critiqued this as a 'reverse Orientalism...flattening the Western self into a simple, homogenous, neat package' which ignores its complexity (Kusserow, 1999, p. 546). Kusserow insisted that the destruction of this polarising dichotomy in debates of the self would only progress through calling into question stereotypes 'on *both* sides' (Kusserow, 1999, p. 553). She thus advocated that anthropology engage in much wider-ranging ethnographic explorations of the self from western contexts to break down this reductive caricatured version of western personhood. Since this advocacy at the turn of the century, there has been a huge increase in anthropological explorations within western contexts that breakdown simplistic understandings of western personhood, including in relation to dementia and eldercare (see Lamb, 2014; Leibing, 2017).

By the start of the twenty-first century, 'the west versus the rest' binary had thus already been thoroughly critiqued in anthropological debates on personhood. Englund and Leach, writing during this period, noted that it had become 'current anthropological wisdom' that '*all* persons are both dividuals and individuals' (Englund and Leach, 2000, p. 229). Yet, despite anthropology's long-debated problematisation of this binary, I found that it still had significance ethnographically in Andalusia in relation to elder and dementia care. As relatives caring for loved ones described to me notions of 'traditional' care, or explained how Andalusians were 'still stuck to the family', I observed how the influence of this binary was still playing out in how people conceptualised the ways through which they cared for their elderly relatives. Care institutions in *Pueblo* adopted formal cognitive exercises into their care routines which appeared to subscribe to highly individualised conceptualisations of personhood. Yet, these were often met with scepticism by the *abuelos* who were made to engage with them, who appeared not to recognise or engage with the promoted need to work hard towards eternal independence in older age. There appears then to exist a tension between anthropological and emic understandings of personhood in relation to this 'west versus the rest' binary. Whilst anthropological debates continue to deconstruct and problematise this binary, on the ground ethnographically this binary continues to play out in a multitude of ways. In exploring the lived experiences of people with dementia and their care-givers in Andalusia, I use rich,

subjective experience to reveal these ongoing tensions that appear ethnographically. I next move on to explore how Southern European ethnographies in particular can help continue to dismantle this problematic binary.

Anthropological investigations from within Europe, as emblematic of 'the west' have been particularly helpful in unpacking this problematic 'west versus the rest' binary. The dossier from *American Anthropologist*, entitled 'Provocations of European Ethnology', with contributions from anthropologists whose work included investigations within Europe, laid out this argument (Asad et al, 1997). In this dossier, Herzfeld, critiqued the way, until two or three decades before he was writing, 'our discipline often seemed preoccupied with just about every part of the world *except* Europe' (Herzfeld, cited in Asad et al, 1997, p. 713). Anthropology's historical lack of priority given to ethnographies in Europe left a hole in the discipline. However, since then, there has been a copious and thriving anthropology of Europe, of which I hope to add with this ethnography. To continue the ongoing deconstruction of this binary, it is thus important to reveal the diversity of cultural experience in western as well as non-western contexts.

As Europe is understood in anthropological imagination as sitting at the top of the throne of cultural hegemony the "'anthropologizing" of Europe' can be argued to be 'a necessary methodological counterpart to the dethronement of Europe as the fount of all wisdom' (Asad et al, 1997, p. 713). Verdery, in her contribution to the dossier, took this position, arguing that the 'most trenchant critique of European hegemony must therefore begin in Europe itself' (Verdery, cited in Asad et al, 1997, p. 715). She argued that the anthropology of Europe sits at a 'prime vantage point' for combating ethnocentrism, and particularly Eurocentrism, through its capacity to deconstruct hegemonic ideology (ibid.). Europe, as the founding site of fundamental concepts that have set the blueprint of current global structures, such as state formation and democracy, is therefore a critical site to unpack and dissect these concepts. Lass, in his contribution to the dossier, supported this position, stating how investigating Europe allows for a 'confrontation with Western culture' that makes specific claims on theoretical abstractions, objectification, and reflection (Lass, cited in Asad et al, 1997, p. 723). Ethnographies of Europe thus can be understood as a critical part of combating ethnocentrism and western cultural hegemony.

Verdery continued this critique by posing the question 'What sort of variety is there, in fact, within the West?' (Verdery, cited in Asad et al, 1997, p. 717). She questioned whether in reality there is any overarching similarity across differing parts of Europe in terms of their politics, economic structures, divisions of labour, gendered roles and so on. She went on to critically ask whether by including 'supposedly characteristic features of an unexamined West, are anthropologists reinforcing ideologies we might wish instead to challenge?' In homologising the

diversity of cultural life in Europe under the umbrella of ‘the west’ anthropology may have inadvertently strengthened the global polarised dual-ideology that places Europe in a position of power. Ironically, as a discipline concerned with deconstructing hegemonies on power, anthropology may have been supporting exactly the ideologies it wished to deconstruct. In the decades since this debate began however, a rapidly growing body of European ethnography and critique has ultimately led to a questioning of these western ideologies, with the emergence of such initiatives as the ‘decolonizing’ of curriculums in western universities (see Mogstad and Tse, 2018).

Southern Europe, and Spain in particular, I argue is a particularly useful ethnographic site to explore in relation to this debate, as it occupies a kind of paradoxical position. Spain is at once a country that sits within the heart of western Europe, as an industrialised state, with one of the largest economies in the world, and one of its highest life expectancies. Yet, Spain presents a contradiction, as it is also frequently lambasted in mainstream discourse as being ‘slow’ and needing to ‘catch up’ with its western allies. Exoticising cultural stereotypes frequently construct images of Spanish people as unproductive, or even lazy. Such stereotypes also exist within Spain, but are applied to Andalusia specifically. Andalusia is frequently presented in mainstream national Spanish discourse as an underdeveloped, ‘backwards’ region that needs to play catch up with the rest of Spain. This conflating presentation of both Spain and Andalusia in popular cultural imagination make it a particularly interesting and useful site to further unpack this ‘west versus the rest’ dichotomy as it provides a point of contradiction. I hope that in revealing the everyday lived realities of life in *Pueblo*, and uncovering the interdependency of intergenerational family networks who are grappling with shifting ways of managing dementia care, that I can contribute to the ongoing dismantling of this problematic binary.

Andalusia, with its strong prioritisation of family life, robust intergenerational family networks, and emphasis on the importance of caring for older relatives within the family home, presents a contradiction to reductive understandings of the autonomous, individualistic western side of ‘the west versus the rest’ binary. I have so far outlined my definition of personhood in terms of its application to anthropology. What is missing however, is the highlighting of what dimensions personhood takes in *Pueblo* specifically. I will reveal this through the recounting of rich everyday ethnographic observations that make up this thesis; however, I foreshadow it with a summarised exploration of the specific form of personhood that I found to be present in *Pueblo*. In *Pueblo*, people are collectively and morally experienced to be persons through the continuous maintenance of deeply interdependent social interactions and relationships. This profoundly relational form of personhood is revealed through observing the intergenerational care-giving practices of families looking after relatives with dementia. These families engage in specific, carefully constructed care-

giving practices to ensure their loved one's interdependent personhood is maintained. In care institutions, this deeply interdependent personhood of *abuelos* is upheld through the maintenance of strong links to the wider community, in constructing deeply community-centred care practices, that celebrate this socio-relational understanding of relating oneself to others that dominates Andalusian cultural life. In presenting people's everyday lived experiences of dementia care I reveal a deeply interdependent, relational sense of personhood as existing in this western European cultural setting. I hope this thesis will thus continue to unpack this problematic binary that has historically dominated anthropological debates on personhood, and continues to play out ethnographically.

### *Cross-Cultural Examinations*

Geertz, in his landmark work that marked the turn towards interpretative anthropology, wrote 'it may be in the cultural particularities of people- in their oddities- that some of the most instructive revelations of what it is to be generically human are to be found' (Geertz, 1973, p. 43). By embarking on ethnographic explorations that reveal the diversity of human cultural life across the globe, anthropologists consistently seek out comparisons, and in doing so unearth similarities and shared understandings, positionalities, and motivations that cross cultural boundaries. This thesis is primarily an ethnographic exploration of the everyday lived experiences of people with dementia and their care-givers in the town I name *Pueblo* in Andalusia, Spain. However, it travels far beyond the craggy slopes of *Pueblo's* small community. Journeying into ethnographies from distant countries, such as India and Peru, I seek out useful cross-cultural comparison in works that also grapple with critical questions of personhood, dementia, kinship and care. The insights from these works have greatly aided and shaped my own thinking in relation to Andalusia. I lay out here how cross-cultural comparison works in this dissertation, and set out the rationale for it, as well as acknowledging this approach's limitations.

Cross-cultural comparison, I argue, is of particular relevance to this thesis due to the way it can address some of the problems discussed in the previous subsection around 'the west versus the rest' tension. This binary, despite having been long-debated and undermined in anthropological discussions, continued to play out ethnographically in Andalusia in relation to framings around medicine, social care, and notions of 'traditional' and 'modern' when people discussed dementia care. Part of the purpose of cross-cultural comparison in this thesis is thus to continue to unsettle this problematic binary. I do this through my portrayal of a deeply relational, interdependent personhood that I found to be present in Andalusia, that is maintained in persons with dementia through engagement in a profoundly socio-relational, *community-centred* care. In presenting

insights from ethnographic fieldwork in the western setting of Andalusia, and drawing comparisons of this data, to find similarities and shared understandings from ethnographic work in both 'western' and 'non-western' settings, I further challenge this problematic dichotomy. The thesis thus makes use of comparative material and cross-cultural ethnographic examples, drawn both from more 'proximate' contexts- of European and other 'western' settings- and less 'proximate' contexts- such as South Asia and other 'non-western' settings- in order to explore the capacity of an Andalusian ethnography to continue to challenge the 'west versus the rest' binary.

Using cross-cultural comparison has thus been deeply beneficial to this thesis, however, it is important to highlight some of the issues and limits of this technique. Degnen's (2018) work incorporated a wide-ranging selection of anthropological literature to explore conceptualisations of personhood and how it is (re)produced across differing cultural contexts and stages of the life course. In the introduction to her work, she engaged in a helpful discussion on the role and risks of cross-cultural comparison, warning of the ease with which one can slip into building 'a curio-cabinet with uncomfortable echoes of the armchair anthropologist' in drawing comparisons from distant ethnographic contexts (Degnen, 2018, p. 11). A way of avoiding this dilemma that she found helpful, was to contextualise the work of others. It is however, not possible, she warned, to ever portray the full richness of the original works when drawing comparisons. However, she explained how through incorporating these texts into her own work, readers could take her account as a 'spring board' into engaging directly with the original works themselves (Degnen, 2018, p. 11). I follow Degnen's (2018) approach in this thesis, and aim to always contextualise the ethnographic works which I draw comparisons to, and explain how they can aid my understanding and analysis of *Pueblo*, despite the geographical and cultural differences between them. I take care, however, not to generalise or universalise findings from diverse cultural contexts onto my interpretations of people's lived experiences in *Pueblo*.

## *Dementia*

Alarmist public health narratives around dementia emerged in the late 1970s when it was conceptualised as a dangerous disease that usually occurred in later life, rather than an inevitable effect of ageing. Such medicalising narratives enhanced dementia awareness, but, coupled with fears over population ageing, also stigmatised dementia by describing an impending crisis that could overwhelm public healthcare, justifying dementia's biomedical control (Ballenger, 2017). Foucault's [1963] (1975) 'clinical gaze' theory helps demonstrate how one externally recognised meaning of dementia was isolated, reducing the ageing body to biomedical explanations of brain dysfunction. Medicalising crisis narratives increased biomedical research funding, but neglected research into

dementia care (Ballenger, 2017). Public fears over ageing and dementia led to the 'successful ageing' paradigm mentioned above, that Lamb (2014) identified, whereby hard-work to follow biomedicine's recommendations on staying healthy was understood to stave off ageing's derogatory effects, thereby positioning dementia as a personal failure to 'age well'. Thus, medicalising alarmist narratives around dementia created fears of dementia as a disease that was understood as a public and personal health failure.

Such singular dementia understandings are also problematic as 'dementia' encompasses wide-ranging conditions. The World Health Organization describes dementia as 'a syndrome in which there is deterioration in memory, thinking, behaviour and the ability to perform everyday activities' (WHO, 2020). Alzheimer's Disease is the most common and contributes to 60-70% of cases, however, other forms include vascular, Lewy body, and frontotemporal dementia (ibid.). The singular crisis narrative of dementia as a disease thus obscures the variations under one label. Taylor (2008), an anthropologist who described caring for her own mother with dementia, critiqued how, by collapsing diverse conditions under the term 'dementia', a unilateral experience is projected. The dominating 'horror story' narrative is thus often understood as everybody's experience. Taylor described enjoyable moments shared with her mother since diagnosis, to contradict the horror stories people expected her to recount, thereby highlighting dementia's subjectivity. Through this ethnography I explore the diversity of dementia to help reveal the wide-ranging subjective experiences of dementia and its care.

Working against reductive narratives is critical anthropological research that attempts to deconstruct medicalising understandings of dementia through revealing cultural influences. Cohen's (1998) ethnography of dementia in India revealed how, rather than using biomedical language, dementia was constructed through social narratives around the decline of the joint family, embedded within the spiritual concept of *seva*, through which families understood care as a reciprocal loving act through dedicated compassionate service to elder kin. *Seva* was considered under threat through modernisation, resulting in elders' forgetfulness and confusion. Lamb's (2000) ethnography exploring ageing in India found similar narratives around the decline of *seva* with the entrance of western influences. Dementia was thus understood, rather than as a disease of the brain, as a disease of the family. Such critical anthropological ethnographies deconstructed medicalised dementia understandings to reveal how culture can shape people's understandings and experiences of dementia and its care.

Researching middle-class families in India, Brijnath's (2014) ethnography of dementia care found these critical narratives around modernity had reformulated. The language of globalisation,

biomedicine and modernity had been largely accepted, but indigenised into localised understandings of ageing, dementia and care. She demonstrated how medicalised explanations were mediated through local cultural understandings which shaped how society treated dementia. Yahalom (2019) through his ethnography of dementia care in Mexico similarly found medical definitions of dementia were filtered through cultural understandings, whereby ageing-related illnesses were understood as caused by new demands of the global economy and its influence on traditional patterns of family care. Acceptance of dementia as a disease existed in *Pueblo*; however, like previous works, I found how dementia and its care were interpreted was inherently shaped through place-specific cultural understandings and practices. In Andalusia a strong sense of duty to care for one's elders and interdependent kinship networks profoundly influenced local responses to social transformations. A demographically ageing population, with rising dementia rates, alongside women's increasing entrance into the labour-market, and economically unstable younger generations, interacted with an influx of international discourses around ageing, care and independence that shaped local conceptualisations of dementia care. This research will therefore contribute to debates exploring the complex ways through which medicalised conceptualisations of dementia as a disease are filtered through place-specific cultural contexts.

### *Personhood and Dementia*

Dementia questions reductive conceptualisations of personhood that centre around autonomous, cognitively-functioning persons as bounded, independent units. Post, in his reflective piece exploring dementia and personhood, posited the question 'Is my loved one still there under all of this confusion?' (Post, 2016, p. 48). Confusion, forgetfulness and apparent cognitive disorder challenge western 'hypercognitive values' (ibid., p. 151). Such hypercognitive values in western constructions of personhood situate the mind as 'the seat of the person' (Degnen, 2018, p. 153), and rationality as essential to personhood (Buch, 2015; Gjødsbøl and Svendsen, 2018). Western liberal values that prioritise independence and autonomy are also threatened through the dependency caused by dementia (Gjødsbøl and Svendsen, 2018). Dementia thus provides a critical example to investigate anthropological questions of dependency, personhood and relatedness. This research therefore helps to deconstruct problematic, reductive conceptualisations of western personhood using ethnographic insights of people's lived experiences of dementia, and dementia care-giving, to reveal the diverse reality of personhood as profoundly relational.

Conceptualisations of personhood that emphasise the importance of individualism, independence and autonomy thus dehumanise people with dementia through the devaluation of dependency. Kleinman explained how dementia in North America was seen as 'the final assault of

aging on the autonomy of the person' (Kleinman, 1988, pp. 25-26). This can be pointedly demonstrated through Degnen's highlighting of her observation of the expression 'losing one's self', used by her interlocutors in her ethnographic research in the North of England, to describe people who were showing signs of cognitive impairment (Degnen, 2018, p. 206). Understandings of people with dementia in western contexts are thus often framed around notions of people's sense of self, as a conscious, reflective, self-aware entity, being in jeopardy. Dementia can be understood in such contexts as standing in 'antithesis' to the successful ageing movement's objectives, which can even result in the person with dementia becoming a 'nonperson' (Leibing, 2017, p. 207). As Taylor highlighted, reflecting on her own lived experiences of looking after her mother with dementia, people asking her about her mother would enquire 'Does she recognize you?' when really, Taylor argued, the question should be 'Do you, do we, recognize *her*?' (Taylor, 2008, p. 315). Failure to accept cognitive diversity threatens recognition of more interdependent, relational personhood understandings. This thesis recognises the diversity of personhood that is experienced by people with dementia and their care-givers and how dependency connects to relatedness to expand on narrow constructions of western personhood as autonomous and individualistic.

'Person-centred care' is problematic when viewed anthropologically, as a contextual product that stipulates specific cultural meanings around personhood and independence. Leibing (2017) critiqued how researchers promoting the personhood movement in dementia emphasised *enduring* personhood, reifying nostalgic imaginings of people pre-dementia. It is worth noting here that the 'personhood movement' is sometimes used to refer to the person-centred care movement, so that it is not conflated with personhood debates in anthropology. Such emphasis on personhood as static and unchanging parallels the successful ageing paradigm's unrealistic promotion of 'permanent personhood' critiqued by Lamb (2014). This problematic understanding of personhood as static can be further critiqued using Degnen's (2018) extensive investigation of anthropological literature on personhood, that reveals the way personhood shifts and changes over the life course. Leibing advocated the need to also recognise negatively-perceived symptoms as part of personhood, thereby acknowledging 'needing care and providing care as central to many people's experience of what it is to be human' (Leibing, 2017, p. 214). Personhood as limited to the version of the person pre-dementia fails to recognise the reality of who the person is now, albeit contradictory to western values upholding cognitive functionality and autonomy. Researchers should thus avoid emphasising static or nostalgic imaginings of personhood in people with dementia, and instead recognise how all persons experience a shift in personhood as they age and move throughout differing stages of the life course.



Research recognising personhood within dementia in post-onset state can however be found through Kontos' (2005) notion of 'embodied selfhood'<sup>2</sup>. Through ethnographic research at a care home in Canada she observed how residents with advanced dementia continued expressing their unique selfhood through bodily expressiveness. This understanding of personhood as embodied enables recognition of personhood in those with advanced dementia who inevitably do not conform to social norms of self-expression. Rather than clinging onto a nostalgic vision of the person before dementia, taking an embodied approach to personhood embraces a more expansive definition that has space for the at times bizarre or nonsensical-seeming behaviours of people with advanced dementia. Further research embracing a diverse embodied personhood in people with dementia is Graham's (2015) analysis of 'wandering'. She critiqued medicalising interpretations of movements of people with dementia that explain such movements through cognitive malfunction, labelled as 'wandering'. She de-pathologised such interpretations to understand the tendency of some people with dementia to continuously walk as their 'intention to be alive and to grow' (Graham, 2015, p. 732), rather than disregarding them as a disease symptom. This embraces a more diverse, corporeal understanding of personhood.

Taylor's (2017) research is attentive to how dementia care-givers in North America embraced diverse forms of personhood in people with dementia, diverging from narrow personhood definitions. She highlighted how some people caring for friends with dementia used creative forms of expression, like art, to embrace their friends' dynamic embodied personhood. Using ethnography, I pay attention to the diversity of embodied personhood in people with dementia, observing how corporeal interactions express personhood. I use critical anthropological ethnography to reveal the diversity of people's embodied sense of personhood, that stretch beyond narrow ethnocentric definitions that necessitate cognitive functionality and independence.

Throughout this ethnography I demonstrate the intrinsically social, *relational* nature of personhood, from those with dementia and their care-givers, and explore how this transpires through community processes. Barlett and O'Connor (2010) advocated transforming personhood in dementia to 'citizenship' to challenge constructions of people living with dementia as passive care-recipients and instead recognise them as active agents. I apply this approach anthropologically to reveal how sociality and community processes, incorporated through diverse care strategies, deeply influence and reshape the personhood of people with dementia. Svendsen et al's (2018) research in a Danish care home observed how staff referred to people with dementia not as residents but

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<sup>2</sup> It is worth noting that Kontos (2005) appears to use 'selfhood' in reference to what I am referring to throughout this thesis as 'personhood'. My understanding of the term 'self' or of 'selfhood' refers to a conscious subjectivity, which does not appear to necessarily be present in the descriptions of the residents Kontos describes.

‘citizens’, because they were recognised as having contributed to the state through paying taxes throughout their lifetimes and thus were entitled to publicly funded long-term care. This shows how macro-community relations, in this case the state-to-citizen relationship, plays out in micro-communities such as dementia care institutions. Contrastingly, in *Pueblo*, staff at the care institutions would refer to older people as *abuelos* (grandparents) which emphasises the relationship of older people to their kinship networks, who are expected to take responsibility for their care, in a context of limited state support. This could be understood as a reflection of Andalusian society’s valuing of family relationships as a fundamental core of eldercare provision. These differing examples show how context and community play crucial roles in the construction of personhood through dementia care. Throughout this ethnography I emphasise the diverse ways through which social context and community processes influence how dementia care is experienced and thus advocate for a shift from person-centred to ‘community-centred’ explorations of dementia care.

This ethnography, as discussed in detail above, also helps deconstruct the dichotomy dividing western individualist versus non-western relational forms of personhood. By focusing on the western context of Andalusia, Spain, engaging in supposedly non-typically western forms of kinship dementia care to support interdependent personhood, this research inherently challenges this dichotomy and reveals the relational nature of all personhood. Through exploring dementia, a condition that challenges reductive, normalising westernised personhood conceptualisations, the profoundly human need to give and receive affection, concern, safety and love towards others is emphasised. This ethnography thus contributes to ongoing debates which recognise personhood as inherently relational. Furthermore, it demonstrates the way personhood as deeply social, is constructed through communities, the social processes of which vary across place-specific contexts. Recognising and embracing personhood as inherently relational is beneficial in reducing the counterproductive development of feelings of shame, burden or isolation by the focus of western healthcare narratives that emphasise the need for people to remain unachievably independent throughout ageing, or post-dementia onset (Buch, 2017; Lamb, 2014). This ethnography will thus continue to develop this progressive conceptualisation of personhood as relational that has already been engaged with by existing critical social researchers, by exploring social and collective processes as crucial components of community-centred dementia care. On a broader level it pushes medical anthropology’s focus from investigating the diversity of individual illness subjectivities onto critical explorations of how relational community practices shape collective approaches to personhood, illness and care.

## *Kinship*

During fieldwork, Paloma, a teacher in her mid-forties, showed me around her home in *Pueblo* where four generations of her family live together. She, her husband and daughter live upstairs, her mother and father on the middle floor, and her grandmother on the ground floor. This intergenerational co-residence facilitated care of Paloma's grandmother at home when she became dependent through dementia. Meanwhile, José was a retired olive farmer and shepherd in the early stages of Alzheimer's disease. When José's memory deteriorated his adult nieces and nephew organised for him to spend three-months in one of their homes before moving to the next and so on, enabling each of them to care for him. José's nieces and nephew explained this enabled them to care for José largely at home, but reduced responsibility as care was shared. These examples, discussed in chapter three, demonstrate how families negotiated strategies to ensure care was provided to relatives with dementia through kinship networks, and attest to kinship care values that still prevail in Andalusia.

Kinship is of long-established anthropological interest. However, focus on reproduction was critiqued from the 1990s onwards by anthropologists such as Carsten who advocated for a shift from kinship to relatedness (Carsten, 2000). Fixation on reproductive structures, Borneman criticised, 'subordinated what was human about kinship', avoiding deeper anthropological questions around what it means to be kin, to care and be cared for (Borneman, 2001, p. 49). I thus take kinship as encompassing, including connections, emotions and desires beyond reproduction to explore the human need to care and be cared for.

Emerging research into dementia care takes more encompassing approaches to kinship. Meher, Trnka and Dureau's (2017) ethnographic research at an Indian care home found carers of low caste, rather than approaching work as economic necessity, elevated its moral value. Carers understood work as *seva*, the sacred duty of selfless service to elders by younger kin. Despite lacking biological relationships, carers understood their role as fulfilling *seva*, therefore perceiving themselves as spiritual kin to care-receivers. I continue explorations of spiritual kinship care by exploring how *abuelos* constructed kin-like relationships towards *Pueblo's* Virgin Mary saints.

Exploring kinship through unpacking how people construct loving relationships positions kinship as enabling. As Ferguson (2013) found through his ethnography in South Africa, kin-dependence was understood positively as enabling social personhood through kinship and quasi-kinship dependencies. Key ethnographies already mentioned by Brijnath (2014), Lamb (2000) and Cohen (1998) revealed how dedicated eldercare was deeply valued within Indian kinship culture. Care for elder kin in Andalusia is understood through long-established imaginings of Mediterranean

culture as holding strong family values and pride in kinship reciprocity. In chapter four, I describe how middle-aged women acted as 'matriarchs of kinship care', proudly caring for dependent elder and younger kin.

Kinship as emotionally meaningful is dependent on subjective experiences. Leinaweaver's (2013) ethnography of eldercare in Peru revealed how choices over elderly relatives' care were framed around gratitude and ingratitude. Younger kin who felt elderly parents had granted them opportunities, like education, expressed gratitude through performing compassionate care to parents in older age. However, elders who had failed to provide opportunities to their children, as a way of expressing ingratitude were sent to care homes. This suggests kinship, rather than defined solely by reproduction, was formed through gratitude and love.

Care research has also revealed how kinship can be experienced within formal care. Ibarra (2013) observed how paid carers could form meaningful kin-like relationships towards those they cared for, particularly when the care-receiver's family was absent, as carers saw themselves as fulfilling kinship roles. I explore how intimate relationships developed between care staff and *abuelos* and how, for live-in carers, the intimacy of living together bonded them, with some migrant carers explaining how this could reduce social isolation and facilitate belonging.

The intimate and demanding nature of formal care work has also generated kinship amongst care workers. Fisher and Kang (2013) described how Filipino staff in a US care home created community and kinship. Difficulties working in the institutional care environment were compensated by the presence of other Filipino workers. The job's demands and long working-hours meant they got to know one another quickly and connected through shared cultural backgrounds, positioning them as family substitutes. Ibarra (2013) and Fisher and Kang (2013) also revealed how migrant carers would recommend biological kin for roles in their workplaces, so care settings frequently became occupied by actual kin as well as kin-like relationships developing between those non-biologically related. I discuss how belonging, community and kin-like relationships were experienced by formal carers in chapter seven.

It is reductive to understand kinship as entirely enabling. Kinship can also be profoundly restrictive, or used manipulatively to incite feelings of obligation and duty (De Neve, 2007). A tangible image of Mediterranean culture is globally romanticised as exhibiting strong family values, with imaginings of the extended loving family as a fundamental part of this. However, such romanticised imaginings can obscure or accelerate guilt and obligation felt by younger kin to provide unrealistic dedicated care to elder kin, to fulfil idealised fantasies around Mediterranean kinship. I thus explore too the restrictive and demanding expectations of kinship in *Pueblo*.

Restrictive kinship aspects are heavily influenced by gender. Brown (2013), investigating Brazilian 'Third Age' groups, found middle-aged women attending did so partly to maintain health so they could continue providing support towards frail kin. This was part of 'unwritten gender and kinship rules' that governed expectations around who should care for dependent kin (ibid., p. 130). Many kin experienced stress from care-giving, but continued framing their role through pride and desires to support family. This revealed how restrictive kinship elements are deeply influenced by gendered expectations, and are neither entirely restrictive nor enabling, but a nuanced mixture determined by subjective experiences. Reflecting this analysis, in chapter four, I explore how associations of kinship to care tie into ideas of maternal altruism. I depict narratives of middle-aged women in *Pueblo* who act as invincible 'matriarchs of kinship care', engaging in self-sacrificing caring practices to fulfil this gendered kinship role, which earns them respect across their kinship network. Kinship and its expectations are thus complex and cannot be defined as entirely enabling or restrictive.

Restrictive kinship is not only experienced by relatives. Formal carers experiencing kin-like relationships with those they care for can result in restrictive, demanding expectations. The expectation of care to be 'kin-like', exemplified in *Pueblo* by formal carers references to non-related care-receivers as *abuelos* (grandparents), could result in feelings of obligation to go above and beyond formal duties stipulated by their job role. Additional tasks during time off, such as taking calls from distressed *abuelos*, or visiting *abuelos* on their birthdays were examples of extra unpaid tasks formal carers reported. Although such interactions can be interpreted as genuinely caring, they also attest to how formal carers, through associations of care-giving with kinship, were expected to do more than the low pay the job stipulated. This demonstrates how formal care unravels complicated power webs, whereby financial elements mix with emotional, leaving care workers vulnerable to exploitation. Romanticising care as loving and 'kin-like' can thus obscure the capacity care has to exploit and restrict when enacted through emotive kinship narratives.

## *Care*

Anthropology is well-equipped to explore care as a complex social interaction influenced through context. Brijnath (2011) emphasised the importance of understanding contextual values around eldercare to facilitate culturally-appropriate dementia care models. Cross-cultural analysis can uncover alternative approaches to dementia, ageing and care, whilst revealing wider insights into the contexts investigated. As Buch's review of anthropological research into ageing and care concluded, eldercare research goes beyond older people's lives to investigate 'the diverse ways that

increased longevity is shaping the meanings, experiences, and consequences of life itself' (2015, p. 277). Anthropology, attentive to cultural differences through ethnography, uncovers a 'polysemic understanding of care' (ibid.).

Duclos and Sánchez-Criado (2019) advocated critical care research that makes visible the contradictory realities of care. A dementia care-giver can be 'doctor, nurse, beautician, lover' (Brijnath and Manderson, 2008, p. 608), care-giving's multiple aspects cause complex disjunctions in experiences. Meanings can also transform, as Lamb revealed in her analysis of kinship eldercare in modern-day India. *Seva* is understood as both 'wonderful, natural, intimate, Indian', yet simultaneously 'disintegrating, uncertain and, perhaps, even backward' (Lamb, 2013, p. 69). Through ethnographic exploration of everyday dementia care practices in *Pueblo I* uncover complex, contradictory and fluctuating care meanings.

Care as fundamental to human existence connects to wider questions around personhood and morality. Degnen (2018), through her exploration of the shifting nature of personhood across the life course, explained how personhood is something that needs to be worked at, maintained and protected. She went on to explain how people with dementia might be reframed through drawing on 'notions of personhood as social, as distributed in wider networks of family, friends' (Degnen, 2018, p. 209). External persons, including family, friends and formal carers thus can have an integral role to play in working at maintaining personhood in people with dementia. Svendsen et al's (2018) ethnographic research in a dementia nursing home in Denmark supports this. They analysed how, by keeping entirely dependent, non-self-regulating people with advanced dementia alive, care home staff were 'crafting worth and personhood for uncommon persons' (Svendsen et al, 2018, p. 21). Care for people with advanced dementia thus raises philosophical questions around existence, leading care to be framed as profoundly *moral*. As Kleinman stated 'Caregiving is one of the foundational moral meanings and practices in human experience' (2012, p. 1550). Mattingly's (2010; 2014) research of families caring for sick children uncovered how unforeseen illness presented families with 'ongoing moral deliberations' (Mattingly, 2014, p. 4). She portrayed how families engaging in care became experimenters in how to maintain moral selves through unpredictable circumstances, explaining deliberations through the metaphor of practicing care within 'moral laboratories'. Taylor (2017) applied Mattingly's theory to investigate people engaging with people with dementia through art who sought imaginative sensory forms of relating, demonstrating how people experimented within 'moral laboratories' of care. This ethnography continues explorations of the 'moral laboratories' that dementia care-givers navigate, exploring how care-givers developed

creative care strategies, intricately incorporating cultural components, such as using community religious rituals, to promote connection.

Care-givers' narratives often use morality to express pride through care. Meher, Trnka and Dureau (2017) explained how formal carers in India, constructed their role as moral through *seva*. Meanwhile, Brown's (2013) research with care-givers to elderly relatives in Brazil found women prided themselves in busyness, emphasising how the care-giving's demanding nature constructed them as self-sacrificing, compassionate and proud kin. Understanding care-giving as moral may be fundamentally tied into feelings of love and pride for the person being cared for. Such narratives of pride however are threatened through stigma surrounding care-giving. Brijnath and Manderson (2008) highlighted how family dementia care-givers in India had to discipline the uncontrollable demented body to protect the wider body of society from dementia care realities. Care work, associated with 'dirt, death and sex' (Fisher and Kang, 2013, p. 169) carries social stigma, influencing the poor working conditions of formal carers and the lack of state support for family care-givers. The association of care work with intimacy and dirt also feminises care as women's work (Twigg, 2000).

This ethnography begins investigation into non-human and spiritual aspects of dementia care which remain largely unexplored. Social research has begun exploring how everyday material objects are used in dementia care. The sensory nature of care that depends on materiality has been demonstrated by research such as Pink, Morgan and Dainty (2014) who revealed how care workers learn care through 'tactile knowing' in handling everyday objects. Twigg and Buse (2018) explored how the materiality of clothing and dressing can enable and constrain dementia care. Research into spiritual objects' materiality in dementia care remains unexplored, however. Given the latter life stage of most people with dementia, it raises critical questions around life, death and the afterlife, and it is thus important spirituality in dementia care is explored. In chapter five, I reveal how spiritual objects shape dementia care strategies in *Pueblo*. I highlight how Virgin Mary saint statues, and their diverse material representations- images, trinkets and other objects- provide spiritual comfort and care to *abuelos* with dementia. The ubiquitousness of the religious symbols these objects represent, combined with their tactile materiality, provided therapeutic dementia care tools. This research thus continues novel explorations into material aspects of dementia care, opening explorations of the non-human and spiritual elements of materiality and how this shapes care meanings.

Emphasis on 'person-centred care' through individualist personhood conceptualisations, may inadvertently have neglected research into how community influences dementia care. Clarke and Bailey (2016) explored the impact of place on dementia care experience, finding place familiarity

to be supportive, and thus advocating explorations of how community interacts with dementia care. Barlett and O'Connor's (2010) advocacy of 'citizenship' in people with dementia, aimed to capture dementia care's 'community spirit'. My ethnography explores how community, belonging and social collectivity influence people's subjective experiences of dementia care. I reveal how *Pueblo's* collective religious rituals were deliberately incorporated into dementia care and reveal how its care institutions formed integral parts of its wider community, yet also provided micro-communities for *abuelos* living within them. Building on Barlett and O'Connor's (2010) conceptualisation of 'citizenship' in dementia care, this ethnography takes an anthropological approach by exploring collective cultural practices, sociality, and belonging to begin explorations of dementia care that are not just person-centred but 'community-centred'. In the following section, I investigate the concept of 'belonging', which plays a critical role in constructing the community-centred care that I observed in *Pueblo*.

### *Belonging*

*'Aquí me siento como en casa'* ('I feel like I'm at home here'), Esperanza, an *abuela* in her eighties, described how she felt about living in *Pueblo's* care home. She recounted how, although she still sometimes missed her old '*casa*' ('house/home') in town, she now felt 'at home' in the care home. Many *abuelos* at the care home did not share Esperanza's feelings, and complained of an intense and constant longing for their old '*casa*'. Yet, what does it mean to feel 'at home'? This question dives straight into the heart of a critical concept this thesis grapples with – belonging. In moving away from their long-term homes into formal care institutions, *abuelos* were confronted with new struggles for belonging, but, what does it mean to belong? Why is belonging important to *abuelos* in *Pueblo*? And, what can belonging help us learn about dementia care in this context?

The concept of belonging in anthropology and the wider social sciences, despite being frequently referred to, has been neglected by theoretical scrutiny. Bissell et al, exploring questions of belonging, described it as a 'shadow concept, always present, but dominated by other concepts which have arguably received more sustained analytical treatment' (Bissell et al, 2019, p. 2). May's book, investigating belonging in relation to social change, similarly describes belonging in the social sciences as 'ubiquitous' yet 'curiously undertheorized' (May, 2013, p. 3). The lack of analytical work around belonging may be partly due to its ambiguous nature, as it appears to have multiple, contradictory meanings. Wright's ontological analysis of belonging, highlighted the contradictory nature of the concept, that is 'at once emotional and political and personal and societal' (Wright, 2015, p. 400). Belonging thus appears to be a slippery concept, widely referred to in the social sciences, and possessing a multitude of meanings, yet lacking, as Miller, in her philosophical exploration of the concept critiqued, 'a conceptual apparatus' (Miller, 2003, p. 216). It is therefore



critical that I lay out what I mean by belonging, what it means to *abuelos* and others in *Pueblo*, and how it can deepen understandings of dementia care in this context, particularly in relation to my call to recognise care as community-centred.

The theoretical murkiness and taken-for-granted nature of belonging make ethnography a useful tool to unpack it. Belonging, unlike dementia, personhood, kinship and care, was not a concept I had set out to explore. I did not directly ask *abuelos* about belonging, but noticed its importance as I engaged myself in people's everyday lives in *Pueblo*. Belonging seemed to have a profound impact on how people constructed and experienced dementia care. Bennett (2014), argued that using phenomenological approaches to study belonging was important due to its intangible nature. Such approaches, she claimed, unlock 'sideways perspectives', to investigate the unconscious ways that people 'do' belonging (Bennett, 2014, p. 7). Thus, through embedding myself into people's everyday lives and care routines in *Pueblo*, ethnography allowed me to uncover the ways in which people 'do belonging' in *Pueblo*, and how care practices could both constitute and restrict belonging.

Belonging in *Pueblo*, in one way, was experienced as a feeling, described as '*estar en casa*' ('being at home'). The home (*casa*) is deeply significant in Andalusian culture. Despite the sociability of people on the street in *Pueblo*, there was a marked privacy around people's homes. Most social activities would take place in public places and houses were generally seen as private and usually only accessed by family. This privacy around the house constituted a strong private/public dichotomy which has been found to be present in other Mediterranean societies, such as shown within Dubisch's (1986) ethnographic work in rural Greece. When discussing future care arrangements for older relatives, people would often comment '*no hay ningún sitio como tu casa*', reflecting the English 'there's no place like home', to justify the need to arrange complex rotational care strategies, whereby relatives took turns spending months living in older relatives' homes to avoid them having to be moved into care institutions. *Abuelos* frequently spoke about missing their old '*casa*' ('house/home'), and expressed concern about what was happening to it, and whether it was being cleaned and maintained whilst they were in the care home. Comparisons were frequently made between the care home and their old houses. *Abuelos* complained about the noise at the care home, and contrasted it to the quiet setting of their house. Others, who disliked the food served at the care home, would comment that it was not as good as the food they used to have at home. Given that houses in *Pueblo* were predominantly only accessed by family, this missing of the physical house may have alluded to a longing for family. It appears then that '*casa*' ('house/home'), and a feeling of being '*en casa*' ('at home') were an important part of belonging in *abuelos*.

It was however, a *feeling* of being at home, rather than needing to be in a specific physical place that appeared to constitute belonging in *abuelos*. Esperanza, in describing '*Aquí me siento como en casa*' ('I feel like I'm at home here'), was praising the care home as giving her a feeling of being '*como*' ('like') at home, but was still not claiming the care home as her home. Wright (2015) explained how phrases such as 'sense of belonging' and 'feeling of belonging' are the most ubiquitous uses of belonging, and emphasise its emotional aspect as a feeling. Antonsich (2010), reviewing academic work on belonging, highlighted how scholars have neglected to analyse belonging as a *feeling* of being 'at home', in favour of mobilising belonging as a form of collective identity. He emphasised that belonging is first and foremost 'a personal, intimate feeling of being 'at home' in a place' (Antonsich, 2010, p. 652). This feeling of being 'at home' appears to have positive emotional effects, and Miller (2003) linked belonging to a sense of wellbeing. In chapter seven, I explore how staff at the care home deliberately engaged in care practices that attempted to harness this feeling of being 'at home' as a way of generating wellbeing in *abuelos*. For example, in early autumn, the head chef helped *abuelos* to make *migas*, a heavy bread-based dish that was typically made at the start of the olive harvest, and *abuelos* recounted memories of cooking *migas* at home with their families during the harvest. Some *abuelos* with dementia who were unable to recall short-term memories, through the smell of cooking *migas*, were triggered into recalling long-term memories. The use of this familiar, everyday activity, that *abuelos* associated with home and family was thus deliberately harnessed by the care home to constitute this feeling of being 'at home' in *abuelos*, including those with dementia. An emotional, intimate *feeling* of being 'at home' thus appeared to constitute belonging for *abuelos* in *Pueblo's* care home.

This emotional feeling, or sense, of belonging has been analysed as also linking to a deeply relational sense of personhood, through enabling a feeling of connecting with others. As Antonsich highlighted, 'to feel at home in a place is not just a personal matter, but also a social one' (Antonsich, 2010, p. 649). Belonging in *Pueblo* was also experienced collectively, as a way of connecting to others, which in turn maintained the relational, interdependent personhood that I identify as present in Andalusia. May's (2013) work explores the relationship of belonging to self and society. She explained how belonging is of fundamental importance to the self, as we consciously understand who we are through the places and people with whom we belong. May takes a relational view of the self which emerges through relationships with others, and she thus explains how an individual sense of belonging is 'collectively negotiated' through mutual understandings of who counts as 'we' and what this 'we' stands for (May, 2013, p. 13). As discussed earlier in the literature review, she finds belonging a more helpful theoretical tool than 'identity', as identity focuses on the autonomous individual, whereas belonging focuses on what connects people to one another.

Gammeltoft (2018) used ethnographic case studies of two women in Vietnam going through extremely difficult personal situations to show how people use belonging to help them find stability and meaning in times of crisis. Belonging helped these women navigate the difficult situations they found themselves in by encouraging them to seek the help and guidance of those close to them. The women desired belonging as they wanted to remain tied into their existing 'social webs' as they offered them 'a sense of meaning and direction' which enabled them 'to be someone' (Gammeltoft, 2018, p. 91). By belonging to 'social memberships' through connecting with others, people can thus construct their own selves (ibid., p. 89). In chapter seven, I explore how interactions between *abuelos* in the care home allow them to generate a sense of solidarity and belonging with one another which gives them a renewed sense of purpose, enabling them to manage the challenges of their new lives by re-creating community in the care home. I portray, for example, how community meetings held at the care home, provide a space for *abuelos* to voice their concerns and desires for change, and tie them into the social fabric of the care home, to connect with others and generate belonging. Through such social interactions, *abuelos* living at the care home generated a feeling of community, which aided in the maintenance of relationships and the relational, interdependent personhood that existed in *Pueblo*. Belonging in *Pueblo* was thus also a way through which people could connect with others, which strengthened the relational, interdependent sense of personhood that existed in Andalusia.

Belonging goes beyond connecting with people, but also constitutes connecting to places and material objects. May (2013) explained how the connections between people, places and material objects that occur through belonging overlap and interlock to play into our sense of self. These insights are reflected in Edwards' (1998) ethnographic work, based in a post-industrial town in the north-west of England, where she explored how belonging to the town was generated through a diversity of attachments that included links to people as well as things and places. In chapter five, I portrayed the deep comfort that appeared to be gained by *abuelos* from their interactions with *Pueblo's* municipal Virgin Mary statues and other objects that represented these. *Abuelos* would speak to, touch and kiss these objects to gain spiritual protection, and generate interdependent relationships. Each of *Pueblo's* two neighbourhoods had their own Virgin Mary saint statue and *abuelos* in the care home would decorate their bedrooms with photos and trinkets relating to the statue from their own neighbourhood. In doing so, they reaffirmed their commitment and belonging to their neighbourhood, which provided them with comfort and stability whilst they adjusted to their new life in the care home. I also described how *Pueblo's* municipal fiestas were carefully incorporated into care practices at *Pueblo's* care institutions, enabling *abuelos* to actively participate in these rituals which reaffirmed their community membership and strengthened their sense of

belonging to the wider community. The incorporation of these municipal rituals into institutional dementia care practices highlights the central insight of this thesis of the need to move away from a focus on individual, person-centred approaches to dementia care towards investigations of dementia care as community-centred. Understanding belonging as connecting people to other people, places and material objects that embed them into their local context makes it a useful concept to explore in terms of making care community-centred. Opening up explorations of belonging are therefore critically helpful in working towards investigations of dementia care as community-centred.

Exploring the careful ways that care institutions deliberately incorporated certain practices into their care routines to facilitate belonging and a community-centred care highlights how belonging can be strategically constructed. As Bissell et al raised in their discussion of belonging, ‘belonging...is not a given, but requires work’ (Bissell et al, 2019, p. 4). This perspective is supported by Miller’s analysis of belonging, who explained belonging as ‘something we must create for ourselves’ (Miller, 2003, p. 223). Understanding belonging as something that requires effort, and can be constituted, is useful in analysing the actions of care institutions and care-givers in *Pueblo*. In chapters three and five, I discuss the case of Ana, who cares for her elderly mother with dementia through a rotational pattern of care she shares with her sisters. Ana described how, despite her mother’s lack of ability to verbally communicate, she would recount to her family events, pin up *Pueblo*’s calendar on her bedroom wall, and listen to the devotional songs sung to their neighbourhood’s Virgin Mary saint during the *fiestas*. These practices were specific to their neighbourhood and their family, and were ways through which Ana appeared to be attempting to nurture belonging in her mother. Ana fervently explained to me how, despite the lack of verbal communication from her mother, she truly believed her mother knew what was going on around her, describing how her mother would look more alert and move her lips during the devotional songs sung during the *fiestas*. Belonging can thus be deliberately harnessed by care-givers towards people with dementia, to try and draw out their deeply-rooted connections to people, places and things.

One of the ways through which I observed belonging to be substantiated in *Pueblo* was through the collective performance of religious ritual. Wright, in her analysis of belonging emphasised the importance of understanding belonging as a ‘process’ which includes ‘performances of belonging’ that actively create belonging (Wright, 2015, p. 392). In chapter five, I analyse *Pueblo*’s collective religious rituals and the ways through which these foster belonging in *abuelos*. I describe how during the *fiestas* held in honour of the Virgin Mary saints, there is a huge procession which parades through the streets of *Pueblo*. People dress in religious costume, a marching band plays

music, and incense is wafted into the crowd, whilst the Virgin Mary statue is carried on a large ornate processional float. The processional route makes specific stops at the care home and on the street where the day centre is located, to incorporate the care institutions into these rituals. As I described at the opening of this chapter, *abuelos* at the care home who are able to, are accompanied by staff to sit or stand outside the care home and await the arrival of the Virgin saint statue. This highly sensorial, collective ritual performance, that uses objects, music and people dressed in costume that play into *Pueblo's* collective spiritual identity, form a way through which social solidarity and belonging is substantiated. This sense of belonging is tuned into by residents in *Pueblo* of all different ages. However, I argue it has particularly impactful meaning on *abuelos* who may be struggling to adjust to their new lives in the care institutions or experiencing social isolation or rupture to their sense of belonging by the change to their daily environment. By participating actively in these community rituals, *abuelos* were able to experience a strong sense of belonging to *Pueblo* and be reaffirmed as community-members. Such engagement in collective ritual performance, highlights the value of approaching elder and dementia care as community-centred and opens up the need to explore the differing ways ritual performance can be harnessed as a way of constructing community-centred dementia care.

Finally, it is important to discuss belonging in relation to power. Although I have highlighted how belonging can be actively constituted, and harnessed for the benefit of those who experience it, it can also be forcefully restricted. Belonging, through being inclusive and welcoming to those who experience it, inevitably can be exclusive and hostile to those who do not. Antonsich highlighted how belonging is unavoidably conditioned by power relations, and that in spite of belonging on one level being experienced as an 'intimate feeling' of being 'at home' in a place' also acts as a 'discursive resource that constructs, claims, justifies, or resists forms of socio-spatial inclusion/exclusion' (Antonsich, 2010, p. 644). He drew attention to Probyn's (1996) notion of 'longing' to raise the inevitable existence alongside belonging of 'not-belonging' (Probyn, 1996, cited in Antonsich, 2010, p. 652). *Abuelos* telling of a profound longing for their old '*casa*' ('house/home') and old daily routines were commonplace in both *Pueblo's* care home and day centre.

In chapter six, I explore how care practices used in *Pueblo's* care institutions, such as the activities groups, were at once harnessing this sense of belonging in *abuelos* who engaged with them, whilst also excluding others based on their gender, class or cognitive status. I describe how the regular activities groups were suspended for many weeks in the run up to the care home's Christmas play. This event was open to the wider public, as well as being broadcast on the local municipal TV station. This engagement with the wider public in an annual religious ritual, could be regarded as an example of fostering belonging in *abuelos* to create a care that was community-

centred. On the other hand, the majority of the care home's residents were excluded from participating in this play, with only highly cognitively functioning *abuelos* permitted to participate and thus the play could be seen as deeply exclusionary. Wright highlighted how there are 'myriad ways to not belong' (Wright, 2015, p. 395). I include a multitude of examples of the ways in which formal care practices could restrict belonging in *abuelos* in *Pueblo's* care institutions. The cognitive exercises, for example, which I analyse in chapter six, clashed against the worldviews, backgrounds and class dispositions of many of the *abuelos* being made to engage in them, leading them to experience feelings of boredom, frustration or even distress. It is important that in exploring belonging, and the ways that a sense of belonging can be constituted, I also explore the ways through which belonging in *Pueblo* was subjected to power conditions and could act as a restrictive force that repressed and excluded.

In summary, belonging is a theoretically murky concept that is often taken-for-granted and thus, benefits from close-up, ethnographic investigation. In Andalusia and *Pueblo*, the importance, and intimacy of the '*casa*' ('house/home') shapes the way belonging is constituted. Belonging is experienced as a deeply intimate feeling of being 'at home'. Belonging is a process that also involves the social connecting of people to one another and is critical to the sense of interdependent, relational personhood that exists in *Pueblo*. Belonging is however, not only formed through people's connections to others, but is also constituted through a multitude of interlocking connections to things and places. Belonging can be actively constituted, and this thesis explores the diverse ways that elder and dementia care practices attempt to harness belonging in *abuelos*. This thesis also analyses how collective religious rituals are used to create 'performances of belonging'. Such analysis helps demonstrate the importance of investigating dementia care as community-centred. However, inevitably where there is belonging there is also 'not-belonging', and I have also highlighted how belonging is constituted through power relations and can also be experienced as restrictive.

Emphasising sociality, community and belonging in dementia care ultimately attends to the overarching emphasis of this thesis that dementia care is a deeply *social* and *relational* practice that must be explored through a community-centred focus. Dementia care cannot be reduced to purely medicalised understandings but must be explored through people's subjective lived experiences to reveal the intimate, interconnecting, relational care foundations within particular cultural contexts. Care practices reveal the fundamental sociality and interdependence of humankind. This ethnography journeys through the everyday interactions of subjective dementia care experiences in *Pueblo*, displaying how care is not just person-centred but profoundly community-centred, to reveal

how care is an inherently relational practice that demonstrates human desire to connect with others.

## Overview of Chapters

The following chapter outlines historical context, methods and ethical considerations. I parallel how memories link to personhood in dementia care, by revealing how collective memories shape Andalusia's contested history. I uncover how regional oppression from central state generated community solidarity and family interdependence, influencing Andalusia's approach to dementia care. A traditional moral duty for younger kin to care for elders is shifting alongside social changes, resulting in increasing demands for state-funded care. The methods section describes how I conducted fieldwork in *Pueblo* and established roles within healthcare settings and family homes. I also uncover ethical challenges encountered whilst researching.

Chapter three portrays how intergenerational kinship networks in Andalusia were central to people's construction of a deeply interdependent personhood that shaped dementia care strategies. It describes intergenerational co-residences in *Pueblo* which facilitated shared dementia care across family networks. I introduce local families, outlining how, acting through interdependent personhood, they engaged in complex patterns of rotational care to enable relatives with dementia to remain at home. I discuss how local attitudes towards formal care shift alongside social transformations, with people increasingly demanding state-funded care. I present *Pueblo's* day centre, highlighting how families understand it as '*un punto medio*' ('a midpoint/compromise'). I also uncover how, due to state failings to provide adequate care, families privately hire low-paid women migrants as live-in carers to enable relatives with dementia to remain at home.

Chapter four uncovers how dementia care in Andalusia is gendered. Understandings of dementia care as dirty and intimate construct it as feminine. I portray the intimacy of dementia care through care-givers' narratives and my experiences care-giving in *Pueblo*. This leads into discussion of how sexuality can enable dementia care, yet also be dehumanising. Dementia care's bodily nature, as dirty, intimate and sexualised is constructed as feminine work that must be kept invisible. The chapter also illustrates how middle-aged Andalusian women, sandwiched between younger and older generations, become invincible matriarchs of kinship care. I reveal local women's narratives, displaying the overload caused by this demanding responsibility, yet how, in spite of challenges, women attach profound value to this role at the centre of kinship networks, describing their care-giving practices as acts of love that bind families together.

Spiritual aspects of dementia care are explored in chapter five. I uncover how devotional practices towards *Pueblo's* Virgin Mary statues generate personhood, positioning them as spiritual interdependent kin who protect people with dementia. The religious symbolism evoked provides reassurance and companionship to people with dementia as end-of-life approaches. I describe how the statues are animated during *Pueblo's* religious *fiestas*, stimulating social cohesion and intergenerational solidarity whilst marking the town as spiritually protected, and providing a reassuring sense of belonging to people with dementia. Multisensorial collective engagement in ritual generates liminal states, whereby embodied memories are reawakened in people with dementia, transporting them into the present, whilst linking them to their community's shared past. This emphasises the need for 'community-centred' dementia care explorations.

Chapter six opens the doors of *Pueblo's* care institutions, revealing the complex power relations lying within them. It uncovers how sense of belonging from *abuelos* living within these institutions is influenced by physical environments. It also investigates how working conditions within these institutions devalue care as a profession. This leads into a portrayal of abusive care-giving practices witnessed in these institutions, including restraint-use on *abuelos* with dementia; impinging on their personhood and increasing risk of harm. It then explores how activity routines within these institutions can empower and disempower. I analyse how cognitive exercises subscribe to Euro-American notions of hard-work sustaining individualist personhood, which, when implemented in *Pueblo's* care institutions, clash with local understandings of ageing and personhood, under which older people's forgetfulness has always been managed through interdependency.

Chapter seven examines how, as dementia care formalises in Andalusia, people strive to (re)create kinship and solidarity to find meaningful connections through community-centred care. It unpacks how community-making processes within *Pueblo's* care institutions generate solidarity amongst *abuelos*, who support one another; exerting agency to become active citizens of care institutions. Care institutions in *Pueblo*, rather than being isolated, are permeable sites, that hold central places in its community, ensuring *abuelos* maintain their sense of belonging to the town. It also explores how dementia, gender and class intersect with feelings of community and belonging. Sense of community and belonging are also experienced by care workers, who despite demanding conditions, strive to generate solidarity. This solidarity is felt particularly strongly amongst migrant care workers, who (re)create a sense of belonging in Andalusia. I also reveal the deeply felt emotions experienced by formal carers towards those they cared for; stretching beyond professional boundaries to form kin-like connections.



## Chapter Two: Historical Context, Methods and Ethical Considerations

This chapter explores the historical context, methods and ethical considerations of this ethnography. It begins by discussing memory and personhood in dementia care and paralleling this to Spain and Andalusia's contested historical memories. Transitioning into democracy, Spain's government actively forgot its turbulent history. Andalusia, a historically socialist region, suffered violent oppression through the civil war and resulting thirty-six-year dictatorship. Regional oppression caused an embedded distrust of central state; resulting in autonomy and dependence on family and local community, which influences a moral duty to care for family through kinship elder and dementia care. Existing research demonstrates the high presence of intergenerational households, kinship eldercare and anti-institutionalisation discourses in Andalusia. Care is however shifting alongside social changes; demographically ageing populations and women's increasing labour-market participation combine with the influx of rich northern Europeans in Andalusia using professional eldercare services to shift people's attitudes towards formal eldercare, although the 2008 economic crisis has re-strengthened family dependence. The methods section describes how I conducted fieldwork. I established active roles through my engagement in a day centre, care home and carers' support group; aided through my occupational therapy professional identity. I also participated in care routines of local families supporting people with dementia, taking an empathetic approach to enable informants to share care narratives. Finally, I reveal ethical issues I encountered throughout fieldwork, concluding that the most effective way to ensure ethical health is through ongoing, iterative, critical reflection.

### Historical Context

Throughout this thesis I explore how individual and collective memories influence identity and personhood in dementia care. I use this as a parallel to explore how Spain and Andalusia's historical memories shape development of nation and region-hood, and influence dementia care approaches. I describe how the central Spanish government, transitioning into democracy post-dictatorship, actively forgot its traumatic history. Andalusia, an agricultural region with deep-seated inequality, developed class consciousness throughout the nineteenth-century, leading to regional oppression against Andalusia from far-right Francoist forces during the civil war and resulting thirty-six-year dictatorship. *Pueblo*, like municipalities across rural Andalusia, continued resisting Francoist forces throughout the war and dictatorship. Attempts are now being made to remember past atrocities of the war and dictatorship, resulting in local contestations around Andalusia's history. I explore how this history has created a deeply embedded mistrust of central state from Andalusian people and a turn towards reliance on family networks and local communities over the state.

I outline how family interdependence influences a strong sense of moral duty to care for elderly kin. Existing research highlights Spain's continuing dependence on family for dementia and eldercare, with intergenerational households and anti-institutionalisation discourses prevailing. However, care culture is shifting in response to social changes. Demographically ageing populations with increasing dementia rates, women's growing labour-market participation and the arrival of wealthy northern Europeans settling in Andalusia using professional care services, are changing attitudes towards dementia and eldercare, with more demands on the state to provide care. However, this was slowed by the 2008 economic crisis and resulting mass unemployment which

prompted cuts to state-provided care, resulting in a re-strengthening of Andalusian ties to the kinship network.

### *Contested Memories in Spain and Andalusia*

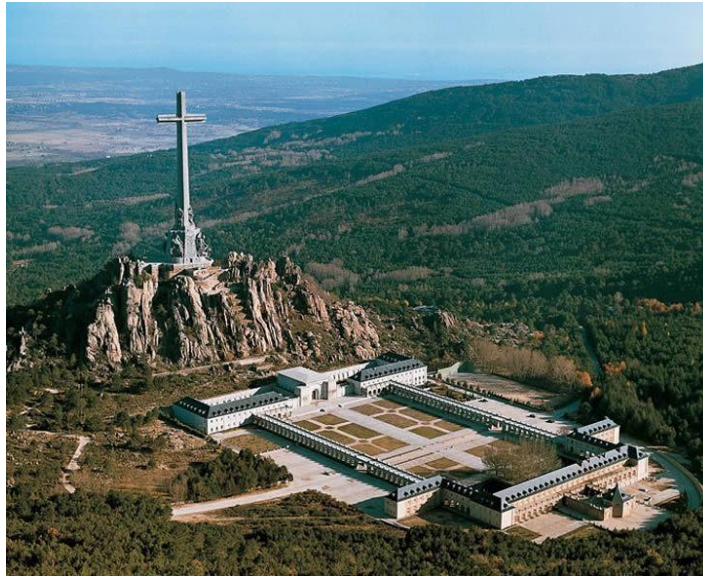
Families caring for loved ones with dementia in *Pueblo* would cite their relative's memories of the long-time past as evidence of them still 'being themselves', despite short-term forgetfulness. When longer-term memories faded, families recounted their own memories of their relative before dementia onset, as though this recalling maintained their relative's old self. Memory has a profound influence on identity and personhood. Whilst I observed individual memory influencing identity for families living with dementia, collective memory played a parallel role in developing national and regional identities in Spain and Andalusia.

During fieldwork in 2019, a tumultuous event in Spain's modern history occurred: the exhumation of its thirty-six year-long dictator, Francisco Franco's tomb. This highly publicised event displayed how local historical memories were contested. Chatting to care home residents in the days prior to the planned exhumation revealed political tensions underlying contrasting historical memories:

'It's tampering with bodies, it's disgusting' one *abuelo* remarked angrily, 'Franco did a lot for Spain, we wouldn't be where we are today if it wasn't for him.'

'But it's the Valley of the Fallen! It's for people who died during the war! He didn't die in the war! He *caused* the war!' someone responded firmly.

Franco's body was buried at *El Valle de los Caídos* (The Valley of the Fallen), a vast war memorial exhibiting a 150-metre-high cross (see figure 1). Franco ordered its construction, largely by defeated republican prisoners, to immortalise his civil war victory. The exhumation was resisted by Franco supporters, resulting in a supreme court legal battle. It was not until October 2019, forty-four years after his death, that Franco's tomb was finally exhumed from this grand memorial (Junquera and Cué, 2019). The conflicts this event unearthed provide a striking example of Spain's contested historical memory.



*Figure 1. El Valle de Los Caídos.*

Spain, holds the global status of a ‘westernised’ democratic country, entrenched within advanced processes of economy, politics, media and technology. Yet one does not have to look far into its past to see civil war, autarky and dictatorship. The 1936-1939 civil war resulted in thirty-six years of dictatorship under Franco, who was never politically overthrown, only ending when he died of natural causes in 1975, and remains an ‘uncomfortable spectre of the past’ (Moradiellos, 2018, p. 6). Spain’s transition from dictatorship into democracy was undertaken through ‘the pact of forgetting’ (Tremlett, 2006, p. 10), whereby Spain’s turbulent history was intentionally forgotten. Spanish institutions disregarded historical memory in its democratic transition, unlike other European countries which had experienced fascism and ensured transition was public (Besier and Stoklosa, 2013). Tremlett explained how Spain instead wore a ‘cloak of silence’ to enter democracy, whereby the civil war and Francoism became unmentionable (2006, p. 7). He suggested this was because many involved in democratic transition had Francoist backgrounds they wished to hide, and for fears of past divisions returning.

It was not until decades later that remembering Spain’s forgotten past began. Families who had lost loved ones under Franco’s regime publicly called to exhume mass graves of the dictatorship’s victims. Sites celebrating Franco’s regime were renamed. Legal cases were fought to clear victims’ names. Efforts culminated in a 2004 decree facilitating the moral and legal rehabilitation of victims of Franco’s regime (Mallinder, 2008). Unbuttoning the cloak of silence through remembering Spain’s past was however riddled with contestations. Although recognition of the repression of Franco’s dictatorship is more widely accepted, many still contest it, claiming leftist extremism provoked the war and that Franco ‘saved Spain’ (Tremlett, 2006, p. 11).

Conflicts around historical memories contribute to Spain's cultural dynamism. The country has been described as a 'little continent', due to the 'deep economic, social, and cultural differences' between its regions (Cazorla, 2010, p. 7). Following Franco's death, the 1978 Constitution reinstating democracy was written. This recognised regional differences through forming autonomous communities which were granted political and administrative control, enabling some regional self-governance (Casanova, Lamura and Principi, 2017). This ethnography focuses on *Andalucía* (Andalusia).



Figure 2. Map of Spain's autonomous communities- Andalusia highlighted.

Memories of Andalusia's turbulent history influence its regional, collective identity. Under 711-1492 Moorish rule, Andalusia was wealthy, with an economy buoyed by commerce, agriculture and textual production. However, after Christian conquest, culminating in 1492, trade withered and land ownership transferred to a tiny aristocratic elite. This vastly unequal wealth distribution endured and by the nineteenth century Andalusia experienced recurrent famines (Manuel, 1989, pp. 48-49). Such conditions bred 'Andalusian solidarity' and 'hostility to Madrid' and nineteenth-century class consciousness led to socialism, anarchism and Marxism (Manuel, 1989, p. 49). During the civil war, anarchists under the Republican alliance fought Francoism; many were agricultural labourers, creating a 'radicalization of the Andalusian countryside' (Collier, 1987, p. 1).



*Figure 3. Socialist publication El Obrero de la Tierra [Worker of the Land], 26 September, 1936, calling rural workers to defend against Franco's forces.*

Once Franco was declared victorious, Andalusia, with its left-wing climate, suffered mass slaughter at the hands of the dictatorship, with over one in ten Andalusians killed in reprisals (Pratt, 2003, p. 48). Andalusians continued resistance throughout the dictatorship, with political militancy operating through informal networks (Foweraker, 1989). Andalusia suffered repressive labour laws during the regime, under which 50-60% of its rural population became landless seasonal-labourers suffering poverty-stricken conditions (Pratt, 2003, pp. 54-55). Famines persisted across Andalusia during this post-war period (Foweraker, 1989, p. 17).

Franco's authorities, supported by the Catholic church, deployed oppressive tactics to control anyone nonconforming, encouraging people to denounce civilians suspected of dissent (Rodríguez-Gallardo, 2006). Being perceived to dissent meant imprisonment in life-threatening conditions, torture or execution. Thus, many civilians remained silent for fear of repercussions (Cazorla, 2010, pp. 30-31). Cazorla, an Andalusian historian, claimed many of Spain's current sociological patterns can be traced to this traumatic period. He argued widespread suffering and politics of fear caused people to turn from the state and immerse themselves into family security:

'the only institution that they could always count on was a very private one: family. This collective pessimism helped poor Spaniards cope with the ruthless post-war years and, at the same time, it all but eroded the values that support civil society' (ibid., p. 4).

Franco made concessions to economic liberalism when his autarky policies failed, and between 1960-1975 Spain's income doubled. However, this socioeconomic development was

unevenly distributed and Andalusia remained in poverty, with high illiteracy and scarce social services (ibid., pp. 12-14). Much of Andalusia's rural population migrated and it remained one of Spain's poorest regions (Manuel, 1989, p. 50).

During the 1980s democratic transition regionalist sentiment emerged (Collier, 1997, p. 3). Collier conducted ethnographic research in Andalusia during the 1960s and 1980s. She found democratic transition meant Andalusians were caught between 'traditional' versus 'modern' contestations. Some described democratic transition causing a 'decline in duty', such as familial obligations, whilst others hailed it as progress through increasing social mobility (Collier, 1997, p. 5).

The 2008 economic crisis more recently devastated Spain's economy, with Andalusia severely affected, suffering mass unemployment. In this climate, recognition of the family as core welfare provider has been re-strengthened (Casanova, Lamura and Principi, 2017, p. 201). Andalusia's historical memories, marked by distrust of the central state, exploitation, rebellion, civil war, dictatorship, reliance on familial and informal support-networks and recent economic crisis, influence its distinct local collective identity, as a region caught between long-established reliance on family and local community, confronting ongoing social change processes under the globalising, democratic Spanish nation.

### *Memories in Pueblo*

José's eyes screwed up in concentration as he struggled to trace the dot-to-dot outline to form today's date, '*El 5 de Junio*' ['The 5<sup>th</sup> June']. But he did not lift the pencil from the page and formed a continuous line from '*El*' to '*5*',

'José, *El* and 5 are not one word, they shouldn't be joined,' I corrected.

'But this dot is next to that dot, I'm just doing what you told me, joining them together,' he replied defensively.

José is 85-years-old and the only regular male attendee of the day centre. Having never learnt to read or write, other than his name, he was struggling to understand where the separations between words occurred.

'I only went to school for a few weeks, then my mother bought some pigs and told me I had to stay home and look after them. I was the head of the family. My father died whilst I was still a baby.'

'What happened to him?' I questioned.

‘He was killed in the war, my uncle too. My brothers and I were raised by my mother and aunt’ he remarked impassively.

‘Which side was he fighting for?’ I asked.

‘Fighting?’ José raised his eyebrows, looking surprised, ‘He wasn’t fighting! He was in the house and they just took him, he and his brother. They dragged them out to a *cortijo* [farmland/plot] and shot them’ he said, unemotionally.

José’s story, told so matter-of-factly, was commonplace for children raised in Andalusia during the civil war and dictatorship. Deaths of those killed by Francoist authorities were usually left unrecorded or marked *desaparecido* (missing) (Torres, 2002). Memories of the war and dictatorship endured in the minds of older and middle-aged generations in *Pueblo*. José’s fatherlessness due to Francoism meant rather than spending childhood at school, he earned his family’s living. He and his brothers looked after the family’s *cortijo*, a small plot and its animals, selling the crops, meat and dairy products. As Cazorla (2010) explained, people had to accept state atrocities quietly and continue with their lives, turning inwardly to a reliance on family security.

José’s memories give insight into the town’s main economy which remains primarily agricultural. *Pueblo* is known for its foodstuffs production, including *jamón*- Spanish ham, a well-known alcoholic spirit, *mantecados*- biscuits eaten at Christmas, and, its biggest industry, the cultivation of olives and olive oil. The presence of this industry dominates the town’s surrounding landscape which is covered with rows of olive trees. Many residents, even those employed elsewhere, own small *fincas de olivos* (olive plantations), which they harvest, sending the olives to refineries to sell the oil. Olive farming is extremely physically demanding.



Figure 4. Olive plantations in Pueblo’s surrounding landscape.

Perhaps the demanding nature of olive farming and the market relations they are embedded within, contribute towards the town's particularly high suicide rate. *Pueblo* rests within a wider area that has the highest suicide rate in Spain, the cause of which is unknown. There are numerous hypotheses: the water type; abundance of olive trees; high altitude; isolation of agricultural workers; scarce job opportunities or genetic predisposition. When I asked residents about this, several people blamed the lake and explained this was why another nearby village resting above the lake had an even higher suicide rate. A teenager described to me how his uncle had hung himself from an olive tree, explaining this as a typical suicide method, whilst a woman I interviewed became tearful as she disclosed her sister's suicide. Suicide had touched the lives of many in *Pueblo*. Although a clear explanation remains unidentified, the elevated suicide rate, along with the town's history, indicates *Pueblo's* residents have suffered ongoing hardship and deprivation.

*Pueblo*, with many low-paid agricultural workers, identifies as a working-class town. As in other rural Andalusian municipalities, the uneven wealth distribution led to a workers' rights movement (Manuel, 1989). This movement began in *Pueblo* in the 1910s, leading in the 1930s to socialist parties winning municipal elections and founding basic workers' rights. Whilst socialist movements spread across Andalusia, the right-wing anti-republican movement was also on the rise in Spain. The leader, Calvo Sotelo, aimed to unite the anti-republican movement through founding the *Bloque Nacional* (National Block). Although they failed to win national elections, they took control through violence, justifying this by explaining they needed to stop the civil disobedience of the socialist movement. They claimed to defend 'traditions' of property, family, order, homeland and religion. Calvo Sotelo was eventually assassinated by bodyguards of the Socialist party leader in 1936, and this event is considered by many historians the trigger that caused Franco's military coup to begin Spain's civil war (Moradiellos, 2018; Payne, 2006). Local historians<sup>3</sup> explain how that year, Francoist fighters seized control of *Pueblo*. Anyone associated with socialist movements were forced into exile, tortured, killed or imprisoned. *Pueblo* did not succumb to seizure without resistance. Paralleling other Andalusian communities, informal networks resisted Franco's regime (Foweraker, 1989). Anti-fascist resistance networks, known as *Maquis*, operated by hiding in the countryside using guerrilla tactics to fight Franco's takeover (Marco, 2016). Local historians report *Maquis* were active in *Pueblo*, and that they would rob fascist dwellings and bring supplies back to its starving civilians.

Several kilometres west of *Pueblo* the rumble of traffic can be heard from the motorway connecting Córdoba to Málaga. Lying under a small cross-section of this road is the communal grave

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<sup>3</sup> These local historians' works have not been cited to uphold *Pueblo's* anonymity.



of civilians who were assassinated by Francoist forces in August 1936. Victims' relatives located the grave, but due to the motorway's construction, have been unable to excavate it. This exemplifies how Spain's cloak of silence, in attempting to forget its violent past, has meant many have never learnt what happened to their deceased loved ones. Spain's rush into democracy cemented over past atrocities leaving them buried and forgotten.

*Pueblo* retains a working-class collective identity. *PSOE*, the socialist workers' party, have consistently won elections since democracy was reinstated. Since the regional government was founded in 1981, *PSOE* had held their position as the main party in Andalusia. Their thirty-six-year uninterrupted rule came to an end however with the 2018 regional elections. Until this point Spain had not had a far-right party win a seat since the dictatorship. Yet following populism's rise across Europe, for the first time since Francoism, the far-right party *Vox* gained twelve seats across Andalusia, forming a local government with the mainstream right-wing party, *Partido Popular* (Gálvez, 2018).

*Pueblo's* flourishing olive industry has caused increasing migration to the town. During harvesting season (November-May), migrants from North and sub-Saharan Africa come to work in the *olivos*, often under illegal/semi-legal contracts, resulting in payment at lower rates than locals. The anti-migration discourse across Europe has not spared *Pueblo*. However, despite the reappearance of the far-right in Andalusian politics, *PSOE* retained their seat in *Pueblo* in the 2018 regional elections, although by a slimmer margin than previous years, with the far-right party *Vox* making a small but significant gain of the vote share. Thus, despite its tragic history of repressive dictatorship, *Pueblo* has still been influenced by Europe's populism rise. However, *Pueblo* remains a town of agricultural workers, with left-wing leanings, which remain deeply-rooted in its local history.

### *Eldercare in Andalusia*

Andalusia's historical distrust of the central state, reliance on informal and familial support networks and sense of autonomy, influence its approach to eldercare. Historically, Andalusian kinship culture has encompassed a *moral* duty for younger kin to care for elderly parents. Pitt-Rivers' renowned ethnography, conducted in a rural Andalusian *pueblo* between 1949 and 1952, described the existence of a 'sacred duty' of younger kin to care for elderly parents. Economically deprived agricultural labourers devoted much of their income and time to caring for elderly parents. Parents gave their children a 'moral education' to ensure they remained dutiful to them in older age (Pitt-Rivers, [1954] 1971, p. 102).

Public health research has highlighted that intergenerational households, where elderly people live with adult children, are common in Spain and associated with good self-perceived health

and low depression rates (Zunzunegui, Beland and Otero, 2001). In Andalusia, regular contact with adult children was positively associated with increased longevity (Cortes, 1998, cited in *ibid.*). Such research suggests duty towards kinship eldercare remains. Spanish public health research reports that care of people with dementia is still ‘not considered a government responsibility but a family issue’ (Lillo and Riquelme, 2018, p. 162), potentially explaining why there is no officially recognised nursing specialisation in older people’s care as it has always been considered a family, rather than public health issue (*ibid.*), with the majority of people with dementia in Spain still cared for by family at home (Rivera et al, 2008; Tobío and Cordón, 2013; Ruiz-Adame and Jiménez, 2017).

Responsibility to care for elderly relatives falls primarily on Spanish women (Lillo and Riquelme, 2018). The importance of interdependent family care goes beyond eldercare. Young people in Spain on average do not leave family homes until their late twenties and early thirties, the majority leaving for marriage (Fernández and Cordón, 1997, cited in Holdsworth, 2005). In Andalusia extended families commonly live near one another, with grandparents providing care to grandchildren due to women’s increasing entrance into labour-markets (Tobío and Cordón, 2013). Thus, public health research supports the notion that long-embedded cultural values, centring around a moral duty to care for family as the core welfare provider, continue to exist in Spain and Andalusia.

Alongside this are anti-institutionalisation discourses surrounding elder and dementia care. Verbeek et al’s (2015) cross-cultural study exploring inter-country variation between eight European countries of factors influencing institutionalisation of persons with dementia, found Spain had significantly lower institutionalisation rates compared with northern countries and high rates of people with dementia living with family. They suggested a ‘powerful cultural tradition of families caring for their dependent older relatives’ and ‘a strong rejection’ of care institutions associated with ‘abandonment’ influenced statistics (Verbeek et al, 2015, p. 1347). Rivera et al found long-term institutionalisation of people with dementia was interpreted as ‘family failure’ (Rivera et al, 2008, p. 5). Even middle-class families with resources to pay for private care kept relatives at home by using complicated rotation patterns between family members’ homes. Rodríguez-Martín et al interviewed residents and families in a Spanish care home and found relatives describing having failed their ‘moral obligation’ to care, explaining institutionalisation as a family ‘humiliation’ (Rodríguez-Martín et al, 2014, pp. 557-558). Thus, care for relatives with dementia in Spain and Andalusia is shaped by cultural discourses around the importance of family, anti-institutionalisation and a strong moral duty to kinship eldercare.

Recent social changes, however, indicate accelerating shifts in traditional approaches to eldercare. Collier’s (1997) ethnography of families in an Andalusian *pueblo* explored how ‘traditional’

ideals around a moral duty to care for elderly parents transformed under the new democracy. By the 1980s, many adult children had become financially independent through moving to urban centres and entering the labour-market. Although desire to care for elderly parents remained, adult children did not feel obliged to return to the *pueblo* they were born in and felt parents should move to their new residences. Elderly parents, having cared for their own parents in the *pueblo*, expected such care themselves, resulting in generational conflicts as traditional ideals around care duties transformed in response to social change. Populations in Andalusia's *pueblos* are currently decreasing and ageing, as younger generations emigrate in search of studies/employment, reflecting a Europe-wide phenomenon in rural populations (Burholt and Dobbs, 2012) and leaving older dependent people without family to provide care.

Further demographic changes were brought to Andalusia post-democratic transition, through the migration of many northern European retirees to Andalusia's *costa del sol*, attracted by the warm climate and cheap housing. Many ageing British retirees however, found themselves struggling to cope in older age as they realised the Spanish healthcare system lacked homecare and elderly nursing provisions (O'Reilly, 2000). Over time, British and northern European companies have established private luxury retirement complexes and care homes catering for this expatriate population. This may be influencing attitudes towards eldercare institutions. Previously viewed as places for poor elders lacking family, they are now being seen as a luxury ideal, enjoyed by wealthy northern Europeans. Thus, demographic social changes are influencing Andalusian families' expectations of eldercare, who are increasingly looking beyond family networks.

Shifts in eldercare ideals also influence changing expectations of state provision. Casanova, Lamura and Principi (2017) outlined how, although Spain's family care model historically did not rely on public services, its rapidly ageing population and women's entrance into the labour-market resulted in public pressure for welfare reform that fits Spain's family care culture. This led to the 2007 *Ley de Dependencia* (Dependency Law), giving families rights to formal homecare. However, the 2008 economic crisis led to heavy public spending cuts, meaning this law was only completed in 2015 in significantly reduced form, thus care responsibilities have remained largely with families (ibid.). The state's structural negligence of eldercare therefore reinforces families' long-embedded sense of moral duty to care for elder kin as, unless families possess economic resources to pay for expensive private care, the alternative would be immoral treatment through consigning one's relative to inadequate care. A recent trend of families struggling to meet care needs of older relatives is privately hiring low-paid migrant carers to facilitate dependent kin staying at home (ibid.). Thus, although strong cultural discourses centred around family care are reinforced through the state's structural failures to provide adequate welfare, attitudes towards state and family responsibilities are

rapidly transforming alongside processes of social change. As the psychologist at *Pueblo's* care home described, eldercare culture in Andalusia is shifting: '*Estamos en la transición*' ('We're in the transition').

## Methods

I begin this section describing events that influenced the choice of *Pueblo* as my main field site. I then outline how I organised my routine in *Pueblo*, describing how I took 'active roles' through working as a volunteer in *Pueblo's* day centre, care home and carers' support group, and detail how much time I spent in each. Participating actively enabled me to experience the realities of caring for people with dementia in these settings myself. I explain how, as trust developed, I began in-depth interviews and started participating regularly in families' care routines. I also outline the process of analysis I used once the data had been gathered. Through mixing narrative exploration with participant-observation, I compared people's stories with their real-life practices to gain rich ethnographic insights into dementia care.

### *The Search for a Field Site*

I grip the steering wheel tightly; my hands sweat as I navigate the twisty mountainous road ahead. The van screeches in protest as I push on the accelerator, but it doesn't muffle out the phone ringing.

'Sí?' Antonio answers. I know from his tone the news is bad. As we feared, his grandmother has just passed away. Our hectic rush was not enough to get him home in time to say goodbye.

I am in the midst of a scoping trip during the beginnings of fieldwork in Andalusia, searching for a town to adopt as my main field site. I am accompanied by my partner of six years, Antonio, who is from Andalusia and whose grandmother, Paquita, was part of the inspiration for the research. I was interested in how, like many older people in Andalusia, she rotated her days between her adult children's homes. Her family believe this shared care across the family network helped her live in good health into old age.

I began fieldwork staying with Antonio's family in Almería, a small city in eastern Andalusia. During this time, I conducted scoping trips in search of an older people's day centre willing to participate in my research. However,

unexpectedly during my stay Antonio's grandmother Paquita fell ill. She caught a deep gravely-sounding cough, and within days her breathing became laboured and she was taken to hospital. Doctors admitted her into intensive care, diagnosed her with pneumonia, and gave her a prognosis of days to live. Remarkably, she survived that admission, recovering from pneumonia but left extremely weak. During her hospital stay, she became increasingly confused. On several occasions she mistook her breathing mask for a pair of glasses, was disorientated and could not hold a coherent conversation. Doctors for the first time gave her a diagnosis of Alzheimer's disease.

For years prior to that admission Paquita had shown increasing memory problems, asking the same questions, telling stories repeatedly, and struggling to complete basic tasks she had never had trouble with before. Her family understood this forgetfulness as a normal part of ageing. In fact, they would praise her memory, as despite her struggle to remember things in the recent past, she could recount in detail stories from her life that had occurred decades ago, which her children took as evidence that she had no cognitive impairment.

Having survived pneumonia, Paquita was discharged, but doctors warned that her prognosis remained poor. When she returned home, the entire family were involved in looking after her in those last weeks of her life. Attempting to maintain the routine as she had lived for the last ten years, she rotated her days between her three adult children's homes. Paquita could no longer walk and needed to be transferred from bed to chair to wheelchair, she could not get herself washed, dressed, use the toilet, or feed herself, and in the last few days of her life she could not get out of bed. Antonio's parents insisted that Antonio and I not take on too much responsibility for Paquita's care and that I continue working on my research as planned. We had dinner with his parents every evening to spend time with Paquita and help with her care.

Meanwhile, I was contacting day centres and searching for a field site. I sought a relatively small *pueblo*, that was far from the tourist-filled *costa del sol*, with a high elderly population and day centre willing to participate. Antonio planned to join me during initial months of fieldwork and accompanied me on scoping trips. We had hesitated over this last trip, as Paquita had been weak

since returning from hospital. However, in the days leading to the trip she had seemed somewhat improved, and thinking she had stabilised we decided to go.

In terms of the research, the scoping trip had been going well. I had met with various day centres, many of whom seemed willing to participate. The last day centre meeting was in a *pueblo* in Córdoba province. However, Antonio's father had called that morning to say Paquita was deteriorating and she was now refusing to eat or drink, so we decided that after the meeting we would head straight back to Almería. The meeting went well, the day centre seemed enthusiastic about participating and the *pueblo* fitted research criteria. Sadly however, during our frantic drive back, Antonio received that phone call, in which his father let him know his grandmother had passed away.

Days later, writing field notes and reflecting on the trip, I found myself returning to the *pueblo* where we had been when Antonio received that phone call. It fitted the research criteria and the day centre had been keen to participate. Yet despite other *pueblos* also meeting the criteria, both Antonio and I found ourselves drawn towards this one. Somehow the scoping trip inadvertently causing Antonio to miss his grandmother's death influenced me to ultimately choose this town as the main field site. Observing the daily life of Paquita and the care she received from her family had been a key influencer in me deciding to apply for the research funding. Discussing potential field sites with Antonio he agreed, somehow in choosing this *pueblo* as the main field site, we were honouring his grandmother's memory.

Yet should emotions and personal life really influence methodological decision-making? I believe such life experiences inevitably affect methodology, in the messy, day-to-day reality of ethnographic fieldwork. Rather than being a hindrance to research, including descriptions of such emotional experiences uncovers the complex processes at play in knowledge production, enabling transparency, whilst facilitating productive research curiosities. The emotions I experienced as a result of inadvertently causing Antonio to miss his grandmother's death in pursuing my research ambitions, laid the stones of the path I was to walk down during the following months of fieldwork. A path which led me to explore complex questions surrounding, family, duty, obligation, guilt and love.

Several months later, once settled into the field site and discussing kinship eldercare with family care-givers, notions of duty and guilt kept creeping into conversations. Informants spoke of

intense guilt at not being constantly with an elderly dependent relative. One informant who spent years caring for her mother with dementia, recalled how she had been out with friends and returned home to find her mother lying with a broken hip. The guilt, she explained, came from prioritising her needs over her mother's. Her words resonated with me as the experience of causing my partner to miss his grandmother's death for my own ambitions made me feel guilty for placing my needs over those of my partner and his family. I felt empathy towards her and other informants that led me to further scrutinise and explore my own emotions, leading to further research questions.

I continue to be, however, extremely conscious of not transplanting my emotions onto informants. Their guilt was absolutely not my guilt. Beatty discussed ethnographic limits, critiquing how one's emotions cannot be relied upon 'for insights into the emotions of people living very different lives' (Beatty, 2010, p. 432). In the case of Paquita, I was not immediate family, had only known her five years and was never her main care-giver. My experience of her death was entirely different to those of my partner or her children. I am not arguing that my emotions gave me enhanced understanding of informants, but rather that my own emotional experience allowed me to uncover new lines of inquiry. Paquita's death, by making me participatorily experience the emotional force of guilt, led me to delve into this and ask questions around it, asking myself what it was, where it came from, and why it was there. I questioned whether my guilt resulted from emotional indebtedness to my partner's family. They had welcomed me into their lives, despite cultural hurdles. By keeping their son from them when they needed support had I left this debt unrepaid? Was emotional debt something children felt in relation to parents' care? Delamont (2009) distinguished between using reflexivity purely autobiographically and using self in relation to research. My reflections led me to ask myself questions that facilitated useful inquiry with informants. Throughout this thesis I engage in relevant emotional reflections in relation to my research questions to aid critical analysis.

### *Everyday Life in Pueblo*

Fieldwork initially centred around working as a volunteer at *Pueblo's* day centre, which I began in November 2018. The day home was able to look after a total of 18 *abuelos*, and whilst I was there it was generally working to maximum capacity. Eight members of staff worked at the day centre- the director, four carers, one physiotherapist, one housekeeper/cook and one driver. As a volunteer I participated in the cognitive exercises, physical activity programme, and craft activities and helped with the transfers, feeding and toileting of *abuelos*. I spent time talking to *abuelos* and staff, encouraging them to share their views on dementia care. I volunteered at the day centre three times a week, on Mondays from 2pm until 6pm, on Wednesdays from 2pm until 6pm, and on Fridays from

9am until 2pm. If there was a particular event or social activity, for example, World Alzheimer's Day in September, I would attend outside of these times.

Several months into fieldwork, in March 2019, I organised similar volunteer work at *Pueblo's* only care home. In total there were 68 residents living at the care home when I arrived, although the care home had a total of 75 beds (the number of residents varied as *abuelos* moved in/out or passed away). There were only 30 bedrooms as the majority of residents shared bedrooms, with only 15 single rooms. My main role was to assist the occupational therapist (OT) and psychologist in running the activity groups. I volunteered at the care home twice a week, on Tuesdays from 10am until 2pm, and on Thursdays from 4pm until 8pm. As with the day centre, if a special social activity or event had been organised by the care home, for example the Christmas play, I would come in outside of these times.

In May 2019, at a social event organised by the day centre as part of a *fiestas* celebration, I met a social worker who, hearing about my research, suggested I attend a course she ran at the local health centre for family care-givers. The course provided information on how to care for dependent people, and peer-support for family care-givers. The carers' group was attended by a maximum of 14 carers. The course ran weekly, every Thursday, over seven weeks from May until June 2019, with each session running from 6pm until 8pm. During the sessions, I joined in with group discussions by drawing on my own experiences of dementia care.

Adopting these roles in healthcare settings provided me with an immediate fieldwork routine, whilst serving as an initial foundation on which to build relationships. Spradley (1980) described a continuum of participant-observation ranging from non-participant observer to complete participant-observer. I situated myself at the latter side of this continuum. I followed a similar methodology to Johnson, Avenarius and Weatherford (2006), who emphasised the benefits of 'active participation', by adopting non-researcher roles within research settings, enabling intimate access and trusting relationships to develop. Thus, volunteering at the day centre, care home and carers' support group gave me active roles. Having previously worked as an OT to people with dementia in the UK also gave me greater legitimacy and people appeared to value my contribution.

The danger, however, of this 'active role' was that the clarity of my researcher role was blurred by informants viewing me as an OT/volunteer. I had to ensure I continually engaged people in discussions about my research. Often people categorised me under a role they recognised, such as volunteer or student. I recall once, having explained about my research to a social worker and thinking she had a clear understanding, she introduced me to another professional as a student



studying abroad. Her understanding was not entirely misguided, as I was a student from another country, but the specifics of me being a researcher, rather than taught-student, had not been fully understood. Hence getting my research purpose across was challenging. Regarding me as a healthcare student or professional may have influenced the narratives informants provided.

Adopting active roles in *Pueblo's* healthcare institutions, I learnt social meanings through my body's interactions with its surroundings, undertaking a 'practical apprenticeship' to embody the *habitus* of my new social roles (Bourdieu, 1984; 1977). Prentice described how during her ethnography she worked at a factory and found this active role helped build rapport with workers, which enabled 'a visceral empathy for the trials of daily work' (Prentice, 2007, p. 57). Pink (2009) criticised traditional participant-observation for prioritising the visual and recommended situating oneself as an 'emplaced ethnographer', using multi-sensorial participation to understand how meanings are expressed through diverse sensory modalities. I thus attempted to 'emplace' myself, focusing on sensory aspects of dementia care, which proved useful given people with dementia were often unable to communicate verbally and care-givers had to rely on sensory communicators, like touch.

By embodying these practical care-giving roles, I built meaningful relationships with informants to reach an embodied 'visceral empathy' (Prentice, 2007, p. 57) for professional carers. I physically felt the aches and pains of the daily bending, lifting, and moving to support people with dementia who were no longer fully conscious of their own bodies' movements, whilst also experiencing the stress of working with the constant background noise of people wailing, and the frustration at trying to engage someone in conversation who keeps forgetting what you are saying. I found myself absorbed into local public health discourses around dementia care. However, as Prentice warned, such embodied participation can cause an over-internalisation of informants' viewpoints to cloud critical analysis. Thus, my active participation also necessitated a complex 'distancing and disembodiment' (ibid., p. 60). After returning from healthcare sites, I allowed myself several hours break before writing field notes, to facilitate this.

I was particularly susceptible to clouding of critical analysis, as I had previously worked as an OT to people with dementia and had thus absorbed a UK public healthcare knowledge-base around dementia care. Public healthcare of dementia in Spain shares many similarities to the UK. Therefore, not only did I have to distance and disembodiment from active roles working alongside care-giving informants in *Pueblo*, but also had to step away from knowledge I had developed as an OT in the UK. As an OT I had learnt what 'good health' and dementia care should be, whereas researching in

*Pueblo*, I had to use participant-observation to analyse the reality of how people cared for others with dementia.

It was not just formal 'active' roles in public healthcare sites, however, that laid the foundations for fieldwork. General activities in *Pueblo*, unrelated to dementia or healthcare, also provided opportunities for rapport and relationships which could lead to unexpected insights. As Danely highlighted when conducting fieldwork exploring ageing in Japan, it was often 'chance discoveries' that led him to encounter new perspectives on ageing (2014, p. 2). Thus, embedding myself into a diversity of general activities in *Pueblo* enabled the possibility for such discoveries to emerge. Public spaces were often abuzz with social activity, particularly during spring and summer months. Plazas were filled with residents, old and young, sitting on benches and catching up on the latest goings-on. Groups of *abuelos* would cluster around street corners, each bringing their own fold-up chair, and sit for hours chatting and watching passers-by. People would start conversations with me in the street, curious to find out what I was doing, asking direct questions like 'Who are you?' and 'What are you doing here?'. I learnt to leave the house with at least twenty-minutes extra to allow for chit-chat with neighbours, who would sit outside their houses keenly awaiting conversation and query me on what I was up to. *Abuelos*, I found, particularly valued this social activity in public spaces and expressed this by referring to enjoying '*vida en la calle*' ('street life'). Street life facilitated much of public social interaction in *Pueblo*, and in carrying out my daily routine I could dip into it to get to know local people.

I rented a house in *Pueblo* with Antonio and our landlady, Cristina, by coincidence, had spent years caring for her late mother with dementia and had also attended the day centre where I volunteered. Cristina had previously lived in the house she rented to us and cared for her elderly parents who lived several houses up on the same street. Both her parents had recently died and she had moved into their larger home. During my time living there we became close. She was interested in my research, describing her caring role to her elderly parents as one of her proudest achievements. She lived alone and would often knock on our door in the evenings looking for company.

Over time I got to know other neighbours on my street, particularly as the months drew on and the stifling midday heat became too strong to go out in, and people started taking out fold-up chairs in the evenings and sitting in front of their houses, alone or with others, chatting to passers-by and engaging with street life. Our immediate neighbours were a married couple in their early 70s, Javier and Olivia, who had returned to *Pueblo* from Madrid to care for Olivia's elderly father until he passed away. Sadly, not long after Olivia's father passing, Javier had a stroke himself and Olivia

dedicated her days to caring for her husband. Many insights discussed in this thesis, developed in part from informal conversations with neighbours that transpired sitting out in the summer evenings (see figure 5).



*Figure 5. Fold-up chairs placed in front of people's house in the evenings during summer months.*

I threw myself into other activities to get to know local people. I took free Spanish lessons at the adult education centre, where I became acquainted with many seasonal migrants who had come to work on the olive plantations. I joined the municipal town band, who practiced weekly and played at the town's many *fiestas*. I took part in a local radio chat show, volunteered at a local animal shelter, attended exercise classes, spent time in cafes, bars and parks, and attended *Pueblo's* many *fiestas*, events and religious rituals; all provided informal ways to get to know people. It seemed like every weekend there was another celebration of a saint or one of the town's patron Virgin Mary statues.

Many relationships I formed with key informants were people that I met through these informal means. As relationships and trust developed, I began conducting in-depth interviews. With some informants I began to regularly participate in care in their homes. In total there were three households with whom I visited regularly to assist with their care. I started visiting a middle-aged woman called Claudia who lived nearby and was struggling to care for her 88-year-old mother with dementia. Claudia was having particular difficulties in getting her mother to take a shower. So I agreed to take her mother out for a walk and then encourage and assist her to shower. I visited another elderly couple, 97 and 91 respectively, once a week for a coffee at their home and accompanied them for a walk around a nearby park. The woman was extremely grateful for my help

as she felt unsafe leaving the house with just her husband because, having memory problems, he would often walk away, forgetting he was with her. I also started going to a café for breakfast once a week, with the 80-year-old mother of one of the staff from the day centre, who was in the early stages of dementia.

This gradual building of trust, which could only occur effectively over months, enabled in-depth exploration into people's everyday lived experiences of dementia care, allowing me to develop critical anthropological insights. I used participant-observation to gain understandings of both explicit and *tacit* aspects of cultures (DeWalt and DeWalt, 2011). Dementia care raises intimate questions around the nature of kinship, care and personhood. Exploring through extensive engagement in people's everyday lives thus enabled tacit understandings to emerge that may not have occurred if I had solely relied on other more short-term qualitative methods like interviews. This was particularly important given previous research has shown how emotions such as guilt affect how people describe kinship care of dementia (Rivera et al, 2008; Brijnath, 2014). Participant-observation enabled comparison between how people described dementia care and how they engaged with it in real-life embodied practice.

### *Field Sites*

*Pueblo* is a town of approximately 10,000 inhabitants within a mountain-range in the Córdoba province. I focused on a rural setting as I was interested in values centred around community and autonomy which have been described as characteristic of rural Andalusia by previous research (Luetchford, Pratt and Soler Montiel, 2010). People from *pueblos* were described as more tied into the local community than people from cities. Cities and coastal *pueblos* have been more influenced by the high-influx of tourism since the 1960s and the arrival of northern European expatriates (Cazorla, 2010; Tremlett, 2006). Thus, I chose somewhere with less tourism, where I was less likely to be perceived as a tourist/expatriate, facilitating integration.

Focusing on a relatively small community made it easier to get to know people and make my research known by word of mouth, which helped with gaining informed consent. Ellis (2007) found during ethnographic research in fishing communities that because communities were small and isolated, even people she did not know personally knew about her research. I similarly found that sometimes people had heard about my research before I raised it as they knew someone I had already spoken to. *Pueblo* is, however, not isolated; people, media, and ideas constantly traverse its boundaries. Yet its relatively small population and location facilitated a more in-depth sense of everyday community life within the limited timeframe, than had I conducted the ethnography in a

larger place. Researching a sensitive topic, it was crucial I formed trusting relationships with informants which was easier in a smaller town where I frequently ran into people. Further reasoning for selecting *Pueblo* was its high proportion of older inhabitants and the day centre's enthusiasm about participating.

I did not, however, limit investigation to a singular site, but took dementia care as a conceptual site, evolving fluidly. I engaged in 'following the threads of cultural processes' (Marcus, 1995, p. 97), allowing multiple field sites to occur 'gradually and cumulatively, as new insights develop' (Hannerz, 2003, p. 207). At the day centre I worked alongside a carer whose sister worked at the care home. This internal contact, someone to testify to my character, I believe encouraged the care home's participation. It was at a social event for the day centre that I met the social worker running the carers support group who invited me to attend. Taking a small town as the central field site thus enabled the gradual spreading through word of mouth of my research, facilitating relationship-building that is essential to ethnography. Yet, it still allowed flexibility to seek further sites as insights developed, such as various informants who lived in nearby towns. The research was thus able to reap the benefits of both close-up intimacy and fluid openness that ethnography enables.

### *Narrative Exploration*

Doing ethnography facilitated exploration between people's lived care practices and narratives. By engaging with informants in daily family care routines and participating as a volunteer to people with dementia and their care-givers, I explored how people constructed narratives through their everyday care experiences. I asked people how they navigated the sacrifices and dilemmas of care to make sense of their practices. Ethnography enabled exploration of these narratives to emerge slowly over time as I embedded myself into everyday life.

Listening to people's stories went beyond data collection to build trusting researcher-informant relationships, which were crucial as I was researching an intimate topic. Informants got to know me through my participation in everyday family routines. Ethnography facilitated the exploration of differing narratives within families and across generations. I contrasted how people described their relationships and care practices with observations of their real-life interactions. I initially began engaging in loose, informal ethnographic interviews, which took the form of 'casual, friendly conversations' (Spradley, 1979, p. 58) emerging spontaneously as I embedded myself into my active roles and care routines in *Pueblo*. These ethnographic informal, conversations continued throughout fieldwork.

Once I had been living in *Pueblo* for approximately four months, and had started to develop relationships with a variety of *abuelos*, family care-givers and care staff, I started conducting semi-structured interviews which led to identifying preliminary themes, that I later discussed with informants to check accuracy, developing until solid themes emerged. I conducted several interviews across generations and witnessed grandparents, parents and grown-up children debating changing care cultures. In total I conducted 48 interviews using a semi-structured format whilst on fieldwork. These were made up of: 12 family care-givers who were caring for a relative with dementia or had done in the past in the community; six *abuelos* in early stages of dementia or with some cognitive impairment who could still understand and consent to participate in the study; 15 members of staff across the day centre and care home; the manager and five carers from *Pueblo's* home care service; and one social worker and 8 migrant carers at a migrant support NGO in Málaga. After the Covid-19 outbreak, in spring and summer of 2021, I conducted follow-up semi-structured interviews online with a total of 10 informants. These were made up of: four carers from the home care service; three members of staff from the care home and day centre; and three family care-givers.

I always ensured I gained informed consent to conduct semi-structured interviews. I also sought out further consent to record these semi-structured interviews wherever possible. If the person gave consent for me to record the interview, it enabled me to playback the interview to myself, transcribe, make notes and clarify my understanding. The majority of people I asked to record were happy for me to do so. I decided however, not to record interviews with *abuelos* with dementia, as I was conscious of complex ethical issues already existing when researching and gaining consent with people with dementia, and of *abuelos* potentially lacking familiarity with recording equipment and not wanting to add to any confusion that they were already susceptible to from dementia symptoms. Initially, I started transcribing the interviews verbatim, however I found this used up a lot of time and, after consulting with my supervisors, we decided my time was better spent making detailed but summarised notes of key points from the interviews.

As an OT I had learnt about building rapport through a person-centred empathetic approach (Creek, 2010). However, as a researcher, I had to remind myself I was collecting data, not seeking therapeutic objectives. Interviewing with a person-centred approach enables informants to feel safe to discuss personal information (Skinner, 2012), particularly important in researching sensitive topics. Sometimes informants became tearful during interviews, particularly those retrospective interviews when they talked about relatives who had since died. I was conscious to deliberately hold a sensitive, caring approach, showing concern and sympathy to those who became upset. Having worked as an OT had prepared me for hearing distressing stories and for knowing how to respond.

Wentzell found informants described interviews about a sensitive health problem as ‘cathartic’ (2013, p. 66), and I similarly found informants would sometimes thank me for the chance to have spoken about their experience, particularly when speaking about a relative who had died, as they had appreciated the opportunity to ‘remember’ them. Therefore, using empathy to show interest in informants’ lives, giving them space to share their stories, helped facilitate trusting relationships leading to intimate narratives.

I conversed in informants’ native language of Spanish, enabling narrative exploration through emic conceptualisations. Cohen’s (1998) ethnography demonstrated the importance of this; whilst investigating dementia in India, he initially used western medical terms, but found people used an entirely different language to describe older-age senility. By speaking in informants’ native language, they framed concepts within their own language. I spoke Spanish fluently from the start of fieldwork, but it took time to adjust to the regional dialect, particularly with older informants. Researching this sensitive topic, it was crucial I used nuanced empathic language to facilitate rapport, rather than rely on interpreters which could have damaged intimacy (Marschan-Piekkari and Reis, 2004).

I maximised informant participation and data-gathering through flexible, nuanced use of observation combined with interviewing, allowing ‘observation and interview [to] mutually interact with each other’ (Agar, 1996, p. 158). Observing people engaging in daily practices, such as cooking, eating, or socialising, I asked questions like, ‘How often do you do this?’ or ‘Do you enjoy it?’ Some people with dementia were unable to engage in ongoing verbal communication, thus participant-observation crucially enabled me to witness the lived reality of people with dementia’s sensory embodied experiences.

### *Data Analysis*

Throughout fieldwork, I kept a working document on Microsoft Word, which I entitled ‘Potential Themes’. As I wrote up fieldnotes from participant-observation and transcriptions and notes from interviews, if I noticed multiple occurrences of similar topics from various informants, I added these to this document. Keeping this working document during fieldwork allowed me to revisit topics I was identifying as potential themes iteratively with informants to check their accuracy and revise accordingly, before conducting more detailed data analysis. Once I had completed fieldwork in Andalusia, I began the process of analysing all of the data I had gathered in detail. This data consisted of my fieldnotes which I had kept throughout my time in *Pueblo*, as well as transcriptions and notes from the interviews I had conducted, both those I had recorded and those which I had not

recorded. I printed all of these fieldnotes and interview transcriptions and notes out, as I found the physicality of holding the data in printed format helpful in enabling me to analyse the data by seeing it in front of me. Once all the data had been printed out, I used coloured pens to highlight data that fitted within emerging themes, with each colour representing a different theme. I found that I quickly ran out of colours and had to start using numbers instead to code the many emerging themes. Once I had gone through all of my data using this coding technique, I then created a mind map themes chart which included my research questions and the themes which had emerged under these questions. I then reread through all of my data, with the highlighted themes to check and cross-reference with the mind map. I discussed this process with my supervisors who helped me to guide these themes into an initial outline of suggested chapters which formed the skeleton of my PhD thesis. I continued to cross-reference my printed out coded data throughout the write up of my thesis, as the highlighted codes were crucial for when I was seeking out ethnographic evidence for the themes and insights discussed.

## **Ethical Considerations**

Ethical considerations were a complex maze continuing throughout and beyond fieldwork. I found myself debating which path to take, hesitating over which would be most respectful to informants whilst enabling research aims to be explored. I attempted to follow the Association of Social Anthropologists of the UK and Commonwealth (ASA) and Economic and Social Research Council (ESRC) ethical guidelines (ASA, 2011; ESRC, 2021), and did not begin fieldwork until I gained approval from the university's ethics committee. However, although guidelines are useful, they are not a cure-all prescription ensuring ethical health. Guidelines offer advice, but cannot replace 'self-critical, imaginative and responsible ethical reflection' (ESRC, 2021). I realised that maintaining ethical practice in research is akin to looking after one's holistic health in life, it is an everyday, iterative process. To maintain the research's ethical health, I adopted an enduring, holistic, and reflexive approach.

One technique to maintain this iterative approach to ethics in practice was engaging in self-reflection through keeping a field diary. Punch (2012) advocated diaries to record emotions during fieldwork to enhance reflexivity and ethical sensitivity. I originally intended to keep a diary which was separate to field notes. However, the two overlapped and instead I wrote field notes which included emotions in a diary-like style. Ethical issues formed a messy landscape and I continually uncovered thorny webs of issues throughout fieldwork and into the write up. By writing about these issues in my field notes I was able to facilitate continuous questioning and exploring of solutions as ethical issues arose during fieldwork.



For example, one issue I reflected on in my fieldnotes was concerning a semi-structured interview with Magdalena, a family care-giver. We arranged for the interview to take place at her home, where she lived with her mother who had a diagnosis of Alzheimer's disease. When I asked to begin the interview, Magdalena said to go ahead and I realised that she was expecting the interview to take place with her mother sitting beside her. Although it still generated useful data, the questions I had planned to ask her required her mother not to be present so she could freely express how she was experiencing care-giving, which she was not able to do with her mother listening. It felt, however, inappropriate to ask to speak with her alone because as her mother's main care-giver, I sensed she did not feel comfortable leaving her mother alone. The interview then felt clumsy and awkward as I had not prepared suitable questions. Later, when writing up fieldnotes about the experience, I realised that within the information sheet I had given her before the interview and during the conversation we had had about the research, I should have clearly explained that it would be helpful to speak to her alone. This is just one example of the many ethical issues I encountered, from which I found that by writing up field notes I was able to reflect and learn.

Participant-observation 'dangerously stretches the anthropological ethic of informed consent' (Bourgois, 1990, p. 52). In approaching ethics as an iterative process, a tricky ethical tension I was constantly faced with during fieldwork was mediating between fitting into local culture whilst ensuring informants' research awareness. I often found myself caught between taking ethical responsibility to ensure informants were fully informed about the research and giving their consent to participate, versus 'fitting in' to life in *Pueblo* and to the care sites and family homes where I was researching. My attempts to 'fit in' through my adoption of active caring roles, as discussed above and advocated by Johnson, Avenarius and Weatherford (2006), although facilitating relationship-building and intimacy with informants, also had the capacity to cloud my researcher identity. Such clouding, could 'encourage people to forget that you are constantly observing them' (Bourgois, 1990, p. 52) and therefore risked reducing informants' awareness of my research which could detrimentally influence the informed consent process. This risk was particularly dangerous in this research project as it included people with memory and cognitive issues. Therefore, it was critical I treated informed consent as a process.

Although I approached informed consent as ongoing and iterative, I still ensured I used clear and concise information sheets and consent forms, written in Spanish, which explained the purposes of my research and what participation involved. This meant informants could refer back to the forms if anything was unclear. It also ensured informants had the contact details of myself, my supervisors and the university's ethics committee if they were concerned about anything relating to the research

or what I was doing. I also included adapted information sheets and consent forms for people with dementia, which were less detailed in their description and used a larger font to make them easier to read.

The informed consent process was more complex however, than one-off form-signing. I often found despite giving people the information sheet, they were reluctant to read it. Others could not read so I read the information aloud, but then they were unable to refer back to it. Consent unfolded over time as I deepened engagement with informants, revisiting their continuing desire to participate. It had to be approached as an iterative process to ensure informed consent was continuous and that informants fully understood my role as researcher. For example, on my first day volunteering at the day centre, I explained about my research project and how I would be gathering data from the everyday observations I made whilst working as a volunteer. I had also given every member of staff an information sheet. Yet despite this, when months later, I began interviewing staff in semi-structured interviews, it became clear that although some members of staff understood I was conducting a research project, others had thought I was on a clinical placement as an OT student. This could have been because they were used to healthcare students completing placements. So, I had to spend time explaining again the purposes of the research and my role as a researcher, to ensure they understood and could thus give their fully informed consent to participate. By readdressing informed consent in this ongoing processual way before starting these interviews, it not only ensured informants were consenting to the interview, it also meant their consent for using insights gained through my role as a volunteer was revisited and clarified. I would also continually remind staff about the research and its progression, and that although I was an OT, I was there as a researcher. This iterative approach ensured that informed consent was an ongoing process that was continually revisited and reclarified throughout fieldwork.

This informed consent process was complicated further by the inclusion of informants with dementia. Approaching informed consent as an iterative process was crucial with all informants, but especially when including those with dementia. Dewing (2007) discussed how many people with dementia have been simply excluded from research due to the complex issues around gaining informed consent with people who experience memory issues. However, completely excluding the involvement of people with dementia in research generates an ethical issue in itself. Wilkinson warned that people with dementia 'remain a silent and excluded voice', and that assuming they cannot participate in research 'is a reinforcement of negative stereotypes of incapacity' (Wilkinson 2002, pp. 9-10). It thus could be considered unethical to research dementia or dementia care without including the experiences and insights of people with dementia themselves. This view is

further supported by the prominent UK dementia charity, the Alzheimer's Society, which employs the policy of 'Nothing about us without us', which advocates that people with dementia be included in research. Since 1999, the charity has established a research network programme with volunteers affected by dementia who contribute actively to their funded research (Alzheimer's Society, 2018). I was therefore keen to include people with dementia in the research, but wanted to ensure I did this whilst upholding high ethical standards by using an iterative approach to gaining informed consent.

Clarke and Keady, investigating data collection with participants with dementia, explained how when researching with people with dementia, informed consent must be 'a process that is continually negotiated' (Clarke and Keady, 2002, p. 38). Dewing (2007) explained how both capacity and informed consent in people with dementia can shift and fluctuate over time and thus advocated spending extended periods with informants with dementia, to understand when they give/do not give consent. Ethnography facilitated this as I got to know informants over a prolonged period, engaging with people with dementia on a daily basis. Previous OT experience conducting capacity assessments with people with dementia also helped. In total I conducted semi-structured interviews with only six people with dementia or cognitive impairment due to the complexity of gaining informed consent. I had already spent months interacting with each of these *abuelos* through participant-observation before conducting the interviews. This ensured that I could begin the informed consent process early, and continually revisit it to recheck and revalidate that they understood the research and the purpose of their contribution.

These *abuelos* I conducted semi-structured interviews with all still had strong long-term memory recall, but had some issues with their short-term memory. I followed Dewing's (2007) recommendation of initially learning about the person with dementia by speaking to their next of kin and people with whom they were close, and ensuring that they believed the person had capacity to understand and consent to the research. In this preparatory stage, I also spent time getting to know the *abuelo* myself, and understanding 'cues' for when they were 'in a relative state of well-being' (Dewing, 2007, p. 16). When it came to explaining the purposes of the study to the person with dementia, I would ensure I used repetition and asked the person to repeat back to me their understanding to ensure that they could both recall and understand what they were consenting to. Using this repetitive, gradual, staged approach to gaining informed consent enabled me to conduct semi-structured interviews with people with dementia and cognitive impairment.

One of the *abuelos* I interviewed was an 82-year-old resident at *Pueblo's* care home, Mari Carmen, who had been diagnosed with Alzheimer's Disease approximately a year before I met her.

Engaging as a volunteer at the care home, I observed that Mari Carmen spoke with insight about her diagnosis. She informed me of her diagnosis before staff did and understood that her memory was declining. When I explained to her that I was researching dementia she was interested and said she would like to help with my study as she felt passionate about the need to understand more about the condition. Following these conversations with Mari Carmen, I spoke to care home staff and her daughter about the possibility of conducting an interview with her and they agreed she would be a suitable candidate. Following Clarke and Keady's (2002) guidance on interviewing people with dementia I ensured I kept the interview short in duration and conducted it over multiple sessions. So I split the interview questions over two, 30 minute sessions. After speaking with Mari Carmen, we decided the best time to run the interview would be in the morning when she explained she felt 'more alert', which I understood as indicating that she might have stronger recall. I went over the information sheet and asked questions to check her understanding. When I ran the second part of the interview, I began by asking her about the purpose of the study and her role and clarifying anything she was unsure of. Dewing (2007) also advocated 'consent monitoring' with people with dementia who are involved in research. Ethnography made this possible, as I was engaging with Mari Carmen on a regular basis when I attended the care home as a volunteer, so when I came across her in the care home, I would take any opportunity to remind her of my study, thank her for her participation, and check she was still happy for her data to be used. Through this gradual, ongoing iterative process of gaining informed consent, made possible through regular, sustained ethnographic engagement, I was able to include interviews with some *abuelos* with dementia.

I also wanted to ensure I included some data drawn from *abuelos* who were at later stages of dementia and whose ability to narrate their own storied selves were disrupted, to give a fuller picture of the vast range of experiences of dementia and its care. Speaking to care-givers, I always ensured I gained informed consent to use the information they recounted to me, which included discussions of people with dementia they had cared for. However, I also wanted to include data I had observed myself from participant-observation in family homes and healthcare settings. Some of the observations I recount in the thesis of *abuelos* with dementia are upsetting or disturbing, but due to the cognitive and communication difficulties of these *abuelos* I could not gain informed consent using standard techniques and had to instead gain consent from their next of kin. This technique is known as 'proxy consent' and is recommended as suitable to use when researching with people with dementia who lack capacity to engage in informed consent (Black, Wechsler and Fogarty, 2013). If an *abuelo* with more advanced dementia was not able to consent to participate themselves due to cognitive or communication impairment, and I wanted to include an observation about them in the research, I would gain consent from their next of kin. This involved ensuring that

their next of kin was willing for me to include this observational data in the study. I also maintained, and emphasised to kin, the rigorous upholding of confidentiality.

Even if I relied on using next of kin for consent for my observations of people in latter stages of dementia, I would still ensure I was observing and monitoring the wellbeing of the person with dementia, to ensure my interactions with them were not causing distress. Hubbard et al (2003) examined the challenges and strategies for researching people with dementia in an ethnographic study of quality of life in institutional care settings. They emphasised ethnographic observation as a helpful technique for involving people with dementia in research:

‘Observation...enabled the researchers to ascertain the perspectives of residents with dementia...If the researchers had relied only on interview...then the voice of those with a dementia that affected their ability to communicate using conventional rules of syntax or their memory would have been ignored’  
(Hubbard et al, 2003, p. 360).

By engaging with *abuelos* with dementia over time through ethnographic participant-observation, I got to know *abuelos* on an individual level. This enabled me to monitor and protect their wellbeing and include observations of *abuelos*, who due to cognitive difficulties, could not narrate their own stories or give informed consent to participate using conventional approaches which relied on verbal communication. This ensured that this study was inclusive and involved the everyday experiences and realities of people who were living with dementia, rather than solely focusing on the experiences of their care-givers.

In researching such a sensitive topic, informants often became upset, particularly during in-depth interviews with family care-givers. Aronson, discussing older people’s care needs, found she inadvertently ‘exposed participants’ failures’ (Sinding and Aronson 2003, p. 100). I found interviews could trigger family care-givers to worry about their relatives’ declining abilities. Taking an empathetic approach, I tried using positive reinforcement to lessen feelings of exposure and build trust. However, my stay in Andalusia was temporary, thus another dilemma was whether it was ethically sound to develop close relationships with informants which were difficult to maintain post-fieldwork (DeWalt and DeWalt, 2011). This was particularly true of informants who I assisted in care tasks at home. I thus emphasised before agreeing to participate in care-giving with families, that I was only there for a limited period, reminding informants that I would no longer provide support once I left. One outcome of my stay was that an informant told me that due to my input with her elderly mother’s care, she had realised how valuable it was to have additional help and decided to

apply for government-provided homecare, which she had not previously done because she had thought it to be too bureaucratic a process.

Learning the language and cultural knowledge pre-fieldwork also protected informants from harm through avoiding misunderstandings. I already spoke Spanish and improved during fieldwork. I was conscious of my position as a British social anthropologist interpreting another culture and the power relations involved, avoiding 'othering' (Said, 1978) Andalusian culture. Having my partner with me, who is Andalusian, I believe meant people saw me as less of an outsider who was going to misrepresent them. Of course, it was not that simple, and people sometimes showed concern over what I was doing. Once at a festival with a group of friends from *Pueblo*, one of whom was the son of someone who attended the day centre, someone jokingly introduced me to somebody else as a 'spy' sent by the British government. Although meant as a joke, it seemed to indicate underlying concern around my research, confidentiality and representation.

ASA and ESRC guidelines emphasise confidentiality (ASA, 2011; ESRC, 2021). This is vital at community level, as ethnographers often gain information that informants do not want to share with neighbours, particularly when researching small communities where gossip travels faster (DeWalt and DeWalt, 2011). I had to exercise discretion within families, as I sometimes interviewed relatives within the same family. Researching Spanish families Holdsworth (2005) emphasised avoiding disclosing information from one relative to another. It was important I underlined this to each relative, so they could talk freely. Confidentiality is also important at public level, when writing-up/disseminating research to ensure informants cannot be identified, thus I use pseudonyms for places and informants and explained this to informants.

## **Conclusion**

This chapter has contextualised the ethnography through outlining the historical background and exploring methodological and ethical considerations. This thesis navigates how memory influences personhood within dementia care. I took this as a parallel to explore how collective memory, through processes of forgetting and remembering, has a profound influence on the development of collective national identity in Spain, Andalusia and *Pueblo*. I detailed how the Spanish state transitioned into democracy through actively forgetting its traumatic history. I explored how Andalusia, a region of traditionally working-class agricultural labourers with high levels of class consciousness, was historically oppressed during the civil war and resulting thirty-six-year dictatorship. This turbulent history caused the development of mistrust towards the central state

and its support systems and strengthened solidarity amongst family networks and local communities in Andalusia.

This led into a discussion of how a sense of moral duty to care for one's elderly parents is embedded into Andalusian values around family and personhood. This approach has influenced how people look after the elderly and people with dementia. A moral duty to care for one's elders can be seen in public health research findings from Spain and Andalusia, demonstrating a high prevalence of intergenerational households, kinship care of dementia and anti-institutionalisation discourses. Care culture in Andalusia is however shifting alongside social changes. A demographically ageing population, with increasing dementia rates, and women's increasing labour-market participation, combined with the arrival of rich northern European retirement migrants, who utilise formal eldercare services, is shifting Andalusia's approach to dementia and eldercare. The recent development of the Dependency Law, to provide state-funded care for dependent people serves as evidence of the increasing expectations on government to provide care. However, with the 2008 economic crisis, which heavily affected unemployment and economic growth in Andalusia, cuts were made to the Dependency Law and once again the endurance of the family network as the primary source of support was reinforced.

In the methods section, I described how personal experience influenced my methodology and field site choice. I outlined how I established active roles for myself at *Pueblo's* day centre, care home and carers' support group, which allowed me to experience the ups and downs of caring for people with dementia in these contexts. Over time I started participating regularly in the dementia care routines of local families. These interactions, developed through gradual development of trust over time, enabled people to feel safe to share their stories. Through combining narrative exploration with participant-observation I was able to explore how people's narratives of their dementia care translated into their daily lives. Finally, I dipped into some of the ethical issues that I encountered during fieldwork, concluding that the most effective way to ensure the ethical health of research is through ongoing, iterative, critical reflection.

## Chapter Three: The Autonomy of the Family and Interdependent Personhood

In this chapter I explore how the autonomy of the intergenerational family network in *Pueblo* is central to people's construction of an interdependent personhood that shapes dementia care strategies. I describe how lives interweave across generations through intergenerational households. Andalusian families confronted with dementia creatively deploy rotational kinship care systems to ensure relatives with dementia remain at home. The chapter portrays how a historical distrust towards the state still prevails in Andalusia which influences understandings of state-funded care. Andalusia's ageing population, rising dementia rates, and women's increasing labour-market participation combine with international discourses around state responsibility to shift views on care, with more families seeking care provisions from the state. Families experiment with morality through care; approaching *Pueblo's* day centre as a compromise between traditional approaches and formal versions of dementia care. Calls for state responsibility in elder and dementia care have led to the development of the Dependency Law aimed at providing basic care. State failings however, to deliver adequate care through this law, have led to families privately hiring low-paid migrant women to work as live-in carers; avoiding relatives with dementia requiring institutional care. The chapter thus reveals how, despite ongoing social change, Andalusian families strive to reformulate kinship care to maintain the autonomous interdependency of the family network and enable meaningful dementia care.

### Caring Across the Family Network

*'Buenas noches'* ['Goodnight'], I say for the fifteenth time, as I plant the last round of goodnight kisses on everyone's cheeks. I have spent the evening with the large extended family of Marina, who works at *Pueblo's* day centre. After dinner, I help Marina and her sister accompany their elderly mother, Inés, down the road to where she lives with her youngest daughter, before finally saying my last goodbyes and heading home. There seems to be an unwritten rule that goodnights and goodbyes must be spoken about for at least an hour before you go to bed or leave any occasion in *Pueblo*.

Having grown up in a family where a quick shout of 'night' is the most expected of you, I struggled with these protracted goodnight kisses during fieldwork in *Pueblo*, which felt unnecessarily drawn-out. However, they serve as a fitting everyday example of how families celebrated their need for one another. In this section, I describe the interdependent personhood generated across intergenerational families I encountered in *Pueblo*, exploring how this interdependency shaped dementia care strategies.

I first describe the intergenerational family households that were common in *Pueblo*, analysing how such environments deepened people's interdependent personhood and facilitated shared dementia care across family networks. I highlight the importance of home, showing how families, when faced with dementia, creatively deployed complex rotational care patterns to ensure *abuelos* remained at home or within family households. I



introduce families I met during fieldwork, describe the strategies of care they developed and what narratives they used to explain these.

### *Intergenerational Living*

Encountering families during fieldwork, I noticed that intergenerational households were prevalent in *Pueblo*. Some families lived in intergenerational households with extended family members living in one home together, sharing all shopping, mealtimes and household tasks. Others lived in intergenerational households that were divided into smaller sub-sectional units. I now describe the intergenerational households of several families I met in *Pueblo* and explore how they organised dementia care.

#### *Paloma's Household*

Paloma, a schoolteacher in her mid-forties, showed me around her large three-story intergenerational family house. She, her husband and teenage daughter lived on the top floor in their own self-contained apartment. Her mother and father, both in their early seventies, lived on the middle floor and her 98-year-old grandmother on the ground floor. Each floor had its own kitchen and bathroom. Paloma recalled how when her grandfather was still alive each household floor operated separately during the week and they would all eat together on the ground floor at weekends. However, recently her mother had started spending more time on the ground floor as she was assisting her grandmother who had developed dementia in almost all daily living activities. Paloma, her husband and daughter spent most weekdays on the top floor, whilst her mother split her time between the middle and ground floors to look after her own mother. Paloma's husband, Paco, runs a tutoring business in an extension to the side of the house. Paloma explained that she eats lunch at work, whilst Paco has lunch with her parents during the week. At weekends they all eat together on the ground floor:

'We're so lucky, as we each have our own space for when we want it, but we're always available if we need one other. If my mother is having a hard time with my grandmother, she can just call me and I come down and help'

This household allowed independence between the different generations. However, with everyone under one roof, the setup enabled different generations of family to regularly participate in everyday activities together, strengthening the interdependency of the extended family network. When Paloma's grandmother became dependent from dementia, she could remain in the family home as Paloma's mother was only on the floor above so it was practically straight-forward for her to come downstairs when care was needed. Paloma's mother's life had not changed dramatically, as

she could remain in her own home whilst providing daily care. Intergenerational households thus facilitate family members carrying out dementia care to relatives without care-receiver or care-giver being uprooted. The daily interactions, across different familial generations, that come from living together over many years, made the development into caring relationships of greater dependency a lesser, smoother transition, than had family members lived apart.

#### *Patricia's Household*

Patricia, a 58-year-old woman who had cared for her mother with dementia until she died, lived in the house next-door to her parent's old house. She had grown up with her parents and siblings and when she married, she and her husband bought the adjoining house and had a door installed that provided access from their living room into the kitchen of her parent's house. Patricia described how useful it was when her children were young, as her mother could pop in at any moment to help with childcare. After her father died, Patricia described how her mother became lonely and started spending every evening in Patricia's house. Years later, after dementia onset, Patricia's mother became unable to look after herself and Patricia started spending more time in her mother's house. Patricia and her siblings hired a live-in carer to provide additional help as Patricia was working full-time. Towards the end of her mother's life Patricia was more or less living with her mother, assisting with most of her daily activities:

'Looking after her as she got sicker was the hardest thing I've ever had to do. But how could I not help her? She'd not only raised me; she'd raised my children too.'

With the two households connected physically Patricia's daily routine remained intertwined with her mother's and care was understood to be reciprocal with both households looking after one another's needs. Patricia's description of her responsibility to care for her mother when she became unwell shows how kinship care of dementia was framed through narratives of gratitude stemming from reciprocal relationships. Leinaweaver's (2013) ethnographic work exploring kinship and gratitude, based in the small city of Ayacucho in the Peruvian Andes, is a useful aid to my analysis here. Leinaweaver revealed how processes of gratitude and ingratitude shaped the way people understood and acted on kinship in Ayacucho. Arguing that 'kinship is actively constructed' she displayed how differing constructions of kinship influenced eldercare practices (Leinaweaver, 2013, p. 555). She revealed how adult children of older dependent persons in Ayacucho, who felt grateful for having been granted privileges by their parents, such as education or financial resources, that had allowed them to achieve economic mobility, felt grateful to their parents. These adult children would express this gratitude through engaging in dedicated care-giving practices towards them as they grew older and became increasingly more dependent. Leinaweaver observed how older people

residing in a poorly-resourced care home in Ayacucho, would complain about their adult children's lack of gratitude for leaving them to be cared for by others in the care institution. Such insights reveal how eldercare and kinship responsibility to care can be guided by narratives of gratitude and ingratitude. Gratitude is thus intrinsically connected to ideas of obligation, relatedness and responsibility. This can be seen to be reflected in Patricia's case, who highlighted how the presence of her mother throughout her life, caring for her as a child, and then as an adult, and in helping with her children's upbringing, meant she had benefited from her mother's care. Having benefitted from care offered by her mother, Patricia thus ensured that, despite the demanding nature of caring for her mother with dementia, it was vital she acted out and displayed her gratitude. In asking 'how could I not help her?' she alluded to the ingratitude she would expose if she did not offer her care. These intergenerational households, through entangled family members' routines where daily life was negotiated across generations, generated gratitude that stimulated care-giving. Gratitude influenced feelings of obligation and responsibility around kinship that shaped the strategies of dementia care in *Pueblo*.

#### *Alba's Household*

Alba, the physiotherapist from the day centre, lived in the outskirts of *Pueblo* beside her family's olive plantation. She lived in a house with her husband and two young children, her parents and grandmother in another house within the same plot and her husband's brother and family in another. One day, after a shift, Alba invited me to look around her family's home. Her parents had a large dining room where they all congregated for lunch daily, cooked by her mother. Alba laughingly recounted how after lunch, with everyone's bellies full and the warmth rising from under the *mesa camilla*<sup>4</sup>, tired from a morning's work at the day centre she would drift into an afternoon siesta. She would often awake to the snores of her father, husband and brother-in-law, who after a morning's work on the olive plantation were also exhausted. Taking a siesta together was an everyday activity that Alba shared with her family that provides an example of the intimacy and closeness of extended family members living in intergenerational co-residences.

Alba's husband and brother-in-law worked on the family-owned olive plantation, and everyone would help during the olive harvest. The income from the olive plantation was shared across the extended family network. The co-residence also made it straight-forwardly practical when Alba went to work at the day centre that her mother could drop off and collect her children from school. Her mother thus occupied a middle position, similar to many family care-givers I met in

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<sup>4</sup> *Mesa camilla*, translating into English as 'little bed table' are commonly used tables in Andalusia, which have heaters underneath used to warm households with minimal cost by avoiding heating the entire building.

*Pueblo*, who, in late middle-age, were responsible for providing care to both younger and older relatives (see chapter four). Family finances were shared across the extended family network, as families engaged in everyday tasks like shopping, cooking, and agricultural work together.

Such intergenerational co-residences meant that if older relatives started experiencing health issues, younger relatives could offer support with less disruption to their own lives. Family members formed important parts of one another's everyday lives, stretching across different generations, and spent much of their day-to-day life socialising and engaging in activities together, facilitating a deeper understanding of differing generational issues and a closer interdependent personhood across family networks. This constructed an intergenerational dependency across multiple generations that caused people's sense of self to be closely tied up with extended family networks and shaped the dementia care that people engaged with in *Pueblo*.

### *Rotational Kinship Care*

*'personas somos como los árboles. Transportar uno viejo es muy difícil porque las raíces se agarran'*

[‘people are like trees. Transporting an old one is very difficult because the roots cling’]

(Sosa, 2019)

In *Pueblo*, there was a strong narrative around the importance of home. *‘No hay ningún sitio como tu casa’*, equivalent to the English ‘there’s no place like home’, was frequently cited by family care-givers when discussing living arrangements for relatives with dementia. Family care-givers emphasised wanting to keep relatives at home, even if this necessitated complicated care strategies. In *Pueblo*’s care home, visiting relatives usually stressed the care home had been *‘el último recurso’* (‘the last resort’) and was only taken after many months or years of trying other strategies. Families appeared keen to demonstrate they had not resorted too readily to institutional care, as this seemed to contradict a local moral code that set eldercare as younger kin’s duty. This reflects anti-institutionalisation discourses in Spain identified by previous research, such as Rodríguez-Martín et al (2014), who found care home residents’ relatives expressed severe guilt about the person having moved into institutional care, describing having failed their ‘moral duty’ to care for their relative at home.

When advancing dementia symptoms prevented relatives from looking after themselves independently, family care-givers creatively developed complicated rotational care systems to

ensure the relative could stay at home. Families developed rotational care strategies, despite the disruption this caused them. Rotational care often involved various relatives operating under a rotational rota, whereby they would spend temporary periods living in the home of the relative with dementia, before another relative took their place. For example, a daughter would spend three months living with her elderly mother before being replaced by another sibling who would then stay for the following three months and so on. Or the rotation could occur within the same day, for example, an eldest daughter might spend every morning at their elderly mother's house where she would remain until the evening, before being replaced by another sibling who would spend the night at the elderly mother's house to be replaced once more by the elder sister the following morning. In another approach, when relatives were unable to rotate themselves due to childcare or other issues, the person with dementia would rotate between various relative's households, spending extended periods, for example three months, in each, before rotating on to the next. Although family caregivers frequently described this as unideal as the *abuelo* had to be moved from their original home, it was still considered preferable to moving into institutional care or being cared for by formal carers. Such rotational care systems have been identified by Rivera et al's (2014) study of eldercare in Spain. They found the prevalence of such care systems was increasing as more women entered the labour-market and people were living longer. In response to these social changes and fuelled by a strong cultural rejection of long-term institutional care for older relatives, families formulated complex rotational care patterns to ensure relatives with dementia remained at home, or within the homes of extended family. Below I introduce families I spent time with in *Pueblo* and describe the rotational care patterns they developed to facilitate dementia care.

#### *Andrea's Family*

'We all do our bit,' explained Ana, a middle-aged woman looking after Andrea, her 92-year-old mother at her home as part of a rotational care pattern with her sisters. Ana explained she is the youngest of three sisters and four brothers. After Andrea had a series of mini-strokes, her mobility reduced and she became noticeably more forgetful, following which doctors diagnosed her with vascular dementia. Ana described her mother's decline as occurring gradually over many years. Andrea had worked much of her adult life, selling *churros* and fried potato chips from a kiosk on the corner of a nearby plaza, living with her husband who worked in the olive plantations. Working at the kiosk, Ana described her mother as having been an extremely sociable person. When her husband died, Andrea went to live with her daughters who still lived in *Pueblo*, splitting her time between their homes. Andrea's cognitive and physical health eventually became so poor that in the last two years she became bedbound. Ana and her siblings shared the cost of a hospital bed and changed the rotation pattern to every five months, as their mother was finding the transitions

between rotations more difficult. Andrea can no longer speak or lift herself up, although she can smile and make eye contact, but spends most of her time sleeping. Ana said she cannot be sure whether Andrea really knows who she or her sisters are anymore. Ana's four brothers, who all live locally, do not participate in the rotational care but visit regularly. She understood her brothers to be naturally less capable of doing the everyday care than her sisters, indicating a gendered approach to eldercare (see chapter four).

Ana described her family as '*obrero*' ('working-class'), but as she was one of eight siblings, together they could have afforded formal care costs, but she stressed they preferred looking after their mother themselves rather than placing her in a care home:

'I have a friend whose mother is in the care home. The staff do their best, but of course it's not the same as the care a daughter gives her own mother. We're her blood. We've known her our whole lives. We know who she is and what she wants.'

Despite Andrea's inability to verbally communicate her desires, Ana understood that she, as daughter, was able to know what Andrea wanted and continued to engage her in meaningful, personalised interactions. Ana spoke to her mother to update her on family events, showed her recent photographs of her grandchildren, pinned *Pueblo's* calendar on her bedroom wall and dressed her in the same clothes she had worn the rest of her life. These everyday practices can be understood as attempts to cultivate belonging in Andrea. Bissell et al (2019), in exploring the concept of belonging, argued that belonging cannot be assumed, but necessitates active work. Ana, by continuing to talk to Andrea about family goings-on, and by placing certain objects within sight-photos of family, *Pueblo's* annual town calendar- was attesting to her mother's unique belonging to her family and the wider community of *Pueblo*. Ana, through her care practices, was thus fostering belonging in her mother.

These personal interactions that Ana continued with her mother, despite her cognitive transformation, can also be understood as 'practices of substitution' of personhood (Svendsen et al, 2018, p. 20). Ana explained her own and her sisters' relatedness to their mother as giving them a special ability to provide enhanced care that a formal carer would not possess. The shared rotational care system meant that 'practices of substitution' were collectively engaged in by the kinship network. When Ana finished her turn looking after her mother, she would pass her to whichever sister was due next, giving a detailed handover, and in doing so, ensured that 'practices of substitution' were continued by her sisters. This ensured each sister played a part in the maintenance of Andrea's personhood and highlights how the interdependency of the family

network, through caring using rotational shared care, enabled this. As the sisters substitute for one another through the rotations, care practices both substitute Andrea's personhood and the interdependency of the family network. Such dementia care practices in this context, I thus suggest, take on a collectivity, whereby the shared rotational care of the dependent person deepens their interdependent personhood and strengthens the relationality of family networks.

Such 'practices of substitution' through care-giving can be performed by formal carers. However, family care-givers in *Pueblo*, like Ana, understood these care-giving practices as more effectively reaffirming to their family member's sense of personhood when performed by a close relative, due to a special kind of kindred connectivity. Svendsen et al's ethnography took place in a Danish dementia specialist unit, where there is 'almost no expectation' to care for dependent elderly relatives at home, and it is instead expected to be entirely provided by the welfare state (Svendsen et al, 2018, p. 29). They described how formal carers adopted this embodied role of sustaining the personhood of people with advanced dementia who they had no previous connection to. Yet Ana's description suggests she understood herself and her sisters as taking on special kindred roles as family care-givers, which granted them an enhanced ability to sustain their mother's interdependent personhood, more effectively than would an unrelated formal care-giver.

This sense of younger adult kin possessing a special kindred role in the care of elderly relatives can be explored further through drawing comparisons with Lamb's ethnography (2000) exploring people's experiences of ageing in a rural village in West Bengal in India. Lamb described how junior kin would unquestioningly accept the role of providing extremely dedicated everyday care to their elderly relatives, including taking responsibility for intimate care-giving tasks like washing and toileting. Lamb explained how people in West Bengal conceptualised this as part of '*seva*', considering it as a sacred role of service that enabled them to complete a life-long circle of intergenerational kinship reciprocity. This cycle of family reciprocity dictates how, as parents look after and care for their children as infants, it is the children's obligation as grown adults to provide dedicated care to their parents when they reach older age. Lamb analysed how people in West Bengal conceptualised of a deeply interdependent personhood amongst intergenerational kin, whereby they were bonded together as a family through close social attachments, referred to locally as nets of '*maya*'. People from the same family were considered to share the same body, described locally as '*sapindas*: a word formed from *pinda*, "body particle" or "ball of rice," and *sa*, "shared" or "same"' (Lamb, 2000, p. 36). People described how adult children would care for their aged parents, including when they became incontinent, cleaning up their urine and excrement 'lovingly and without complaint' (ibid.). Such dedicated practices of kinship eldercare ensured that an elderly

relative's interdependent personhood was maintained, as was this sacred intergenerational cycle of family reciprocity.

Despite being a geographically distant cultural context from Lamb's (2000) research setting in West Bengal, Ana's description of possessing a *special* ability that enabled her to provide careful and dedicated care to her mother in older age, because of their kinship connection, resonates with Lamb's findings. Ana, and her sisters, as close kin, were able to uphold their mother's interdependent personhood through daily embodied care-giving practices, and emphasised their ability as higher than that of formal care-givers who were unrelated to their mother. The use of their rotational care system avoided Andrea requiring formal care and facilitated the engagement of all sisters in performing their special care-giving roles as close family members, to ensure that their mother's care was kept within the kinship network. Ana's description of her role suggests that she understood herself, as a daughter, to possess a special ability to sustain her mother's interdependent personhood that was only fully experienced by close kin.

#### *Inmaculada's Family*

83-years-old Inmaculada had been diagnosed with Alzheimer's disease and was being cared for by her three adult children who used a rotational care system. Her youngest daughter, Paula, explained how her mother's forgetfulness had started to impact her ability to perform basic daily living activities, and how, after an incident when her mother left the kitchen gas on, she had invited her to come and live with her for several months at a time, followed by stays at her sister's and brother's homes:

'I said, '*mamá*, your life will be so much easier if you come to live with us. You won't have to worry about cooking and cleaning and all these things that you're getting in a muddle over.' But she couldn't stand the idea. She said that she would rather die than be moved from her home!'

Paula explained her siblings were all close to Inmaculada and would have liked to have her move into their respective households. But given Inmaculada's determination to stay in her own home, Paula and her siblings designed a plan to ensure Inmaculada could stay at home. To enable Inmaculada to remain in her own home, she and her siblings each moved into Inmaculada's home for periods of several months before being replaced by one another in a rotational system.

Paula praised the rotational care system, explaining how she and her siblings, after Inmaculada's diagnosis, had initially been concerned about the '*carga*' ('burden') of looking after their mother. However, Paula stressed that the rotational care system they had formulated, by



dividing care across the three siblings, could '*compartir la carga*' ('share the burden'). They had all worried about how things like work and childcare could be affected by care-giving. However, they organised the rotational care system strategically to minimise restricting impacts. Her brother worked on her family's olive plantation; the quietest time of work being the summer. Her sister worked as a teacher, so was free at intervals throughout the year for school holidays. Meanwhile, Paula helped on the family's olive plantation alongside temporary contracts cleaning for the council. With these different working routines, they organised the timetable of care rotations flexibly to ensure it minimised disruption to their paid work. Paula explained that they generally spent two or three months per rotation, but these were flexible alongside their other commitments. Although she tended to spend longer stints at her mother's house than her siblings, she felt this was fair as she had the least work commitments and was able to have summers free, as this was when her siblings were most available, allowing her to look after her children during the summer holidays.

#### *José's Family*

José was 85-years-old, and in the early stages of Alzheimer's disease. I met José when he began attending *Pueblo's* day centre. Until retirement, José had been an olive farmer and shepherd and had never married or had children, having spent the majority of his adult life living with his mother, brother, sister-in-law and their children. After his mother died, he continued living with his brother and sister-in-law, whose children during adulthood moved away from their parental home. Yet when he started having memory problems, his brother and sister-in-law, being elderly themselves, felt unable to look after him. So, their adult children, José's two nieces and nephew, created a rotational care system between them, whereby José spent three months in one home before rotating to the next. He later started attending the day centre from 9am-6pm during the week.

Despite the benefits of the rotational care system to his nieces and nephew, in sharing the care to minimise disruption to their lives, José's life was disrupted. Shifting from home-to-home every few months caused José considerable stress, which seemed to worsen his memory. One day I ran into him looking lost:

As we were leaving the plaza, I noticed José walking in front of us looking somewhat confused. We went to greet him and asked him how he was, and he replied 'Well, right now, I'm lost'. He said he was looking for his '*sobrinos*' [nieces/nephews], who he'd thought he'd been with. He seemed to have semi-forgotten me, saying he recognised my face but wasn't sure from where. We took him to where he said his niece lived. Although he could remember the way, when we arrived no-one answered the door. Luckily, a neighbour saw us and

explained that José was not staying at his niece's anymore but was now staying with his nephew in the lower neighbourhood. She offered to accompany José to his nephew's house, saying 'This happens all the time'.

Research suggests unfamiliar environments and disruption to routine can be difficult for people with dementia and increase confusion (Digby, Lee and Williams, 2016). An issue with the rotational care system is that it requires the constant breaking of a familiar environment and re-adjustment to a new environment. In José's case, he had never lived in any of the homes of his adult nieces and nephew before. However, when I ran into him looking lost, he appeared to have recognised his dependency on his nieces and nephews, thinking that he had just been with them, and he was able to get to his eldest niece's house by memory. However, he had forgotten that he was currently staying with his nephew, unsurprising given that he was rotating so frequently. The rotational care system between his nieces and nephew's homes then, appeared to increase his confusion.

Family care-givers were aware of the confusion the rotational care systems could cause and would search for strategies to prevent this. Ana explained that due to her mother's struggles in readjusting after a care rotation, her and her sisters had changed the length of rotations from three to five months. However, there was inevitably a level of disruption that still occurred. Mattingly's (2010; 2014) reference to family care-givers acting within 'moral laboratories' is useful here. Families, in weighing up different strategies of care and how these impacted on their lives, were faced with complex 'moral deliberations' (Mattingly, 2014, p. 4). Andalusian family care-givers' attempts to restructure and experiment with differing frequencies of care rotations could be seen as 'experiments in how to live' (ibid.). Engaging in care for relatives, they became 'experimenters' in how to maintain moral selves and relationships through unpredictable circumstances.

Speaking with José several days later at the day centre, he had completely forgotten the incident. I asked him about the rotational care system, and he commented:

'Of course I don't like it! I'm homeless now! Changing all the time. Living out of a suitcase. I miss my old house, with the courtyard and the chickens, and I miss my brother and sister-in-law. And the worst is that my nieces and nephew leave me shut up all day in this *cortijo* [farmland/plot]<sup>5</sup>. But what can I do? I have to accept it. After all they're not my children. I should have got married and had children of my own.'

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<sup>5</sup> José, due to his confusion as a result of Alzheimer's disease, would refer to the day centre as a *cortijo*

Another issue with the rotational care system, which José's response touches upon, was that it interrupted *abuelos'* sense of belonging, causing them to feel displaced, or even 'homeless', as José defined himself. José believed he was in this situation because he was being cared for by his nieces and nephew, rather than his own children, indicating a belief in the closeness of the relatedness of the care-giver to care-receiver affecting the quality of care given. This was despite having lived with his nieces and nephews throughout their childhood; the more distant kinship link he still felt played a part in the care he received. However, many *abuelos* were cared for by their own children through rotational care systems. Although many I spoke to expressed a view similar to José's of feeling displaced, others reported liking the system as they felt it allowed them to spend time with all their children.

### **Shifting Attitudes around Eldercare**

I now explore perceptions of state-provided dementia care. I suggest historical distrust of the state prevails in Andalusian families, influencing attitudes towards state-provided care. I also analyse how Catholicism may further affect perspectives. Andalusia's advancing life expectancy, women's increasing labour-market participation, and growing dementia rates, alongside global discourses around state responsibility and recognition of dementia as a disease, are shifting views on kinship care, with more families turning to state-provided care. Andalusian families experiment within shifting 'moral laboratories' (Mattingly, 2010; 2014) of care to creatively reformulate long-established strategies of kinship care. I introduce *Pueblo's* day centre, founded to provide formal daytime care to people with dementia. I present narratives of relatives, staff and service-users, known locally as *abuelos* (grandparents), who portray the centre as '*un punto medio*' ('a midpoint/compromise') that balances traditional family approaches with formal care.

I then reveal how calls for state responsibility have led to the development of the Dependency Law in Spain. I describe how a historic distrust of state mechanisms has accelerated through the failings of Andalusia's local government to provide adequate care through this law. Families described waiting for state-provided care for unknown lengthy periods, enhancing a deeply-engrained dependence on the family as Andalusian's main support. State incompetence to provide sufficient care has led to an increasing trend of families privately hiring low-paid migrant women to work as live-in carers, enabling dementia care to be kept within family homes.

### ***Resistance towards State Care***

Returning home late after visiting their mother Paquita in hospital, her two eldest children, Silvia and Antonio, carried bags full of food-storage containers.

‘No need to prepare anything for dinner tonight’, Antonio declared, brandishing the bag of containers triumphantly, ‘We’ve been given food from the hospital!’

‘The nurses insisted we take it home,’ Silvia continued, a look of bewilderment fixed across her face, ‘they were asking if we were mum’s registered carers and if we had some sort of a carer’s card! We said, ‘well, she’s our mother, so of course we’re caring for her!’

My partner’s aunt, Silvia, and father, Antonio, had been caring for their elderly mother, Paquita, using a rotational system of care with their sister, Flora, for the last fifteen years, yet did not recognise themselves as ‘carers’ in any official sense. Their bafflement with the free food implied a lack of understanding that healthcare services could support families as well as patients. The food, distributed by the hospital through the *Tarjeta Cuidado* (Carer’s Card) policy, founded by Andalusia’s local government in 2007, was aimed at supporting informal carers of persons with dementia, including the right for carers to be given free meals whilst the person they cared for was in hospital (*Junta de Andalucía*, 2007).

Such reactions to state-provided support for family care-givers were common amongst families I encountered during fieldwork. People seemed to lack expectation of state involvement into what had always been considered a family issue. However, as Silvia and Antonio seemed impressed by the hospital-provided food, I asked them whether they had considered applying for help with Paquita’s care from the government’s *Ley de Dependencia* (Dependency Law), but Silvia shook her head:

‘There’s no need! We’re family and there are three of us. *Mamá* looked after both her parents when they were elderly, and her mother was unwell for years...Why would we want outsiders involved if we can manage it between ourselves?’

I looked towards Antonio, who let out a sigh.

‘It’s a lie!’, he barked disparagingly. ‘I know people who’ve requested the Dependency Law, but waited so long that their relative died before any help was given!...politicians say they’re going to help in these matters but everybody knows in the end you have to look after yourself and your family.’

Silvia and Antonio understood care of elder relatives as having always been a private family matter, with Silvia stressing how her mother had looked after her own elderly parents and that they should therefore continue this pattern. Antonio's comments expressed distrust towards government capabilities. Many families I met in *Pueblo* shared similar feelings towards the state. Caring for older relatives was considered a family tradition that had worked for generations without the intrusion of unreliable state-involvement.

The roots of this pessimism can be traced to the region's historically turbulent relationship with the Spanish state. Under Francoist rule, many Andalusians were killed or imprisoned, whilst poverty and famine ravished the region. This led to a distrust of state institutions, which were seen as not only inefficient but hostile and repressive. The sociological effects of this period had long-lasting detrimental effect on civic values, making people 'pessimistic in social and collective manners' (Cazorla, 2010, p. 4) and leading to a deeply embedded reliance on family for all forms of social and economic life. This 'collective pessimism' and insular reliance on kinship networks 'all but eroded the values that support civil society' (ibid.). State care of older people eroded along with it, thus strengthening the importance of kinship eldercare. This included those with dementia, whose care had, until recently, been 'exclusively considered a family responsibility' (Lillo and Riquelme, 2018, p. 162).

Religiosity may have also influenced attitudes towards eldercare. The presence of Catholicism in *Pueblo* was ubiquitous, with Catholic rituals dominating the community's calendar and being incorporated into eldercare strategies (see chapter five). Franco's thirty-six-year rule was strongly supported by the Catholic Church, and despite local resistance to the dictatorship, it ensured Catholic doctrine was instilled across society's institutions (Cazorla, 2010). Weber [1930] (2001) famously stressed how the Protestant Reformation with its emphasis on individualism, self-reliance and productivity, formed a striking distinction from Catholicism, which centred around authority and spirituality. Reher (1998) argued these differing religious outlooks had fundamental implications for the social organisation of family life and solidified fundamental contrasts between Northern and Southern European cultures. Spain, through Catholicism's influence, he claimed exhibited strong familial interdependency and solidarity that resulted in eldercare being understood as the responsibility of the family rather than the state.

After Franco's death, the Spanish Constitution was written, which stated that under new democratic rule, older people would be entitled to social support, managed by regional governments (*Constitución Española*, 1978). However, despite this constitutional right, recognised in the immediate democratic transition, it was not until 2007 that the Dependency Law finally initiated

basic social care services to people assessed as 'dependent'. This legislation was further delayed and not enacted until 2015 and in significantly reduced form, due to huge public spending cuts made in response to the 2008 economic crisis. The Dependency Law has now led to the development of homecare for older people on the minimum pension in need of care (Lillo and Riquelme, 2018). Yet, many families, like Silvia and Antonio's, refuse to refer their families to social services despite being eligible for these provisions, feeling that eldercare, having always been managed by the family, is not a matter the state need be involved in.

### *Growing use of Formal Care*

By 2018-19, when I was conducting fieldwork in *Pueblo*, attitudes towards state-provided eldercare were already shifting under complex processes of social transformation, fuelled by Spain's lengthening life expectancy, accelerating eldercare needs, rates of dementia, and women's increasing presence in the labour-market. These factors, combined with increases in people's everyday exposure to global discourses around state responsibility and the medical recognition of dementia as a disease, legitimised the need for state social care. People recognised that dedicated care for one's elders was now a somewhat 'dated' viewpoint. During an interview with Paula, who I introduced earlier, she remarked:

'How do I explain it? It's that here, in Andalusia, and above all in the *pueblos*, we're not like you [referring to British people]. We're still stuck to the family. In fact, when she [her mother] was bad, worse, I would sleep in her room with her. Even in her bed if she wanted me to.'

This comparison of Andalusian to British approaches to eldercare was made to me quite regularly. People explained British culture as more 'modern' than Andalusian culture, which was seen as traditional and 'still stuck to the family'. Thus, whilst many middle-aged people I spoke to in *Pueblo* perceived the moral duty to care for one's elders as important, they recognised this as a declining cultural practice that was reducing alongside social changes. Paula stressed that, although she and her siblings engaged in time-consuming care-giving to their mother, she did not expect this of her own children:

'Yes, I do this for my mother, because she expects it...But I don't have this expectation for my children...I don't want them to lose opportunities by looking after me.'

Paula's comments show she understood the kinship care she provided as problematic and dated and did not wish it upon future generations. Although Paula emphasised the merits of rotational care in sharing the responsibility, she still described the care itself as '*una carga*' ('a burden'). Her wish for her children not to miss opportunities indicates a shift to a more neoliberalist attitude desiring economic mobility for her children. Yet, the reality that she and her siblings were still engaging in dedicated rotational care, which caused significant disruption to their lives, also shows some acceptance and desire towards the traditional kinship eldercare approach.

Paula's perspective demonstrates how attitudes towards kinship eldercare have continued to shift since Collier completed her ethnographic research in an Andalusian *pueblo* in the 1960s and 1980s. Collier first began her ethnography in the 1960s, but when she revisited the community in the 1980s, she saw how a cultural transformation had started alongside Spain's democratic transition. After the 1978 fall of Franco's dictatorship, profound social change swept across Spain and Andalusia. No longer operating their lives under tight control, people began to reconstruct new identities under democracy. Returning to the *pueblo* in the 1980s, Collier found Andalusians expressed deep concern at the way democratic transition was causing a 'moral decline' in behaviours and attitudes (Collier, 1997, p. 5). Many of the *pueblo's* adult children had moved away since her original visit and were now living in cities. Some had acquired jobs and economic prosperity much higher than their parents. Collier sought out these informants and found they projected a different narrative and 'painted a happy picture of progress from repression to freedom' celebrating the new opportunities brought by social mobility (ibid., p. 5). Back in the *pueblo*, elders complained of children's unwillingness to return to care for ageing relatives. Paula and her siblings' continued commitment to provide dedicated care to their mother at her home in *Pueblo*, demonstrates how such conflicts were still present in Andalusia, and that families were finding new strategies, such as rotational care systems, to prevent such conflicts from arising and detrimentally impacting on relationships. However, the attitude of middle-aged people in *Pueblo* by 2018-2019 was that their own children's generation should finally be free of this responsibility, constructed as a burden. This indicates a growing acceptance of this shift in attitude away from traditional forms of kinship eldercare. The shift was no longer seen as a decline in moral duty but rather a progressive and desirable social change that opened doors for economic opportunities, reflecting the adoption of a more individualistic neoliberal outlook.

*Pueblo's Day Centre as 'un punto medio'*

The day centre in *Pueblo* provides further evidence of the shift away from kinship eldercare, yet also indicates how people still valued kinship eldercare but had adapted it to modern-day demands. The majority of people who attended *Pueblo's* day centre lived with, or relied on, regular support from family. The day centre could thus be understood as another attempt at negotiation by family care-givers in *Pueblo*, who were attempting to fulfil duties of kinship care whilst managing other commitments. The day centre operated Monday to Friday, between 9:00 and 18:00, with capacity for twenty-five service-users, who were referred to as '*abuelos*', translating into English as 'grandparents'. The majority of *abuelos* had some form of dementia. A typical day ran as follows: the driver, Alberto, and only male carer, Miguel, collected *abuelos* from their homes in the centre's van; on arrival, *abuelos* had breakfast and then went into the gym for light exercise supervised by the physiotherapist; *abuelos* were then seated at tables divided by cognitive ability, with each group engaging in specified cognitive exercises under a carer's supervision for two hours; *abuelos* then rested in the lounge before the more dependent *abuelos* had lunch in the dining room, supported by staff, whilst the less dependent group engaged in craft activities, after which they were served lunch; afternoons were less busy, *abuelos* who needed assistance were taken to the bathroom, and most *abuelos* had a siesta on the armchairs in the day room where they spent the rest of the afternoon, other than a short break for an afternoon coffee/snack; by 16:30 Alberto and Miguel started dropping the *abuelos* home, whilst some families collected relatives themselves.

Of the twenty-five *abuelos* who attended the day centre, only two lived alone, and only one did not have someone from their family taking a significant role in their care. José, who I introduced earlier, began attending the day centre whilst I was on fieldwork. José's eldest niece, Antonia, described the intense relief she had experienced since José had started attending the centre. She described the day centre as '*un punto medio*' ('a midpoint/compromise') as it allowed her and her siblings to remain in work without the worry that José was alone at home putting himself at risk. Yet, they were still able to spend quality time with José in the evenings when he returned from the day centre.

Other family care-givers described agonising over the decision to take their relative to the day centre, expressing guilt at being unable to look after them themselves, but stressing that work, childcare and other commitments made this impossible. Families rationalising over decisions about whether to enlist the provision of the day centre to support their relatives' care can be understood through Mattingly's (2010; 2014) analysis of 'moral laboratories', her term for families' engagement in ethical experiments in how to provide care. Families in *Pueblo*, struggling to provide full-time care to their dependent elders, experimented with moral frameworks of expectations to care, negotiating



traditional kinship care with newer formal care strategies. Use of the day centre thus suggests many relatives did still value kinship eldercare by sharing their home with their elderly relative and providing significant care, but, recognising full-time care provision as impractical, had accepted the help of the day centre with gratitude for '*el punto medio*' ('the midpoint/compromise') it offered.

Conversations between *abuelos*, relatives and staff frequently compared people's family situations and care. Such conversations revealed how people negotiated complicated challenges in the face of dementia and shifting attitudes to kinship eldercare. One *abuela*, Manuela, who after a visit from her daughter who lived in Barcelona started using the day centre, was the subject of much discussion amongst staff and *abuelos*:

'Imagine! Five children and you end up in a place like this!' Julia [a carer] remarked to Sandra [the housekeeper/cook]

'Yes, I know.' Sandra replied, nodding, 'Though I did see the daughter from Barcelona that came in with her and she seemed worried about her. It seems like she's doing the best that she can. But what can she do? She's at the other end of the country. And Manuela said she's caring for a daughter with disabilities too. It's the one in Málaga that I don't understand. Why's she not more involved? She could come and visit at weekends at least.'

Manuela was 86-years-old, had been widowed four years ago and had five adult children. Her three sons lived in a nearby town, her eldest daughter in Barcelona, and her youngest daughter in Málaga. The eldest daughter had been trying to convince her mother to move to Barcelona since her father, Manuela's husband, had died. She had a suitable room available in her flat and was not in employment as her daughter had disabilities so she stayed at home to care for her. When she admitted her mother to *Pueblo's* day centre, she explained she felt upset that her mother kept refusing her invitation to come and live with her. Manuela was in good health for her age. She still completed all her shopping, cooking, household chores, organised doctor's appointments and managed her medication, making her significantly more independent than other *abuelos* at the day centre. After a recent fall, however, she was going out less. Her daughter was worried about Manuela being home alone all day as she was getting lonely and at risk of falling, which was why she had decided on the day centre.

When I asked Manuela why she was declining her daughter's invitation to live with her in Barcelona, she explained she felt too old for change and would miss her house, *Pueblo*, and seeing her sons, who she said visited her as much as possible despite working full-time. She said her

youngest daughter, who was in Málaga, over an hour's drive away, sometimes visited, but was also working and had children. Staff and other *abuelos'* criticisms were heavily directed at the youngest daughter. I found myself questioning their seemingly harsh judgement as Manuela was largely independent, had lived in *Pueblo* her entire life, and had family nearby, so I could understand her decision not to want to move to Barcelona. Staff and other *abuelos* frequently expressed their disapproval that family were not around sufficiently. Julia, a carer in her mid-50s, compared it to her own late mother, who she had visited every weekend, despite working at the day centre full-time and her mother living over an hour and a half's drive away. She described it as terrible that Manuela's daughter visited so rarely when her mother lived alone and felt this should have been the first change made, rather than placing her in the day centre, which was largely used by *abuelos* with dementia. Such disapproval indicates the presence of gendered outlooks around kinship eldercare, which placed higher expectations on daughters to care for elderly parents than sons (see chapter four).

Many people in *Pueblo* still saw duty to care for one's elders as an obligation that should be prioritised over staying in paid employment, indicating that, despite social and economic transformations, a neoliberal mindset had not been fully accepted by everyone. Meanwhile others, who had moved away from *Pueblo* through social mobility, no longer saw this as realistic and considered paying for care of one's elderly parents a reasonable alternative if adult children could not logistically provide care themselves. Others sought a middle-ground by inviting older relatives to move in with them, whilst using the day centre. Decisions about who, where and how to provide eldercare thus reflected the changing socioeconomic context of everyday life in Andalusia, with frequent contestations emerging in the differing approaches to family expectations and care. Mattingly's (2010; 2014) conceptualisation of 'moral laboratories' is again helpful, as families experimented with how to provide care that negotiated the spaces between past, present and future moral expectations. The distress of Manuela's daughter at her mother's refusal to come and live with her in Barcelona, displays how generational conflicts emerged. Families thus faced 'ongoing moral deliberations' (Mattingly, 2014, p. 4) around care. Care strategies were scrutinised and judged against the subjective moral compasses of others.

### *Spain's Dependency Law*

Changing attitudes around care were fuelled by Spain's growing life expectancy, advancing dementia rates and women's increasing labour-market participation. These issues reflect global trends of ageing populations, which are increasing discourses around state responsibility to provide eldercare.

In Andalusia, public pressure had translated into measures being taken by the regional government. The most prominent of which was the *La Ley de Dependencia* (The Dependency Law), formulated in 2007 (Casanova, Lamura and Principi, 2017). The Dependency Law is designated to regional governments of Spain, resulting in a lack of national consensus around eldercare policies (Lillo and Riquelme, 2018). *Pueblo's* local council therefore received their care budget from the Andalusian government and was responsible for managing its distribution. I interviewed Alfredo, who was responsible for managing *Pueblo's* homecare budget. Alfredo explained that care demand was increasing faster than resources had been budgeted for. The waiting list for *Pueblo's* homecare service was extremely long and most people waited over a year from assessment to care being implemented. Speaking to people who themselves or relatives had been assessed as eligible and were awaiting care, there was much cynicism around the law. Sandra, the day centre's housekeeper, whose mother was awaiting a care package under the Dependency Law criticised:

‘People end up waiting until they die! That’s what the waiting list is for. It makes you think something’s being done, when actually you wait so long that in the end the person dies waiting for the supposed care to arrive.’

Many expressed similar views about the Dependency Law being a farce and that the government was merely trying to gain popularity. Others complained they had waited so long that by the time care was implemented, their relative had become more dependent than when the original assessment was conducted, so the care allotted did not meet their increased needs. If they tried to request another assessment, they were faced with entering onto a new waiting list for another assessment. People awaiting lengthy unknown periods of time for essential care were thus left powerless at the hands of the state. Auyero's (2012) ethnography of people seeking welfare in Argentina analysed how through waiting lengthy unknown periods for minimal state-funding, poor Argentinians unconsciously learnt their domination by the state. In *Pueblo*, many families expressed that despite the difficulties of eldercare, they preferred this role being taken on by their own family, to avoid the powerlessness that people experienced awaiting state-funded care. The length of waiting times for the Dependency Law, and its lack of transparency, thus further increased animosity towards the state and strengthened the dependency on family networks for eldercare, influencing people's construction of personhood as interdependent on kin.

### *Migrant Carers*

State failings to provide adequate care to an increasingly dependent elderly population contributed towards a growing trend of families privately employing low-paid migrants to care for elderly relatives. Increasingly women from developing countries are migrating to Andalusia to work as

'*cuidadoras internas*' ('live-in carers'). This necessitates living in the house of the care-receiver, enabling the carer to provide round-the-clock care. The average salary for live-in carers was 800 euros per month and working hours would typically consist of six days and nights staying with the care-receiver in their home, and one rest day per week.

This use of migrant carers supported the traditional Andalusian preference of eldercare being kept within family homes. Patricia, who I introduced earlier as having cared for her mother with dementia in the house next-door, stressed the benefits of having hired migrant carers:

'We couldn't have looked after *Mamá* without the girls [migrant carers]. Without them she would have had to go into a care home...I was working full-time and although I would spend all my time with *Mamá* when I was home, I couldn't be there during the day. Having the girls meant we didn't have to worry as *Mamá* had someone with her all the time...It was a good deal for the girls too. We did it legally, sorted out their papers [visas] and they received all their food and board, so they were able to save money. It worked well, and I'm lucky, being one of five, splitting the cost between us was affordable.'

Families expressed gratitude towards the migrant carers, explaining their input as enabling their relatives to stay home and avoid institutional care. Although families frequently said they would have liked to provide care themselves, work and other commitments made this impractical. Hiring low-cost live-in migrant carers ensured their relative remained at home, so they could still offer some care themselves and thus fulfil their moral duty as kin, but without sacrificing other commitments. The *abuelo* could thus remain home, continuing interdependency across the intergenerational family network but reformulating it to include the use of formal outside care.

## Conclusion

This chapter has portrayed the family solidarity that runs through the core of Andalusian cultural life. The autonomy of intergenerational family networks in *Pueblo* aids constructions of a deeply interdependent sense of personhood, whereby people understand themselves through their participation within family networks. This interdependent personhood across family networks shapes the strategies of dementia care that are evoked. A strong tradition of families relying on one another for support when a relative becomes unwell, dictates that the primary source of dementia care for most people in *Pueblo* remains the family, with this responsibility primarily falling on women (see chapter four).

I displayed how lives interweave across familial generations in *Pueblo* through the maintaining of intergenerational households. I described households where older and younger generations lived under one roof, sharing all aspects of daily life, and others, whereby creative techniques were deployed to enable varying degrees of privacy and intimacy between different generations. I analysed how such living circumstances, through which people were in and out of one another's daily lives, strengthened interdependent personhood across family networks and facilitated shared care when relatives became dependent through older age or dementia.

The chapter went on to emphasise people's beliefs in the importance of *abuelos* remaining in their own homes as they grew older. Families, when faced with extreme dependence through dementia onset, formulated creative strategies to ensure the person with dementia could avoid institutional care. Middle-aged family members in *Pueblo* strategised complex rotational care patterns, shared across relatives, to facilitate dependent *abuelos* being looked after within the family, whilst allowing them to continue engaging in other responsibilities, like employment and childcare. I discussed how middle-aged family care-givers emphasised the benefits of rotational care as it allowed them to minimise disruption to their daily lives as care was shared across family networks. Such shared care further deepened people's familial solidarity and interdependent personhood. However, I also revealed how for some *abuelos* with dementia and memory loss, the continuous disruption to their physical and social environment by rotational care could be disorientating and worsen their confusion.

In the latter half of the chapter, I focused on local families' perceptions of the involvement of the state and formal sources of dementia care. I described how a historically rooted distrust of the state exists within families in Andalusia, due to years of historical regional oppression. Families, having traditionally approached eldercare as a private family matter, for generations ensured care was shared within the extended family, and thus showed reluctance towards enlisting outside support, particularly from the state. The long-standing influence of Catholicism in Andalusia may also have strengthened local attitudes towards kinship eldercare.

The use of formal care, including state-funded provisions, however, aided by Andalusia's ageing population, women's increasing labour-market participation, and rising dementia rates, was increasing, as long-established attitudes towards kinship eldercare shifted. A sense of kinship eldercare in Andalusia being dated and needing to catch up with the 'modern' world was emerging. I described daily life in *Pueblo's* day centre, which had been founded to serve the needs of people with dementia. I revealed how people described this day centre as '*un punto medio*' ('a midpoint/compromise') between traditional kinship eldercare and modern formal dementia care.

The day centre was welcomed by relatives who had been struggling to meet the high demands set by the traditional Andalusian eldercare approach, whilst maintaining their engagement in other aspects of their economic and social lives. I portrayed the contestations that I observed occurring between *abuelos*, relatives and staff, as families experimented within complex and changing 'moral laboratories' (Mattingly, 2010; 2014) of care.

I uncovered how, recent social changes and shifting attitudes towards state support in elder and dementia care have led to the development of Spain's Dependency Law. This law, although formulated before the 2008 economic crash, was not implemented until years later due to public spending cuts as a result of the crisis. The inadequacy of this law to provide basic care needs to older people meant people spoke with disdain at the ineffectiveness of state-provided support, which in turn strengthened their ongoing dependence on family networks as the primary source of support for people with dementia. Long waiting lists for families awaiting care through the Dependency Law, caused a deepening of state distrust and sense of disempowerment.

State failings in providing sufficient dementia care have also led to the growing trend of families privately employing low-paid migrant women, who come to Andalusia in search of economic opportunities through working as live-in carers. I described how families found the hiring of such carers advantageous, in enabling their elderly relatives to stay at home and keep some care within the extended family network. This strategy of dementia care, in keeping people within family homes, thus was described as a desirable alternative to full-time institutional care. The chapter has revealed how, despite ongoing processes of social change, Andalusian families continue to reformulate kinship dementia care strategies to maintain the autonomous interdependency of the intergenerational family network as an ongoing source of solidarity across families faced with older age and dementia.

## Chapter Four: Gendered Understandings of Dementia Care

This chapter uncovers how dementia care in Andalusia is gendered. It analyses local understandings of women as naturally suited to the bodily nature of dementia care. Conceptualising the demented body as 'dirty' further feminises dementia care. I present local care-givers' narratives and my own care-giving experiences in *Pueblo* to demonstrate dementia care's intimacy, leading into explorations around how intimacy can become sexualised. Care-givers, to make sexualised interactions from care-receivers unthreatening, would inadvertently dehumanise people with dementia, diminishing personhood. Understandings of dementia care as bodily, dirty, intimate and sexualised, construct it as feminine work that must be kept invisible to protect the public personhood of the person with dementia. The chapter then explores how middle-aged Andalusian women, sandwiched between younger and older generations, are constructed as invincible matriarchs of kinship care. Increasing discourses around carers' and women's rights, have resulted in state support for this challenging role. Yet, in developing structural systems that enable this role to continue, the assignment of this demanding role to women is restrengthened. Local women's narratives portray how this role can cause stress, anxiety and overload. Yet I demonstrate how, in spite of the challenges faced, women gain agency and attach profound value to this special role at the centre of their family networks, explaining their care-giving practices as acts of love that bind their families together. The gendering of dementia care thus both subordinates and empowers, revealing the complex power dynamics flowing between gender, kinship, care and love in Andalusia.

### The Bodily Nature of Dementia Care

'I heard a 'whoosh' whizz past my ear and then it landed, 'BAM', right on the centre of the table, lying sprawled across the freshly laid tablecloth, a great lump of swollen, discharge-filled sanitary pad! She'd whipped it out of her knickers and thrown it like a frisbee! My 11-year-old son was ogling it. I cleared it away as quickly as I could, but he asked me about it later: '*Mamá* what was that thing that grandmother chucked across the table earlier?' and I thought to myself, 'Now how am I supposed to answer that?'

Peals of knowing laughter erupted from the group of women as Magdalena recounted her vivid tale of the flying sanitary pad. Magdalena was caring for her mother with advanced dementia at home. This carers' support group was formed entirely of women, mainly in their 40s to 60s. Most looked after elderly parents, many of whom had dementia. The seemingly erratic behaviours of relatives with dementia presented the challenge of integrating the disease into everyday family life. In this section, I present care-givers' descriptions of managing bodily aspects of dementia care, revealing how perceptions of these bodily practices gendered dementia care. I outline local understandings of women as natural care-givers that relate care to their reproductive systems. I then explore how care-givers described caring for people with dementia as centring around the maintenance of a 'dirty' body, further feminising dementia care.

People described women's reproductive capacities as facilitating enhanced nurturing and care-giving skills. Ana, who was looking after her mother who was bedbound with advanced dementia, participated in rotational care with her three sisters, each of whom had their mother stay for five-month periods. Ana and her sisters were three of eight siblings, so I questioned why her brothers did not participate in the rotational care:

'We've had to deal with periods and sanitary pads our whole lives...We've looked after our children when they were little and we're used to changing dirty nappies...I'd worry if I left *Mamá* with any of my brothers overnight. They might not remember to change her incontinence pads as often as they should, or maybe they wouldn't put them on correctly and *Mamá* could be uncomfortable...men can't do those things like we can, so it doesn't make sense to leave it to them when we know how these things work.'

Ana explained how women, because of having learnt to manage their reproductive bodily substances throughout their lifetimes, are capable of managing personal care in dependent persons. She contrasted this with men, suggesting they were less able to manage bodily care aspects as they lacked experiences that women had built over their lifetimes. Emphasising women's reproduction, Ortner (1974) theorised women's societal subordination through their association with nature, whilst contrastingly men were associated with culture. Ortner proposed this nature versus culture dichotomy as explaining women's assignment to the domestic sphere and men's to the public sphere. Ortner's theory is useful here, as Ana emphasises women's management of their reproductive capacities as related to the bodily practices required in dementia care-giving. Ana's explanation, however, also suggests that rather than being entirely innate, women have learnt these skills through everyday practice. As learnt behaviours, these could potentially be learnt by men, although Ana emphasises these skills have been learnt across 'our whole lives' and thus positions women as more qualified than men.

It is important however, to highlight that, although Ortner's (1974) theory is useful for understanding the association of women in *Pueblo* to nature, and the 'bodily' private/domestic context of dementia care-giving, it is less effective in its explanation of subordination. Dubisch (1986) countered Ortner's argument with ethnographic evidence from fieldwork in rural Greece. Her critique is helpful in analysing power relations at play in the context of dementia care-giving in *Pueblo*. Dubisch critiqued how, in Greece, strong beliefs around the polluting power of female sexuality and bodily processes have been frequently understood by ethnographers as indicators of women's subordination, seemingly reflecting Ortner's theory. However, Dubisch criticised Ortner's



model for being misleading in this context, as in fact women in rural Greece were *controlling* (rather than creating) pollution, which she explained as granting them a large responsibility and power in 'preserving the essential boundaries that support social and cultural life' (Dubisch, 1986, p. 196). This was a particularly important power to be granted given the high value placed on the family and domestic spheres in rural Greece, as in other Mediterranean cultures. In Andalusia, Ana, like other female family care-givers in *Pueblo*, understood women's experiences of managing their reproductive capacities as making them capable at managing the bodily aspects of dementia care-giving. However, this does not explain women as 'dirty' or 'polluting' in and of themselves, but only that they were allocated the role of *controlling* the 'polluted', 'dirty' body of dementia. Thus, female care-givers could even be understood as being granted a degree of power through this important domestic role as it was crucial in maintaining the wider boundaries of social life. This reveals the complexly paradoxical nature of power enacted through care-giving, which could empower as well as restrict. I will discuss this in more detail in the subsection entitled 'The Andalusian Matriarch of Kinship Care', in the latter part of this chapter.

Association of women to the body was analysed in Twigg's research into bathing care work in the UK, which explained how definitions of 'women's work' are 'rooted in ideas of women's essential nature as more emotional, more bodily' (Twigg, 2000, pp. 10-11). She explored how care work was gendered due to its bodily nature, which included practices like toileting and bathing. Such tasks, considered 'dirty work', gave care work a low status, associated with women. Constructing women as having specific abilities developed through biologically established differences between women's and men's reproduction, produces a powerful assumption that positions women as natural care-givers.

All carers in *Pueblo's* care home were women, and in the day centre there was only one male carer, supporting understandings of care work as suited to women. The only male carer, Miguel, worked at the day centre and had differing responsibilities to female carers, engaging in more manual handling practices, whilst female carers were assigned more personal care. This could be due to modesty, as women, who formed the majority of *abuelos*, may have felt more comfortable with women managing their personal care than men, who were conceived as better kept further away from the intimacy of bodily substances. The high presence of women in carer roles and this gendered division in responsibilities suggests a socialised understanding of women as more suited to manage the intimate bodily practices of dementia care.

The cleaning of 'dirty' bodily substances when caring for relatives with dementia was conceptualised as gendered. Care-givers in *Pueblo* discussed the emotional difficulties faced by the

sensory disgust of managing relative's bodily substances. Carolina, who was in her fifties, described emotional challenges in dealing with her mother's incontinence:

'Before dementia, my mother had been such a proud and clean lady. She would never leave the house without make up on...that's what made it so tough to see how she'd become so careless about her appearance. She no longer seemed to take interest in what clothes she wore, and she stopped showering completely...The hardest thing was when she stopped even taking herself to the toilet. I remember the first time she soiled herself. I knew what must have happened immediately because when I came into the lounge I was hit with this revolting smell. But *Mamá* was just sat on her armchair with the TV on and a blank expression across her face. She could have been sitting in her own filth for the past hour...and the most upsetting thing was that she didn't even care...I had to fight back tears when I took her into the bathroom and she still didn't want a shower, '*Mamá* please!' I had to beg to let me undress her...I ended up practically throwing her into the shower with still some clothes on as I just wanted her to get cleaned up.'

The desperation Carolina described in wanting to clean the 'dirty' bodily substances from her mother may link to a sense of loss over her mother's personhood due to dementia progression, epitomised through incontinence. Isaksen, through her analysis of care and disgust, described how 'embodied dimensions of Western individualism are related to having control over one's body- and over one's emptying functions in particular' (Isaksen, 2002, p. 804). Carolina's frantic desperation to wash her mother may demonstrate how she was trying to prevent this loss to her mother's personhood. The sensory experience of disgust intensified Carolina's emotional distress around this loss. Carolina's description may reveal the relationality of her own personhood to her mother's. I explain personhood as collectively experienced through continually (re)produced social interactions. Carolina's interactions with her mother, in washing her immediately after she had been incontinent, thus can be understood as Carolina attempting to sustain her mother's personhood.

Carolina appeared to be more disturbed by the incontinence than her mother. Sandberg highlighted how it is often care-givers who are most concerned about 'maintaining an orderly appearance' in dementia (Sandberg, 2018, p. 30). She explained how care-givers engage in 're-gendering' to persons with dementia to maintain appearances reflecting their previous life. Carolina, in emphasising how her mother had always been a 'proud and clean lady', and her desperation to clean her suggests she was attempting to re-gender her mother to her old self, pre-dementia onset,

who would 'never leave the house without make-up on'. I suggest this re-gendering is not only attempting to rebuild Carolina's mother's individualised personhood, but that Carolina's desperation to clean her reinforces their interdependent relational personhood as mother-daughter kin.

Management of relatives' incontinence was gendered. Magdalena, who cared for her father before her mother, described how it was more emotionally challenging dealing with her father's incontinence than her mother's:

'I'd looked after my father before my mother. He had a stroke, so he'd suddenly changed from being this independent person to relying on me doing everything...I remember clearly the first time I had to change his pads just after he'd been discharged from hospital. I took him to the bathroom and pulled down his trousers and he looked so ashamed...I was trying to make him feel comfortable so I didn't want to show how distressing it was for me, or make him feel I was disgusted...I tried making a joke about how he'd seen me in a similar state when I was a child. But I think I only made him feel even smaller...It was always more of a struggle with my father than my mother. With my mother I suppose she'd been the one teaching me about periods and things...it was less embarrassing doing those things for her. With my father it felt like our relationship shouldn't allow me to see him in that state.'

Magdalena referred to an intimacy with her mother related to their shared experience of menstruation. She felt her father was ashamed by her changing his incontinence pads and she expressed regret for having inadvertently infantilised him. This reflects Connell and Messerschmidt's (2005) conceptualisation of hegemonic masculinity which requires men to be strong and invincible. Such masculinity was observed by Driessen in his ethnography of rural Andalusia, describing ideal male characteristics as 'tough (duro), strong (fuerte), formal (sobrio), autonomous' (Driessen, 1983, p. 125). Despite local interdependent notions of personhood across family networks, this independence stipulated by local masculinity conceptions is threatened by dependency on others. Magdalena was worried about making her father feel small, which conflicted with local understandings of masculinity as tough and strong. Magdalena showed concern over his shame and it was challenging for her to hide her own feelings of disgust to protect her father's pride and their relationality as father-daughter kin. The control involved in repressing her embarrassment shows the emotionally challenging nature of care-giving to dependent elderly relatives. The management of bodily 'dirt' requires particularly challenging emotional work to protect ideologies associated with idealised masculine identity when care-giving as a younger female relative. The management and

control of 'dirty' bodily substances thus appears gendered; dementia care is feminised and assigned to women, considered natural care-givers to the polluted body of dementia.

### **The Intimacy of Care-giving**

Engaging in dementia care during fieldwork, I recognised the gendered intimacy of care-giving. I observed in *Pueblo* how women with dementia appeared to develop sisterly intimacy through care practices, whereas men with dementia would be more likely to sexualise care-giving. During fieldwork I met Claudia, who was struggling to care for her 88-year-old mother, Adela, at home. Adela had significant memory loss from Alzheimer's Disease. When interviewing Claudia about her mother's care she became tearful and I explained about participant-observation, offering to help with Adela's care. We agreed I would assist with showering, which was extremely challenging as Adela usually believed incorrectly that she had showered recently.

During initial weeks visiting Adela, I accompanied her for walks, attempting to build trust so she would be more comfortable with me. When the time came to shower Adela she initially refused, insisting she had showered that morning, which I knew to be untrue. After much encouragement, Adela reluctantly agreed. When undressing she became embarrassed:

'Oh!! I'm so old! Look at this saggy skin! I'm so sorry you have to see this, *guapa* [pretty- an affectionate term]' Adela cried, moving her hand across her chest self-consciously.

'No, don't worry!' I replied, trying to reassure her. 'I used to work in a hospital and was always helping people shower. It's nothing. Honestly!'

I helped her take down her underwear and catching sight of her dirty sanitary pad, the embarrassment took over again.

'Oh no! My pad! Oh dear! What a sight for you to see!' Adela winced.

'No really don't worry! It's nothing I haven't seen before honestly. I use those myself,' I said.

Exposing her naked body was distressing for Adela. The experience of being naked with a near-stranger was an alarming digression from cultural norms. Isaksen suggested being naked when others are dressed can cause feelings of 'powerlessness and helplessness' (Isaksen, 2002, p. 799), whilst Twigg and Buse (2018) highlighted how removing clothes from someone was distressing as it violated norms of bodily privacy. Nakedness could also be associated with childhood. Revealing her

naked body may have left Adela feeling exposed, vulnerable and infantilised. I tried reassuring her by highlighting that I too used sanitary pads, attempting to relate myself to her so she felt less singled-out. Twigg (2000) revealed the emotional labour required of care-givers, having to be acutely aware of the person's emotions to ensure they felt comfortable. In undressing Adela, I recognised her feelings of exposure and tried reassuring her to reduce her vulnerability.

As weeks passed with Adela, I became aware of our bodily interactions creating an intimacy. During showering, Adela opened up about her past which led to feelings of relatedness. Stories of Adela's life were mapped across her body. Turning around, she placed my hand along the deformed curvature of her spine, describing how her spinal condition had worsened due to the hunger she experienced after Spain's civil war. Pressing her hand on her chest, she traced the scar from where a breast had been removed when doctors found a potentially malignant lump. She described how she had raised Claudia alone, recounting the difficulties she had faced falling pregnant unmarried during Franco's dictatorship when pregnancy out of wedlock was deeply abhorred, causing her to flee to Germany. She held her arm against mine to contrast our skin tone, commenting that I was becoming '*morena*' (affectionate term for tanned skin) from the sun and laughing at how '*blanquita*' (affectionate term for white skin) she had become in older age. These life stories, marked across Adela's ageing body, were shared through the bodily interaction of showering, enabling intimacy to develop.

I reflected that our intimate interactions felt more comfortable as women. One day, as I dried her hair, Adela commented that she felt like we were '*hermanas*' ('sisters'). Ibarra, researching care workers, highlighted how kinship sometimes forms between care-giver and receiver as 'intimate physical and emotional contact helped engender ties of relatedness' (Ibarra, 2013, p. 198). Such intimate sisterhood suggested that the unequal power felt between us initially had dissipated. Although in reality the power imbalance remained, this fictive kinship made it less noticeable; by labelling our interactions sisterly, our relationship felt more equal.

The intimacy of bodily care could lead to unwanted sexual attention. Interviewing carers from *Pueblo's* homecare service, this was commonly raised. The extract below is from an interview with María, a carer in her mid-twenties, working for *Pueblo's* homecare service:

'One of the people I look after lives on his own and has dementia. He's a sweet, gentle man, and I know it's unintentional, but sometimes when I undress him, he'll start acting strangely. He'll give me this look, like he's suggesting something. Then sometimes he'll try to embrace me. Or once he even tried kissing me, and when I told him off, he looked so upset! I know it's because of the dementia. I

sometimes wonder if he thinks that I'm his wife. It's understandable, as I'm undressing him....It's part of the job though, dealing with things like that and I don't really mind with Guillermo as I know he's just confused and doesn't mean anything by it.'

María recounted managing unwanted sexual attention from Guillermo without describing it as distressing, normalising it as 'part of the job'. She explained how care-giving's bodily intimacy meant it was understandable that somebody with dementia could confuse an interaction as sexual. Taking Geert's definition of the western person as 'a bounded, unique, more or less integrated motivational and cognitive universe' (Geertz, [1973] 2006, p. 31), María's understanding of Guillermo's behaviour as unthreatening could thus seem somewhat dehumanising, as she deemed him no longer in control of his actions. However, María also explained how she had scolded Guillermo for his behaviour, which had caused him embarrassment. Therefore, rather than removing his agency she triggered an emotional response in Guillermo for his actions and therefore also re-enforced his relational sense of personhood. This example highlights the contradictory nature of personhood that criss-crosses between individuality and relationality. Although elements of individuality, such as control over behaviours, may appear lost through dementia, these are frequently reinstated through care-givers' interactions that attempt to reinstate human connection and relationality.

I can relate this to my own experiences of interacting with José, an *abuelo* who I introduced in chapter three. José was 85-years-old, and experiencing increasing forgetfulness. He had never married and had worked on olive plantations and as a shepherd. Now, he spent his days rotating between the homes of his two nieces and nephew. Since his forgetfulness had worsened his family had decided he should attend the day centre. As with other local men of his generation, when not working he spent his time '*en la calle*' ('in the street'), socialising with other men. This reflects Driessen's ethnographic insights, who explained how men in Andalusia's rural *pueblos* faced accusations of 'anti-masculine' behaviour if not engaged in male socialising during leisure time (Driessen, 1983, p. 127). Collier (1997) also described this gendered division of men being in the street and married women at home when she conducted her ethnography in Andalusia. The removal of José's freedom to participate in street life and instead having to attend the day centre, surrounded by widowed women, presented difficulties for a man of his generation. He often became confused, lambasting the day centre as a '*cortijo*' (a farmland/plot) where he had been locked up 'like a dog', pacing in circles and complaining.

José was skinny, had little appetite and, when agitated, refused to eat. Staff were determined he eat more. An effective technique used by female staff was engaging José in flirtatious interactions. The following is an interaction I observed between Camila, a thirty-something-year-old carer and José, who had been getting increasingly agitated and was refusing to eat:

‘José, *guapo!*’ Camila called cheerfully, ‘Come here and sit down next to me for a minute, *cariño* [darling],’ patting the armchair beside her. José followed her call and sat next to her. Camila picked up his hand and drew it to her lap.

‘Come on, my *chiquitillo* [little boy], I want to have a chat with you’ she said warmly whilst stroking his hand. José’s entire body relaxed and he gazed up at Camila, clearly enjoying the attention.

‘It’s hard for me to be here all day is all’ José said, looking up at her.

‘Mmmmm, I know it’s hard, *cariño*. But it’s only a few hours more, then you can go,’ Camila replied.

‘You’re a good woman,’ José stated, ‘You’re very *guapa*, very *cariñosa* [caring].’ José was gazing at Camila now in seeming adoration.

‘Now come on *cariño*, I want you to eat something. You’ve had nothing all morning. ¡*Venga!* [Come on!]’ and with that, still holding José’s hand, she led him into the dining room to be served lunch. Her technique had worked seamlessly.

Younger female staff creatively used their sexuality to enable effective care-giving. The use of such flirtatious interactions, conforming to traditional hegemonic understandings of femininity, was used by female carers to enable care-receivers to engage in certain behaviours, and shows how local understandings of effective care-giving were tied into notions of feminine sexuality.

This example could also be understood as ‘childing’. Camila’s soothing reassurances and tactful hand-holding could reflect a maternal relationship towards José. I observed similar paternal-like practices expressed by Miguel, the only male carer, towards José. Thus, it cannot be understood as entirely sexualised. This apparent infantilisation of people with dementia by care-givers, may reflect power hierarchies similar to that of parents to children. Such behaviours could be understood as infantilising to people with dementia, reducing their sense of adulthood and dignity. However, they could also be legitimised as enabling the person with dementia to be comforted.

Flirtatious interactions could be understood as attempts to reduce this infantilisation to restore the adult care-receiver's individual identity as an adult through recognising their sexuality. Sandberg (2018) explored grooming care-giving practices, such as putting make up on people with dementia, that perform a 're-gendering' to rebuild their selfhood. Interpreting Camila's interactions with José as flirtatious could be understood as her attempting to 're-gender' José, thus avoiding infantilisation by sexualising him.

I experienced similar interactions with José and found them useful to comfort him. Afternoons could sometimes drag at the day centre. Most staff left by mid-afternoon, *abuelos* would take a siesta, and do little else other than coffee time at 4:30pm. José however, would become increasingly agitated, pacing, grumbling, and checking the time, impatient for 6pm when his nieces would collect him. During afternoons it would normally just be Julia and I left to look after the remaining *abuelos*. Julia was a carer in her 50s suffering from chronic anxiety, stress and fatigue. She worked long hours and frequently complained about her job. When José became agitated, Julia would instruct me to distract him. José appeared to enjoy talking to me, but whenever we spoke, he almost always started interacting in the sexualised way I had observed him interact with other younger female staff. Our conversations would go something like this:

'Tell me a bit about looking after your goats, José,' I would say, as he loved talking about his animals.

'Ah! Yes! My goats! Yes, I looked after hundreds of goats in my time. I would get up every day before sunrise to feed and milk them. I would spend all day walking across the mountains in the hot sun. It was hard work. But I loved it. I'm a man of *el campo* [the countryside]. There's nothing I like more.'

'It sounds like a wonderful job,' I would say. He would then start gazing at me intensely and might reach for my hand.

Sometimes he would sit beside me or stroke my arm. If I told him not to, he would retract and never pushed. I did not find his interactions threatening.

'How *guapa* [pretty] you are! How good a woman you are! So *cariñosa* [caring]! If only I were a bit younger, I would marry you! I could go with you to your country. Which country is it, remind me?' he asked, beaming.

'England' I replied, 'I don't think you'd like it there, José. It's very cold and it rains a lot.' José was extremely skinny and always complaining of being cold.



‘No! I would go there with you! I would be forever happy if I was with you!

What a shame that I’m not a younger man!’

I had conversations like this with José most days. His adorations initially made me uncomfortable, but I became used to it. I would try distracting him to talk about other things, asking about his life, family and work. But generally, the conversation would return to his professions of adoration. If younger female staff were present, José would shower them with this unrequited sexualised attention. If José became agitated, Julia would request I sit with him. However, like María’s interactions with Guillermo, I did not feel distressed by José’s advances. Although initially uncomfortable, I began to see these interactions as ‘part of the job’, especially as I noticed these conversations calmed José. Perhaps because I knew José did this to all young female staff and knew he would forget and repeat the interaction, it felt unthreatening. On reflection, I wondered if this was due to an understanding of people with dementia as having less control over their actions and that I was therefore dehumanising José’s sense of personhood. Care-givers would thus accept sexualised attention, or even initiate it as a form of comfort.



*Figure 1. José going out to the day centre’s patio for a walk.*

Such acceptance of sexualised interactions, however, was not shown by care-givers towards *abuelos* without dementia. Care-givers appeared more distressed by sexualised interactions from cognitively functioning *abuelos*. In conversation with a group of male *abuelos* without cognitive impairment at the care home, I realised they recognised this:

‘It’s not fair how the carers treat us differently,’ Pedro, a 93-year-old *abuelo* complained.

‘What do you mean?’ I asked.

‘Say for example, Celia [a carer], you must have seen her. She’s a *bombón*!’

‘What’s a *bombón*?’ I queried.

‘A *bombón* is a girl who’s very beautiful!’ another resident chipped in.

‘Yes, exactly,’ Pedro continued. ‘It’s a girl who’s so beautiful that she’s, you know, like a *bombón*! Like a chocolate! Delicious,’ he smiled and the other *abuelos* laughed.

‘Now, Celia is absolutely a *bombón*! Very young, very beautiful. But when she gets us up, she’s so attentive to my roommate Sergio. She will undress him and wash him everywhere, you know, even [gestures to his crotch]. But me! She makes me wash myself! All the carers are always saying how wonderful Sergio is! But Sergio says almost nothing! He’s totally [points to his forehead and taps it whilst shaking his head] lost it, you know! But the carers love him! And the worst is that he doesn’t even appreciate it! He’ll just sit there whilst she’s touching him!’

Staff had complained to the manager about Pedro’s sexualised behaviour, with several refusing to work with him. Others exercised caution by setting boundaries around intimate bodily care. It seemed the sexual advances of *abuelos* without cognitive impairment were less tolerated by staff than those by people with dementia. Staff appeared to conceptualise people with dementia as lacking control over their own actions, which somewhat dehumanised them, making them unthreatening.

This sexualisation of care work was highlighted by Fisher and Kang’s (2013) research with migrant carers in a US care home. They revealed how carers faced daily sexual harassment, illustrating the multiple inequalities of gender, class and migration status they were subjected to. They criticised how formal care-givers were more likely to be blamed for sexual advances than care-receivers, critiquing the emphasis of research on abuse by care-givers, rather than investigations into harassment from care-receivers. The sexualisation of care-giving thus appears normalised in formal care. The way such interactions are interpreted differently when they concern *abuelos* with dementia, compared to *abuelos* without cognitive impairment, reveals local understandings around agency and personhood.

### **The Invisibility of Dementia Care-giving**

I now discuss how intimate care-giving practices, conceptualised as natural, bodily and feminine, were made invisible to confine dementia to the domestic sphere. Magdalena's flying sanitary pad story, and her rush to clear it away from her son, show how family care-givers shouldered the responsibility of managing the uncontrolled bodies of relatives with dementia. Magdalena described managing her mother's behaviour in public:

'It's not easy. I can't tell you how many times I've been out in the street with my mother and she's done something bizarre...talking to strangers about complete nonsense as though she's known them for years, and it really scares people...when I used to take her to *Mercadona* [the supermarket] she would grab things off the shelves and put them in her pockets...I've started only taking her out for a short walk once a day around our neighbourhood. I'm too afraid to take her anywhere else as I never know how she'll behave, but it's important she goes out at least a little bit.'

Magdalena felt responsible for her mother's behaviour, and thus felt she had to ensure she spent more time at home for fear of social judgement. Brittain and Degnen's (2022) research is useful here, to guide analysis of Magdalena's experience of being a care-giver taking a loved one with dementia out in public. Their research used qualitative interviews with dementia care-givers in the north-east of England to unpack and explore what makes a 'dementia friendly' community, and examine how elements of social and material environments shape meaningful everyday care practices outside of the home. They found that family care-givers, in deciding whether and how to take relatives with dementia out in public, found themselves facing problematic dilemmas. Family care-givers juggled a 'complex line' between enabling their relative access to public spaces so that they could engage in meaningful everyday activities, whilst protecting them from socially stigmatising interactions that could occur in public places (Brittain and Degnen, 2022, p. 425). Such findings echo Magdalena's experiences, as when she did go out with her mother in public, she expressed the importance of staying within her neighbourhood, where neighbours were aware of her mother's dementia and were not critical or judgemental towards her. Magdalena, thus negotiated this 'complex line', whereby she attempted to protect her mother from public social judgment, whilst still enabling her some access to everyday meaningful activities outside the home.

Such care-giving could be analysed as regulating the demented body in a Foucauldian sense. Brijnath and Manderson described care-givers' responsibility to regulate individuals with late-stage dementia by engaging in 'bodywork' which 'prevents the demented body from threatening the stability of the social body' (Brijnath and Manderson, 2008, p. 608). Magdalena felt obliged to limit

her mother's time in public, largely confining her to the private domestic sphere. This suggests that Ortner's (1974) dichotomies between female/male and private/public exist in *Pueblo*. Magdalena's embarrassment over her mother's behaviour implies both her identity and sense of personhood is interconnected to her mother's. If her mother breaks social boundaries, Magdalena and potentially her family risk a spoiled public identity. This contradicts Geertz's [1973] (2006) widely-referenced conceptualisation of western personhood as unique and bounded and suggests a more interdependent personhood that is connected to kinship networks, demonstrating the contradictory nature of personhood as neither entirely individual nor relational, but a complex mix of both. Family care-givers to relatives with dementia make complex, measured decisions in their care practices to protect this public identity.

Physical restraint use on people with dementia again demonstrates how dementia care's bodywork is often made publicly invisible. During my time in *Pueblo*, I observed many physical restraints being used (see chapter six). One *abuela*, 87-year-old Beatriz, rotated between her two daughters' homes and spent weekdays at the day centre. Beatriz had been diagnosed with advanced vascular dementia, was unable to verbally communicate and needed assistance with all daily living activities. Beatriz had a large malignant tumour on her nose, which was growing rapidly, and had caused one of her eyes to close. By the end of fieldwork, it had split open leaving a craterous wound. Doctors insisted the tumour was inoperable, but advised staff and family to be careful not to allow Beatriz to touch it. Staff grappled with everyday ethics in managing Beatriz' tumour. After various unsuccessful attempts at less restrictive practices, including sticking mittens over Beatriz' hands, staff settled on a makeshift restraint, using foam strips wrapped around her wrists and tied with bandages to her wheelchair. This stopped Beatriz lifting her arms, touching her face or the tumour. The tumour looked incredibly painful and Beatriz, although unable to verbally communicate, would fidget and try to lift her hands from the restraints. I was shocked at the ad hoc use of this makeshift restraint, but later found similar examples of restraints being used in the care home. I observed that when outsiders entered the day centre, staff would toss a blanket over Beatriz to cover the restraints. This demonstrates how the demented body was physically controlled and concealed by care-givers. Care-givers attempted to keep the uglier side of dementia care hidden from public view, controlling the individual body of dementia to keep the societal body intact.

### **The Andalusian Matriarch of Kinship Care**

Through my sleep-blurred eyes I make out something on the dresser. I look at my watch and, realising I've overslept, pull myself out of bed and take a proper look.

It's an impossibly neat stack of underpants! Each one ironed, folded and stacked up like a little tower of pancakes.

My partner's mother, Araceli, at 58-years-old, lives with her husband and adult son in a flat in Almería. At this moment in time, my partner, her eldest son and I, were temporarily staying in their family's additional flat down the corridor. Araceli is the main care-giver to her 89-year-old mother who lives in the same building. Araceli's job follows a siesta-timetable, allowing her to visit her mother throughout the day. Meanwhile, her 96-year-old mother-in-law, Paquita, was requiring round-the-clock care. Although Paquita's children were supporting her, Araceli was also assisting with washing, feeding and changing. Araceli also does all the household tasks for her husband and grown-up son.

Araceli had asked us the previous night to give her our laundry, insisting it was no bother as she was putting on a load anyway. Now my underpants lie neatly stacked on top of the dresser. It got me thinking- how does this woman, who is so busy, looking after different generations of people in her family, whilst holding down a full-time job, have the motivation, time and energy, to not only wash my underpants, but iron, neatly fold and stack them, then creep into the bedroom whilst I'm sleeping to deliver them, too?

Living in *Pueblo* in the months that followed, I came across many women in a similar position to Araceli, at the centre of their extended family networks, and I became curious about the unique role they played in kinship care. I focus here on the experiences of these women, exploring how they formed creative strategies to '*encargarse de todo*' ('take care of everything'). This section begins by discussing the sense of duty described by these women to care for their elderly relatives. I explore how local constructions of femininity in middle-age centre around the altruistic, dutiful, caring, and invincible maternal-figure, stemming from a historical understanding of women as dedicated to their family networks. I uncover how global and local discourses around carers' and women's rights have raised awareness of the role these women play in kinship care, which has led to state support. However, in providing support, structural systems ensure the continuation of this demanding role. I discuss how this role brings stress, anxiety and overload to these women.

In spite of these difficulties, however, I outline the passion these women described for their unique role as kinship care-givers at the centre of their extended family networks. In providing care across different generations of their extended family networks, these women described their motivation to care as firmly grounded in love for their families. Given the cultural importance of the

family in Andalusia, by weaving extended kinship networks together through care-giving, despite the constraints of this role, these women paradoxically also held a degree of power across the private, domestic sphere of their extended family households. I thus refer to these women as 'matriarchs of kinship care', who, in spite of the difficulties they faced, drew deep meaning through this role that was critical to the maintenance of their extended family networks. The motivation these women described to continue engaging in the multitude of demanding, ongoing, everyday care-giving practices, was fuelled by a profound sense of love for their families.

I observed a strong sense of duty to care for relatives with dementia at home still to be prevalent amongst families in *Pueblo*, even when relatives exhibited challenging dementia symptoms. Duty to care was expressed particularly strongly by women. There was a sense that although men were now taking more care responsibilities than previous generations, the expectation to oversee the day-to-day management of care for relatives with dementia still fell on women. Renata, a 55-year-old care-giver to her elderly uncle and mother who both had dementia, explained:

'I live with *Mamá*, so I see her at her worst...It's me who gets her up and dressed whilst she's kicking and screaming. But when my brother comes over, she's totally different. She'll be polite and well-mannered and appreciative of him. A few weeks ago, he came round to repair a leaky tap. He must have spent about twenty minutes fixing the tap and about an hour having a coffee and a chat with *Mamá*. But what do I have to listen to for days afterwards? 'Oh, he's so loyal your brother! He takes such good care of me'...It's not just *Mamá* either, it's everyone. My neighbour's always praising him for being so caring...Honestly, it's as if he's a Saint! But I'm living with *Mamá* and looking after my uncle. I'm there every day, doing every little thing she asks. Yet nobody takes notice of that because it's expected.'

Other women shared similar stories of male relatives gaining greater praise for smaller contributions to their relative's care than they performed daily. Abel (1990), researching US family eldercare, found men tended to take an instrumental, task-orientated approach to care-giving, whereas women were more likely to become submerged in everyday care-giving, requiring more time and emotional energy. Although people in *Pueblo* referred to increasing involvement of men, it was still predominantly women who oversaw the day-to-day care needs of dependent relatives.

At the carers' group, women shared stories of the harsh criticism they faced when a relative had moved into residential care. One woman said her aunt is no longer speaking to her after her mother, who had advanced dementia, moved into *Pueblo's* care home. She described her frustration

that her brother was not subjected to this criticism. Brown's research into family care-giving in Brazil found 'unwritten gender and kinship rules' (Brown, 2013, p. 130) governed expectations around who should care for dependent relatives. She found women were subjected to severe criticism when they did not assume this role. This shows another side of kinship, contrary to care and cooperation, whereby expectations, which are usually gendered, can lead to critical judgements and feelings of guilt.

Gendered expectations positioning women as altruistic maternal-figures meant that female family care-givers expressed struggles to manage guilt when they did not meet the expectations demanded of them. This reflects Romero et al's (2014) findings that found female dementia care-givers in Spain, especially daughters, experienced more guilt than male care-givers. Mía, a 57-year-old lawyer, expressed guilt when her father, after dementia onset and his wife's death, moved into *Pueblo's* care home:

'I felt so guilty when *Papá* moved into the care home. I know that *Mamá* would've been so upset to see him end up there. But it was too difficult. I'm working full-time and so is my husband. I visit every day after work, and I know he's in safe hands. But the guilt never goes away.'

Despite Mía living on the same street as *Pueblo's* care home, allowing her to visit her father daily, which she combined with full-time employment and childcare, she still felt guilty for not looking after her father at home. Pitt-Rivers' ethnography of an Andalusian *Pueblo* described care to one's elderly parents as a 'sacred duty' expected of younger kin (Pitt-Rivers, [1954] 1971, p. 102). Responsibility to care still falls primarily on women, with daughters and wives performing the majority of care-giving roles (Lillo and Riguelme, 2018, p. 165). The guilt expressed by women in *Pueblo* reflects a deeply embedded cultural expectation of women to care for family that prevails in community outlooks of dementia care.

61-year-old Sandra works as cook and housekeeper at *Pueblo's* day centre. After finishing her shift, Sandra would insist on giving me a lift, despite usually being in a rush to visit her elderly mother or collect her young grandsons. I was amazed by the energy Sandra showed to care for the differing generations of her family. One Saturday, I managed to organise a slot in Sandra's busy schedule to chat about her experiences of combining her elderly mother's care with the rest of her family and work responsibilities. Sandra described her daily routine: she would wake at 6am, make herself and her husband breakfast before driving to her daughter's flat; there she would collect her two young grandsons and drop them at school for 8am; then she drove to the day centre for 8:30am; she was on shift until 6pm; after work she visited her elderly mother to help with household tasks or

would look after her young grandsons; by 9pm she went home to prepare dinner ready for her husband when he returned from work at 10pm; afterwards she cleaned up and went to bed by midnight. Sandra's jam-packed schedule sounded overwhelming and it surprised me that she would *still* insist on giving me a lift even though this involved a significant detour. I sensed a similar passionate determination to support others as present in my partner's mother. As time passed, I met many middle-aged women in a similar position to Sandra and Araceli. Sandwiched between different generations of kin and in employment, they juggled a myriad of differing relatives' care needs to '*encargarse de todo*' ('take care of everything') across the family network.

Localised dominant conceptualisations of femininity in Andalusia contrast with masculinity, and change across the life course. Connell and Messerschmidt (2005) explained how 'hegemonic masculinity' dominates in society, associated with power and contrasted with subordinate femininity. Connell (2016) later developed the theory to highlight localised understandings of hegemonic masculinities and femininities which vary across contexts and time. Driessen described conceptualisations of masculinity and femininity in rural Andalusia where he conducted ethnography: 'Andalusia is a strongly male-dominated society...A woman should be virtuous, competent and docile, devoting her life to her husband and children' (Driessen, 1983, pp. 125-126). However, despite this localised hegemonic masculinity, due to the male agricultural day-labourers' work and time spent away from the family household, women dominated in the private sphere, suggesting this explained the tendency towards matrilocality in Andalusia. Collier (1997), who conducted her ethnography in rural Andalusian in the 1960s and 1980s, described how 1960s married women in Andalusia, in spite of Franco's regime giving their husbands' authority, were not subordinated as much as married women in 1980s Andalusia. In the 1960s, women were given assets through parents from marriage and were supported economically in exchange for care of the house and family. She found instead, during Spain's transition to democracy, Andalusian women in the 1980s faced greater inequalities in expectations around their gender than previously, as mothers confronted the difficulties of combining low-paid employment with childcare which caused unmanageable demands on their time (Collier, 1997, pp. 141-152).

Four decades later, I found localised conceptualisations of masculinity and femininity echoed these ethnographies. However, further social transformations had impacted kinship care by increasing expectations of women to gain full-time paid employment and the extended longevity of elderly relatives requiring care. In 2019, middle-aged Andalusian women faced not only juggling childcare and paid employment, but the added expectation of managing the care of rising numbers of elderly relatives with increasingly complex health needs. Furthermore, since the 2008 economic crisis, these women were often economically supporting and providing household care to



unemployed adult children. Understandings of middle-aged femininity in *Pueblo* thus created an image of the strong, invincible, endlessly busy, maternal figure of the extended family network. These women's families depended on them as strong, competent matriarchs of kinship care. However, these women were also struggling to meet the competing demands on their time expected of them.

### *Discourses of Rights for Women and Carers*

Each week during the carers' group a healthcare professional focused on a different aspect of care-giving. One week we were listening to a dentist discussing dental care for dependent persons. Clicking through his PowerPoint slides he revealed a clipart image of a middle-aged woman caring for an elderly man in a wheelchair:

'Excuse the stereotypical image here,' he apologised. 'It was difficult finding an image about care that wasn't stereotypical regarding gender. However, I did write *cuidador* [male carer] alongside *cuidora* [female carer], as nowadays things are changing.'

'Oh yes, things are really changing,' Vera, the social worker interrupted, gesturing around the circle of women, 'Yes, the men are all just busy today, but they'll be here next week,' she teased sarcastically, to an eruption of laughter.

'Yes, because we take it in turns of course!' Magdalena joined in sarcastically.

The dentist, smiled awkwardly, beads of sweat running down his temples.

'Yes...urmm..well..., perhaps it's not so much the case in *pueblos*,' he stammered. 'But I'm from *Córdoba* capital, and we certainly see more *cuidadores* [male carers] than we used to.'

'Look around you!' Vera jumped in again, sounding more serious. 'We're all women. And we always have been. The only difference from before is that now we have to work too.'

The carers' group, funded by *Pueblo's* local council, provided training for family care-givers. The group ran for seven weeks every spring, usually running from the health centre. Although open to all care-givers, Vera explained that only once had a man attended the group for one workshop and he had been the husband of one of their regular attendees.

Post-dictatorship, democratic Spain radically transformed its societal structures. However, Tremlett (2006) argued women's empowerment was left behind, whilst 'on paper' Spain had achieved feminist advances enjoyed elsewhere in Europe, with equality enshrined in law, the day-to-day reality of women's empowerment reflected a different reality: 'changing laws is one thing. Changing mores is something else. And, when it comes to families, Spanish men show little sign of wanting anything...to change' (Tremlett, 2006, p. 209). Throughout the 1990s/2000s, rising sentiment demanded recognition of the unpaid labour of Spanish women. Statistics showing the vastly unequal number of hours women spent on housework and care compared to their husbands, alongside engaging in paid employment, demonstrated Spanish women as the most overworked in Europe (ibid., p. 213). More recently, Spain's increasing longevity, alongside the 2008 economic crisis leaving younger generations dependent on their parents, had accelerated women's struggle in managing competing generational family care needs. Local initiatives, like *Pueblo's* carers' group, had formed partly due to demands for state-funded interventions.

There were also significant changes to state laws around care. *La Ley de Dependencia* (Dependency Law), supported unpaid family care-givers (Lillo and Riquelme, 2018). The 2007 law initiated basic social care services to people assessed as 'dependent'. However, due to public spending cuts after the 2008 crisis, this law was only completed in 2015 in significantly reduced form, and thus care responsibilities have remained largely with families (Casanova, Lamura and Principi, 2017). The maximum homecare *Pueblo's* residents could receive under this law was seventy hours a month. However, for someone to be assessed as having sufficient dependency for this support they would essentially be bedbound and thus inevitably still rely on informal round-the-clock-care. Although this law was designed to support unpaid family care-givers, which it did to some extent, it also facilitated this demanding care-giving role to remain in place. This advancement of carers' rights thus supported informal care-givers, but also enabled the continuation of women's role in dementia care.



Figure 2. A poster promoting Pueblo's carers' group.

The carers' group utilised discourses around remaining active and healthy that subscribed to international discourses around 'successful aging' outlined by Lamb (2014). This paradigm places importance on individual hard-work and effort to maintain independence throughout ageing to avoid draining state resources. It promotes individual agency, self-control and body-maintenance through engaging in practices like exercising regularly and eating healthily to resist ageing. *Pueblo's carers' group*, alongside care-giving, also focused on the protection of care-givers' own health and wellbeing, emphasising protecting one's health for the sake of others in kinship networks. For example, during a session on 'healthy eating' women were invited to share recipes with one another and the importance of 'eating well' was emphasised to ensure one had the energy to '*encargarse de todo*' ('take care of everything'). One woman commented:

'We eat well here. That's why we're all living so long! [laughs] I always ensure my mother eats plenty of fresh fruit and I do the same. It's important I look after my own health as who's going to take care of her if I become unwell?'

Women referred to the importance of healthy eating in relation to keeping well for themselves, reflecting Lamb's (2014) theorisation of an individualist personhood and maintenance of this through self-care. However, women framed this individual attention to wellness as aimed at the protection of their kin and staying well for the sake of the people they cared for. Women spoke about having to 'keep going' and not resting even when they had fallen ill to ensure they continued their care-giving responsibilities. Tips were shared about herbal remedies which women claimed had allowed them to '*encargarse de todo*' even when unwell. Local women had adopted Lamb's (2014)

attention to the individualist need for self-care yet utilised this for the good of the interdependent family network. This again shows personhood as both individualist and relational; personal wellness was often framed through understandings of needing to protect the wider kinship network.

The group also included meditation and Tai Chi as self-help tools for reducing care-giving stress. Another focused on yoga and exercise to help manage joint pain caused by the demands of manual handling. Brown (2013), researching middle-aged women attending Third Age support groups in Brazil, found they centred around generating pride through being active and healthy to uphold independence and endurance through middle to later life. Middle-aged women attending *Pueblo's* carers' group, not only cared for relatives, but ensured the maintenance of their role by looking after their own health in subscribing to active lifestyles. This generated local constructions of the *invincible* female matriarch, actively looking after herself to maintain her invaluable position at the centre of her family network, who was fit and able to care for multiple generations of kin.

Women in the carers' group shared stories regarding government failings to meet their families' care needs through the Dependency Law. Sharing grievances formed joint narratives of themselves as strong and resilient in the context of a failing system of state care, generating solidarity. Women asked one another about care waiting lists, and shared advice on how to ensure care assessments were ranked as high dependency. Maintaining personal health through subscription to the successful ageing paradigm was critical in maintaining their position as compensating for state failings. However, despite critiquing state care systems, by continuing care-giving and engaging in self-care to maintain this demanding position, these women inadvertently normalised the role of the family as the most dependable provider of care for older relatives.

Sharing information regarding state-provided care however, sometimes bred resentment within the group, impinging on solidarity and further decreasing trust in state welfare. When interviewing Magdalena, she complained about the injustice that another member of the carers' group had been given more care under the Dependency Law than she had, even though her mother's needs appeared higher than the relative this person cared for. Thus, the group, despite generating solidarity, could also incite bitterness as group members compared one another's varying situations of care and allocated support. Such disparities reinforced resentment towards the state as being an unequal and ineffective care provider.

### *Stress, Anxiety and Overload in Care-giving*

These women, positioned as central matriarchs of kinship care, struggled with competing care demands. Caring for relatives undergoing changes associated with dementia resulted in deeply

distressing emotions. 88-year-old Adela, who I assisted with showering, was showing increasing forgetfulness which upset her daughter Claudia, who commented:

‘For some of my friends looking after their parents is not so bad because at least they recognise the sacrifices they’re making. But often my mother doesn’t even know who I am. I say, ‘*Mamá!* I’m Claudia. Your daughter!’ and she shows no comprehension. When I tell her I’m going upstairs with Zachary [Claudia’s husband], she looks shocked. ‘You’re going to sleep with him?’ she says, like she doesn’t realise he’s my husband! Then she’ll talk to me about ‘Zachary’s wife’. It’s upsetting because I’m exhausting so much energy on her yet she doesn’t even know who I am anymore.’

The confusion Adela expressed made Claudia feel underappreciated and exacerbated the stresses of care-giving. However, Claudia insisted that she wanted her mother to remain at home, as she had previously worked as a carer in a care home and been appalled by the standards of care. Claudia also had two adult children at home, and a husband with physical disabilities. She worked as a cleaner and factory-worker and her husband was a music teacher. They jointly owned a house together and were economically stable but had little excess income. Claudia, like many women I met, suffered ongoing stress and anxiety as she struggled to ‘*encargarse de todo*’ (‘take care of everything’), juggling the competing demands of employment and multigenerational care across the family network.

### *Agency and Love in Dementia Care*

These middle-aged, sandwich generation women, I describe using the term ‘matriarchs of kinship care’, because, despite facing constraints, they also experienced both love and agency through their roles as kinship care-givers. Despite juggling the multitude of care-giving responsibilities to differing generations of their family networks, they did still paradoxically occupy a position of power at the centre of their kinship networks. This position of power related to women’s position in the domestic, private realm of their family households. In chapter two, I outlined the lively ‘*vida en la calle*’ (‘street life’) which facilitated much of public social interaction in *Pueblo*. This lively public street life contrasted starkly with a privacy around people’s family homes. I observed that people in *Pueblo*, as I had experienced through living in other parts of Andalusia, were guarded around letting others into their family homes, with most social interactions occurring instead in public places like plazas, cafes, bars and restaurants. Houses had only small windows which often had the blinds down which added to a sense of the family home being a secluded and private space. This sharp division between private and public life in *Pueblo*, influenced the position of power that these middle-aged, sandwich

generation of women occupied in regards to the domestic realm of the households of their extended family networks.

Dubisch, in her ethnographic analysis of gender and power in rural Greece, highlighted the importance of investigating this domestic (or private) versus public dichotomy and its relationship to gender roles in Greece and other Mediterranean societies where 'the dichotomy is highly developed and strongly gender-linked' (Dubisch, 1986, p. 10-11). Dubisch critiqued how Ortner's (1974) analysis of universal female subordination as being linked to the dichotomies of female/male and private/public is problematic in assuming that the public realm holds the greatest source of power and thus women, relegated to the domestic realm, inherently wield less power. Domestic life, Dubisch explained, is generally devalued in western society and understood as 'natural' and 'unproblematic' and therefore is often 'overlooked' (Dubisch, 1991, p. 40). She instead argued that in Mediterranean contexts, women may gain a separate sphere of power in the domestic realm, stating 'if we neglect the domestic realm as a source of power...we overlook an important source of power and status for women' (ibid., p. 13). This argument is further supported by Friedl, another ethnographer investigating rural Greece, who emphasised how, in Greece 'the private, and not the public sector, is the sphere in which the relative attribution of power to males and females is of greatest real importance' (Friedl, 1986, p. 42). She stressed how women in rural Greece held positions of real power within family life and that this should be taken into account when analysing relations of power and gender.

Such insights from rural Greece are helpful to relate to the Mediterranean context of Andalusia, where, as I emphasise throughout this thesis, the extended family network continues to hold profoundly important cultural value. However, it is important that I make comparisons between these differing sites in space and time tentatively. When I was conducting fieldwork in *Pueblo* in 2018-2019, Spain had already experienced a huge growth in women's participation in the labour market, whereas women in rural Greece in the early 1980s were existing in an entirely different social context. It is thus important that, although useful comparisons can be drawn here cautiously, in comparing these contexts I do not subsume both into an undifferentiated 'Mediterranean culture'.

In chapter three, I explored how the autonomy of the family through close, intergenerational kinship networks was integral to a sense of interdependent personhood in *Pueblo*. Therefore, middle-aged, sandwich generation women in *Pueblo*, through engaging in care-giving practices that supported their wider, intergenerational kinship networks, occupied powerful positions in the domestic realm. Given the historical distrust of the central Spanish state that existed

in Andalusia (see chapters two and three), the centrality and importance of the private, domestic family realm was amplified in this context. These women then, in maintaining and holding together these networks through their care-giving practices, despite the evident wider patriarchy, I argue harnessed powerful positions as 'matriarchs of kinship care' in the domestic sphere. Dubisch (1986) also warned of how the social and power relations of women within the domestic sphere are more susceptible to being overlooked by anthropologists, and instead the visible public male ideology accepted, because of the privacy of this sphere which is less immediately accessible to researchers. My positionality as a woman, engaging with women in an everyday context ethnographically, facilitated me gaining close relationships with women family care-givers in *Pueblo*. Furthermore, my adoption of active participant-observation roles in family care routines, meant I was thus fortunate to gain access to the intimacy of private households. This allowed me to speak with women family care-givers about their experiences to identify this opaque role of women as 'matriarchs of kinship care'.

As 'matriarchs of kinship care', despite the demands of their role, these middle-aged women care-givers in *Pueblo* expressed empowerment, which displays the contradictory nature of care-giving. Yahalom (2019) understood these contradictions through coining the term 'segre-social' to frame dementia care, as it both segregates care-givers through placing demands on them and enhances their sociality through remaking social connections. Through care-giving, middle-aged women gained control over differing generations of kin, positioning themselves as central matriarchs of kinship care with power over their extended family networks. These women's care-giving practices were performed proudly and they described their role as bonding their family together. This weaving of family relationships was especially important when a relative's dementia was causing relationship deterioration. Below, 62-year-old Fernanda expressed how her care-giving enabled family relationships to improve:

'When my mother got Alzheimer's, it was very hard for my father. He couldn't understand it. She would have delusions, and say things like, 'I'm going to pick the children up from school,' and my father would get angry and correct her 'Merce! Your children are grown up and married...Stop these *tonterías* [silliness]!' So, as she worsened, I started taking her out more. There were times of day, like late afternoon, when she was prone to delusions, so I would take her for a walk or to have a coffee...by the time I dropped her back my father had been to the bar to see his friends or had some rest so he was less impatient with her. I was pleased to see them getting along better because of my help.'

Fernanda demonstrated pride for her care-giving allowing her father the break he needed to cope with living with her mother's dementia. Fernanda also regularly cared for her grandchildren and similarly described how grateful her daughter was for the break it gave her as it improved her relationships with her husband and children. The notion of 'kin work', coined by Di Leonardo (1987) in her analysis of Italian-American families in Northern California, is helpful in understanding the agency experienced by middle-aged women in *Pueblo* through their family care-giving practices. Di Leonardo explained 'kin work' as 'the conception, maintenance, and ritual celebration of cross-household kin ties' (Di Leonardo, 1987, p. 442), in the organising of extended family social events like gatherings over the Christmas period, which facilitated the maintenance of their extended family networks. I argue that middle-aged women in *Pueblo* were effectively engaging in a kind of 'kin work', but through their care-giving practices, which similarly worked to weave their extended family networks together. Di Leonardo explained that women's engagement in 'kin work' across the domestic domain was a source of 'human satisfactions -and power- not available in the labor market' (ibid., p. 451) as it allowed women to gain control and power over their family networks. Returning to the example of Fernanda in *Pueblo*, she expressed pleasure in understanding her role as benefitting both her father and mother, but it also gave her control by situating herself as an essential mediator of social relations across her family network. Thus, despite challenging demands, middle-aged women in *Pueblo* carved agency and value through their unique role at the centre of the family network, becoming proud, matriarchs of kinship care.

Fernanda's father inevitably did provide daily care to his wife himself. Although Fernanda criticised her father's interactions with her mother as incompetent, his attempts were genuine, and when I asked him about caring for his wife, he became tearful, describing it as a struggle. As Fernanda would frequently take over from her father, although well-intentioned and providing him with respite, she may have inadvertently deskilled her father's capabilities to care for his wife. As the gendered expectation was for women to fill the central care-giver position in families, matriarchs of kinship care would, perhaps unintentionally, place themselves in this role and inadvertently deskill male relatives who were willing to help but unsure how, thus preventing gendered expectations from reforming.

The sense of control and power over family networks that was experienced by middle-aged family care-givers in *Pueblo* appeared to be motivated by profound feelings of love for their families. Speaking with women who were overloaded with the myriad of their families' care needs, they still described the emotion overruling all others as being a deep sense of love. Araceli described the joy she feels when she visits her mother:



'I walk in and see her sitting on her armchair with a vacant expression, staring out the window. But when she sees it's me who's come in, her eyes light up and she smiles! She's so happy to see me...That's why I keep going. It's because of the feeling I know she gets knowing I'm there.'

Araceli appeared to enjoy the feeling of being needed that came with care-giving, giving her a profound sense of purpose, which amplified a deep love and genuine care for her mother's wellbeing. Borneman's (2001) reflective piece is helpful here in examining the profound meaning and joy that Araceli found in caring for her mother in older age. Borneman fervently critiqued anthropology's tendency to subordinate the human side of kinship, and to instead concentrate its focus on kinship's organisational form and means of reproduction. He highlighted how, in analysing kinship relations in this way, the discipline was omitting to explore the deeply human 'need to care and be cared for' (Borneman, 2001, p. 51). Anthropology, Borneman advocated, should instead become concerned with the actual situations in which people experience this profound need to care and be cared for. Araceli's words resonate with this call, as they reveal how the overarching motivation that made her continue to care for her mother as she became frailer, was not found through their relationship as daughter-mother in a detached kinship structure, but lay in a deep sense of love, need, and desire to care. Through my time during fieldwork speaking with family care-givers in *Pueblo*, I found that it was the love that relatives felt in relation to those they cared for, that they described as the overarching emotion that motivated them to engage in ongoing, dedicated acts of care-giving.

Family care-givers described love as founded in gratefulness for the relationship they shared with the care-receiver. Adult children frequently framed their care through feelings of gratitude from having been looked after by parents from childhood and throughout their lifetime. Magdalena described how memories of her mother's sacrifices, motivated her to make sacrifices to provide care:

'She cannot express that she is thankful to me because of the dementia. It's the same as how children are often unaware of the sacrifices that parents make for them. When we were children there wasn't always enough food to go around. But my mother, despite going through perils walking across the mountains to get us bread from the next *pueblo*, took nothing for herself. If someone had to go hungry, it was always her. But as children we weren't aware of it, so we were never really grateful. Now it's the other way around [laughs]. Sometimes it's not easy, but I make the sacrifices that I know she made for me.'

Magdalena compared the sacrifices her mother had made when she was a child to the sacrifices she now makes as her care-giver in older age. She understands that due to dementia her mother cannot be 'grateful' for the sacrifices she is now making, but compares this to her childhood self being oblivious to her mother's sacrifices. Magdalena is thus alluding to a sense of intergenerational reciprocal kinship care being maintained across the life course.

Insights from cross-cultural examples into motivations behind kinship eldercare resonate with Magdalena's description of her reasoning for caring for her mother in older age. Lamb (2000), through her ethnography exploring experiences of ageing in West Bengal in India, explained how adult children looked after their elderly parents as part of a sacred reciprocal cycle of kinship care across the life course. This reciprocal cycle explained how, as their parents had cared for them as infants, adult children were morally indebted to care for their parents in older age. Bengali family members, Lamb described, were thus connected to one another through 'long-term relations of reciprocal interdependence and indebtedness' (Lamb, 2000, p. 47). Lamb explained how 'the moral obligation to repay the vast debts incurred was the primary reason adult children cared for their aged parents' (ibid., p. 46). Magdalena, in making the comparison between the care she received as a child and the care she now gives her mother as an older dependent adult, appears to reflect a similar sense of being morally indebted to her mother as was observed by Lamb (2000) researching with families in West Bengal. These cross-cultural insights suggest that intergenerational reciprocal relations of care within families can mean that a sense of needing to fulfil a moral debt towards close kin can be a motivating factor in kinship eldercare.

Leinaweaver's (2013) ethnographic work, based in the small city of Ayacucho in Peru, is another useful cross-cultural example to draw comparisons from here. She revealed how complex processes of gratitude and ingratitude shaped constructions of kinship, and the care given by adult children towards their elderly parents. Leinaweaver uncovered how adult children in Ayacucho, who felt grateful to their parents for economic opportunities and social mobility, understood themselves as returning the favour by looking after their parents through dedicated care in older age. I also observed a sense of gratitude being felt and expressed by adult children in *Pueblo* towards their parents through kinship care-giving practices. Magdalena's care-giving practices towards her mother as an adult with dementia, were justified and framed through gratitude regarding the sacrifices her mother made towards her to look after her when she was a child. This suggests that gratitude can play a significant role in shaping kinship constructions and elder and dementia family care practices in Andalusia.

Gratitude has already been raised in relation to kinship eldercare in Andalusia in Collier's (1997) ethnography of a rural Andalusian *pueblo*. With the advent of democracy and social mobility across Spain, many adult children in the 1980s had left deprived Andalusian *pueblos* to gain economic empowerment in cities. Many of these children moved ageing parents to their new city homes to care for them in older age. These adult children no longer depended on economic support from their parents, as generations before them had, but were motivated by gratitude and desire. This gratitude influencing care-giving suggests that the relationship the care-giver has to the care-receiver is a profound motivator; if gratitude is higher then so too is love and motivation to care, even if dementia has resulted in a change in relationship.

## Conclusion

This chapter has uncovered the complex social processes through which elder and dementia care are constructed as gendered practices in Andalusia. It began by exploring how care in *Pueblo* was constructed as naturally feminine. Positioning women as closer to nature and the body, women are understood as suited to the bodily practices of dementia care. I investigated how dementia care, understood as centring around cleaning a 'dirty' body, further conceptualised care as feminine. I presented family care-givers' accounts of the emotional challenges of caring for relatives' bodies with dementia and how these influenced local understandings of femininity and masculinity. I then delved into local care-givers' descriptions and my own experiences of the intimacy of dementia care and its, at times, sexualised and maternal aspects, which further strengthen understandings of dementia care as feminine. I also highlighted how women care-givers could become the objects of unwanted sexual advances from care-receivers and how they managed this. These understandings of dementia care, being locally conceptualised as naturally feminine, bodily, dirty and intimate, led into an exploration of how care-givers were obliged to make dementia care publicly invisible, confining the demented body to the private realm of the domestic sphere, ensuring the protection of the public identity of the person with dementia and their family.

In the next section, I suggested middle-aged women care-givers in Andalusia, in undertaking primary responsibility for dementia care, alongside multiple other forms of care across their kinship networks, '*encargarse de todo*' ('take care of everything') for the sake of their families, to act as 'matriarchs of kinship care'. Given the importance placed on family in Andalusia, and the sharp public/private divide in this context, middle-aged, sandwich generation women, through their care-giving practices across intergenerational kinship networks occupy a position of domestic power. I revealed the deep sense of duty that many women in *Pueblo* expressed to care for elderly relatives. I explored how local conceptualisations of femininity present the middle-aged Andalusian woman as a

busy, dutiful, caring and invincible mother-figure, developed through historical understandings of women as dedicated to their extended family networks, and exacerbated by recent social changes, including increased longevity and young adults' economic insecurity.

This led into a description of how discourses around carers' and women's rights have raised recognition of the role women play as informal care-givers. This has caused national and local measures, such as the Dependency Law and local support groups, to offer support. However, these state-funded support systems, whilst offering provision, are extremely limited and still depend on unpaid labour from family care-givers to ensure older people with progressive dependencies and dementia remain at home. Local support groups, like *Pueblo's* carers' group, subscribe to international discourses around successful ageing, which employ a self-help philosophy to promote unattainable goals focusing on continually maintaining ageing bodies through dedicated hard-work in care-giving. These state measures thus facilitate the structural support of this demanding role to unpaid women.

This led into a description of the vast challenges family care-givers confront through this demanding role, leading to stress, anxiety and overload. Yet despite the challenges faced, I uncovered the passion women described for their unique role as matriarchs of kinship care; positioned at the centre of their extended family networks. I revealed the power these women harness over their intergenerational kinship networks and the pride they expressed in bonding their families together through care-giving, which they conceptualised through profound love for their families. This chapter has explored the social processes that gender dementia care, which can paradoxically both subordinate and empower, channelling diverse undercurrents of power that flow and overlap to continuously reshape the meanings of gender, kinship, care and love in Andalusia.

## Chapter Five: *Fiestas*, Saints and Spirituality in Community Dementia Care

This chapter explores how spirituality and collective rituals influence community dementia care in *Pueblo*. I describe how *abuelos*' interactions with the town's Virgin Mary saint statues generate personhood, situating the Virgin saints as spiritually protective kinship care-givers. As ubiquitous religious symbols, the saints can be recognised by some people with dementia, providing reassuring familiarity. *Abuelos* nearing end-of-life can draw comfort from these saints, who become mediators between everyday and spiritual worlds. During *fiestas*, the statues are animated in processions, stimulating intergenerational solidarity and spiritual protection, to strengthen residents' sense of belonging, especially valuable to *abuelos* living within *Pueblo*'s care institutions who may be at risk of isolation. In care institutions, activities encouraged *abuelos* to participate in *fiestas*, reaffirming their community-membership. For people with dementia, the multisensorial nature of *fiestas* can be therapeutic by inciting embodied long-term memories, whilst their seasonality can be reorientating. This chapter brings insights from the anthropology of religion into the anthropology of ageing, by arguing that religious rituals have the capacity to generate a spiritually and collectively therapeutic role in community elder and dementia care. This reveals the need to approach dementia care as not only 'person-centred' but also 'community-centred'. It further demonstrates the capability of ethnography to reveal the diverse ways that collective cultural practices can influence elder and dementia care.

One adjustment I struggled with in day-to-day life during fieldwork in *Pueblo*, was talking earnestly in conversations with *abuelos* about the town's Virgin Mary statues. *Pueblo*'s inhabitants were split into an upper neighbourhood, protruding across the top of a sharp mountain slope and a lower neighbourhood, nestled at the bottom of the gradient. Each neighbourhood had its own chapel, within each of which resided a distinctive statue representation of a Virgin Mary saint. The upper neighbourhood housed *La Virgen de la Humildad* (The Virgin of Humility) and the lower neighbourhood *La Virgen del Pilar* (The Virgin of the Pilar).<sup>6</sup> Although I now describe myself as agnostic, my awkwardness in conversations about these statues may have stemmed from my fervently atheist upbringing. I found it difficult talking with *abuelos* about these statues, which they seemed to hold in such profound reverence. What surprised me was how *abuelos* spoke about the statues as real people. One conversation at *Pueblo*'s care home went as follows:

'Chloe! Did you see the procession last night?' Isabel asked me excitedly.

'Yes, I watched the whole thing. I was...impressed!' I replied, unsure of how to better describe my feelings about it.

'Wasn't the Virgin so beautiful?'

'Oh, she was incredible!' Esperanza chimed in. 'Absolutely stunning! I couldn't take my eyes off her.'

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<sup>6</sup> The saint names are pseudonyms to protect anonymity.

‘Yes, she moved with such grace! So elegant!’ Carmen added, nodding enthusiastically.

*Abuelos* used the pronouns ‘she’ and ‘her’ to describe the statues. As time passed, and I observed the multitude of ways people spoke about and interacted with these statues, I realised that to many people the statues were more than statues; through interactions of devotion the statues generated an interdependent form of personhood. The personhood of Catholic statues has been explored by the anthropology of religion (see Mitchell 2010; Whitehead 2018). I marry this work into an anthropology of ageing by analysing how the statues’ personhood provided *abuelos* with spiritual protection to effectively adopt a kinship care-giving role.

These deeply venerated local Virgin Mary statues are each celebrated with annual *fiestas*. During *fiestas*, ceremonies occur where local residents assemble at the statues’ resident chapel, recite prayers and sing devotional songs. *Pueblo* is decorated with colourful bunting and banners praising the distinctive Virgin saint being celebrated. Celebrations include huge processions where the statues are placed on ornamental floats and paraded through the streets of *Pueblo* to the cheers of ‘¡Viva la Virgen!’ (‘Long live the Virgin!’), ‘¡Guapa!’ (‘Pretty!’), and the jubilant music of the town band (see figure 1). Residents attend a *feria* (fair) from midday until the early hours of morning, with funfair rides for children and booths containing stages equipped with dancefloors, where flamenco performances take place (see figure 2).

This chapter explores the dynamic ways that spirituality and collective ritual celebrations can serve as deeply meaningful forms of community elder and dementia care. This section begins by discussing how personhood is generated in *Pueblo*’s Virgin Mary statues, describing how people’s interactions bring the statues to life. *Abuelos*, particularly those with dementia, or nearing the end-of-life, drew profound comfort through devotional interactions with the statues. These interactions created reciprocal relationships, situating the Virgin saints as kinship care-givers and spiritual protectors, who mediate *abuelos* between the natural and spiritual world.



*Figure 1. Residents carry a Virgin Mary statue in a fiesta procession.*



*Figure 2. Residents celebrate at the feria during fiestas.*

## **The Personhood of Statues**

As fieldwork progressed, I began understanding how *Pueblo's* residents attached meaning to the Virgin Mary statues. To many, these statues were more than statues, they were real embodiments of the Virgin saints they represented. Personhood was generated through people's devotional

interactions with the statues. I gradually became more confident talking about the statues, referring to them using feminine pronouns, and even directly interacting with them.

In the weeks leading to the *fiesta* held for *La Virgen de la Humildad*, excitement filled the air in *Pueblo*, particularly in the upper neighbourhood where I lived, which contained the resident chapel of this statue. Colourful bunting and banners were strung from houses and fluttered across the streets, proclaiming '*¡Viva La Virgen de la Humildad!*' ('Long live the Virgin of Humility!'). On the first day of the *fiesta* a ceremony was held in the chapel. People had been talking to me enthusiastically about this upcoming event. I had been instructed to wear my best clothes and spent significant time beforehand getting ready to meet this important member of *Pueblo's* community. The town band were playing in front of the chapel, and there was a lively atmosphere as people queued up outside. I ran into María José, an 84-year-old woman who attended the day centre, queuing with her daughter:

'Have you got in mind something you'd like to ask her?' María José enquired.

'Urrm... No, not really. I don't really know what to tell her' I muttered sheepishly.

'You can say anything you like! She's very understanding. Tell her what you're worried about, and she'll help you. I usually ask her to watch over the health of my family...Don't worry!' She reassured me, seeing the bemused expression on my face. 'She's kind! There's no need to feel nervous! And then of course you can kiss her hand. It's a real honour, to be so close to her. This is the only time of year we can do this, so we must appreciate it.'

'Thanks,' I replied, feeling somewhat reassured, somewhat baffled and, surprising myself, a little excited...

Inside the chapel, as I drew closer to the front of the queue I looked up at the statue. I was surprised by her smallness. People stood several metres back from the statue, giving the person at the front a more private, intimate moment with the Virgin. I could see as it reached their turn to approach her, people would bow, sign the cross, and speak in quiet whispers to the Virgin. After a few minutes of chat, they would go right up to the statue and kiss her hand, then wipe it with a tissue. To my dismay, I realised I did not have a tissue on me! I frantically asked the people in front of me, but was unable to get hold of one before my turn. When my moment came, I asked the Virgin to look out for me during fieldwork, kissed her hand and apologised for not having a tissue, then



awkwardly used my cardigan sleeve to wipe her hand clean. I walked away, feeling a bit silly but also relieved and optimistic. It reminded me of making wishes blowing out candles on a birthday cake, and I found myself hoping my wish would be granted!

The personhood of *Pueblo's* Virgin Mary saints was generated through people's social, embodied interactions with the statues that represented them. People spoke about the statues using feminine pronouns, gave them playful nicknames, made eye contact with them, spoke directly to them and kissed their hands. Through these interactions the statues came to exist as real embodiments of the Virgin saints. Previous anthropological work has found personhood to be co-created through devotees' interactions with Catholic statues. Mitchell observed in Malta how people's interactions towards Catholic statues meant people perceived them as 'persons rather than things' (Mitchell, 2015, p. 25). Whitehead's (2013) ethnography explored people's practices towards a Virgin Mary shrine in the Cádiz region of Andalusia. She also found devotees referred to the shrine's statue using feminine pronouns and that their interactions generated 'relational forms of co-inspired' personhood (Whitehead, 2018, p. 230). *Pueblo's* Virgin Mary saint statues, through people's social interactions, thus came into being. Even my own interactions with the statues, as an agnostic outsider, led me to treat the statues as more than just statues. For many of *Pueblo's* residents, and particularly *abuelos*, who came from a generation where religion played a more predominant role in society, the Virgin saints were deeply important parts of their lives, living beings with whom they maintained meaningful relationships.

### **Virgin Saints as Kinship Care-givers**

Not only did interactions with the statues generate personhood, the interdependent relationships people maintained with the Virgin saints fulfilled a kinship role. The Virgin saints the statues represented transformed into kin, acting as spiritual protectors and care-givers. *Abuelos'* bedrooms in *Pueblo's* care home were covered in objects celebrating the Virgin saints: magazine cuttings; handmade decorations; miniature statues; ornaments and trinkets (see figures 3-5). This contradicts common perceptions of care homes as impersonal, showing how *abuelos* personalised and spiritualised such environments.



Figure 3. A care home bedroom decorated with photos of the Virgin Mary.



Figure 4. A homemade decoration of the Virgin Mary on the wall in a care home bedroom.



Figure 5. Stickers of Virgin Mary statues on the wall of a care home bedroom.

Residents regularly spoke to these objects to communicate with the Virgin saints. Isabel, an 87-year-old care home resident, explained her night-time ritual with her miniature statue that was a replica of *Pueblo's La Virgen del Pilar* statue:

'I'm lucky. I'm never lonely because I have my Pilar here beside me,' [gestures towards miniature statue on bedside table] 'I tell her everything. I tell her about my day, and she always listens to me. Before I sleep, I kiss her and wish her goodnight. Then she watches over me as I sleep...I was having lots of problems

sleeping, especially when I first moved here [to the care home], I couldn't get used to the change. And because of Sole [her ex-roommate who has advanced dementia]. She was not well in the head. She was always getting up in the night and shouting and sometimes she would even shake me awake. It was terrible. But I spoke to my Pilar about it and she handled it. Eventually Sole was moved to another room. I'm so thankful for that, because since she's gone, I've been sleeping much better...If I ever wake in the night, I look over at Pilar and seeing her there helps me get back to sleep.'

Isabel's relationship with the Virgin was reciprocal. She understood the transfer of her roommate to another bedroom as the Virgin's doing; she had shared a problem with the Virgin, who had resolved it. Through the sharing of her thoughts, worries and wishes with the statue, she generated an interdependent relationship with the Virgin saint. The Virgin Mary, as mother of God, is considered the quintessential mother of Catholic theology. People identified with this maternal attribute and reproduced the relationship she occupies within Catholicism. Whitehead explained how the Virgin Mary shrine in Cádiz took on a 'kinship role' by protecting her devotees (Whitehead, 2018, p. 225). In *Pueblo*, the warmth and protection Isabel described the Virgin offering, through telling her about her day, or kissing her goodnight, provided her with maternal protection.

For *abuelos*, the kinship experienced with the Virgin saints was especially meaningful because, as elder members of their families, they had lost parental kin over their lifetimes. This maternal relationship, achieved through interactions with representations of the Virgins, proved especially comforting as it restored kinships lost in life. Isabel recalled how her devotion to the Virgin had helped her manage grieving for her mother:

'When my mother died, I felt I'd lost all hope. It was extremely hard. But with the help of the Virgin, I got through it...I know now that I'd never really lost my mother because she's in heaven, and not only that, but she's with the Virgin. And they both watch over me from heaven. So really, I have two mothers watching over me [laughs]. How can I say I'm an orphan when I have two mothers taking care of me?'

The Virgin saints thus provide not only interdependent care, whereby interactions of devotion are reciprocally repaid through good fortune, comfort and protection, but a relationship experienced as maternal. This was especially meaningful to *abuelos* who had lost parental kin.

The Virgins' capacity to nurture appeared especially important for people with dementia. For those in earlier stages, who were aware of their diagnosis, this protection could be the source of profound comfort. This is seen through my conversation with 82-year-old Mari Carmen, who had been diagnosed with Alzheimer's Disease a year earlier:

'I know my memory is bad, and I know it will only get worse as time goes on. But I try not to worry. I try not to worry because I know even if I cannot remember, Pilar [the Virgin saint] is watching over me, and if I do not remember, she will remember for me.'

Mari Carmen's understanding was that if her cognitive capabilities failed her, they would be filled in by the Virgin. Her words suggest she understands her memories, which form part of her personhood, as interdependent with the Virgin saint. By covering the memory deficiency that made Mari Carmen vulnerable, the Virgin saint looked after her the way a mother cares for a child. Social interactions of devotion towards the Virgin saints can thus become a profound source of interdependent kin-like spiritual care.

For those with dementia experiencing greater memory loss and confusion the Virgin statues, as representations of deeply ubiquitous religious symbols, still appeared to be recognised by some people with advanced dementia. 89-year-old Rosita, who regularly attended the day centre, had been diagnosed with vascular dementia fifteen years earlier. By the time I met Rosita, she was displaying advanced dementia symptoms: she was wandering, appeared disorientated, could not recognise people she knew and appeared to hallucinate. When I tried to engage Rosita in conversation, she would sometimes respond by smiling or talking, mentioning people who staff knew to be her relatives. Often what she said seemed incoherent but there were moments when she appeared more lucid.

Rosita also had an increasing tendency to get agitated, when she would shout or even hit others, which staff struggled to manage. One technique staff discovered by accident was to walk her to the large framed photo of *La Virgen del Pilar* statue, hung on the lounge wall. Staff would gesture, encouraging Rosita to look at the image. Rosita, would sometimes look up at the Virgin and on processing the image, snap out of her agitation, sign the cross with her hand and mutter a prayer. Sometimes this technique worked brilliantly, other times it did not and Rosita continued to exhibit aggression. One carer explained understanding this as evidence of the Virgin's presence and protection over the day centre, whilst another, who described herself as unreligious, said it was because the Virgin Mary was such a recognisable image that it was relatable even to those with advanced dementia who might struggle to recognise other things.

The power of such Virgin saint representations also appeared beneficial for *abuelos* with dementia through the repetitive, multisensorial nature of devotional rituals which were experienced as familiar. Ana was care-giver to her mother, 92-year-old Andrea, who was bedbound with advanced vascular dementia. Ana described generating hope from moments when her mother became more lucid. She explained how, during the *fiesta's* opening ceremony, she would put the local radio station on in the bedroom her mother occupied and they would listen to devotional songs made to *La Virgen de La Humildad*. This Virgin statue rests in the upper neighbourhood, where Andrea had lived her entire life. Ana described how during the live broadcast of this ceremony, her mother would sit up and her features become more alert. She would smile and move her lips to these songs she had memorised since childhood. Ana understood this as her mother connecting with the Virgin saint, whom she had been devoted to throughout her life before dementia. Ana deliberately decorated the bedroom her mother slept in with photos of the Virgin to help her mother maintain this connection. Ana's strategic use of objects that attested to *Pueblo's* unique regional identity, whilst stimulating her mother's senses, can be understood as a way of inciting belonging in her mother. May's work explored belonging in relation to how people make meaning of themselves and society. She advocated the use of belonging as an analytical tool, as it foregrounds diverse sites of identification such as 'the sensory and material aspects of the world' (May, 2018, p. 9). Ana, by playing the radio to her mother during the *fiestas*, drew them both into a shared sensorial experience of belonging by playing into their deeply-rooted connections to the town they both lived in, the spiritual protection of the Virgin Mary saint, and to one another.

Ana was attempting to manufacture the conditions that triggered these more lucid, connected-seeming moments in her mother. Svendsen et al (2018) through their ethnography of a Danish dementia care home described how carers deliberately attempted to stimulate moments when 'the person with dementia responded, albeit slightly, with a nod, a movement, or a verbal sound, expressing some kind of comfort or fulfilment in life', describing these as 'magical moments' (Svendsen et al, 2018, p. 28). I use this conceptualisation in combination with Mattingly's (2010; 2014) explanation of 'moral laboratories' of care. Mattingly's research with families of children with serious chronic medical conditions in the US explored how care became a 'moral laboratory' whereby care-givers, in making complex decisions about care, become experimenters in creating conditions that generated hope. I argue that care-givers to people with dementia strive to create 'moral laboratories' of care that result in 'magical moments' to be experienced by those they care for. In Ana's case, she experimented using multisensory sources – religious images, prayers and hymns – to create the necessary experimental conditions for her mother to experience a 'magical moment' through which she could spiritually connect with the Virgin saint.

The repetitive, structured nature of rituals, such as prayer, appeared to ground people with dementia into the present. Many *abuelos* in *Pueblo* said prayers, explaining these as an important part of their religious devotion. They said prayers to themselves or to religious trinkets, images or icons, before going to sleep, or when in moments of distress. Mari Carmen, within the early stages of Alzheimer's Disease, recalled how worried she had been when she first started experiencing memory loss. She described seeking comfort from the Virgin saint by saying a prayer to *La Virgen del Pilar* each night. Performing this nightly prayer before going to sleep provided consistency, rhythm and routine to calm her worries.

Ritualised devotional practices towards the Virgin saints could be especially useful for people approaching end-of-life. Although people of varying ages engaged in devotional practices towards the Virgin saints, it was more pronounced in older generations. This was partly because this generation came from a time when religious worship was more active across society. However, it could also be due to their life stage, as they were coming closer to death and feeling a need for spiritual mentorship. Mari Carmen spoke of her comfort that the Virgin saint was there at this point in her life:

'Before I go to sleep, I say a prayer to Pilar [the Virgin saint], I ask her that if tonight is the night that I am ready. But I ask that she guides me and be by my side through my journey.'

Mari Carmen's description of her everyday intimate interactions with the Virgin Mary saint statue shows how *abuelos* could form close protective relationships with these saints. Mitchell's (2010) piece, in which he explores the presence and power of Catholic saints in Malta, is helpful to aid analysis here. Through ethnographic insights from Malta, he uncovered how saint statues, which are interacted and performed with during Maltese religious rituals, are not mere artifacts but 'substantive embodiments of saintly presence' (Mitchell, 2010, p. 275). Mitchell explained how these saint statues can connect the material and immaterial worlds, as well as the natural and supernatural worlds. Saints are not understood as being entirely supernatural entities from mythology, as they can be verified as actual historical figures, with lives which can be empirically confirmed. This makes saints special as they are 'hybrids: part historical, part mythological; part everyday, part transcendental; part natural, part supernatural' (ibid., p. 265). The hybridity of Catholic saints, between the supernatural and natural worlds, Mitchell explained, makes them relatable to people in their everyday life. This means worshipers can develop close bonds with saint statues and seek their help to resolve personal problems. Mari Carmen's everyday interactions with the Virgin Mary saint statue reflect the existence of this close bond and intimacy, and suggests that

the Virgin Mary saint statues could be deeply relatable to *abuelos* in *Pueblo*. *Abuelos* could engage in intimate interactions with the saint statues to form close bonds that protected them through times of hardship. Such relationships could be particularly protective and comforting to *abuelos* who faced dementia or concerns over coming towards the end of their lives.

The Virgin Mary saint can be argued to possess a particularly special presence which is especially relatable to people. Hall's (2004) book, exploring worship and devotion towards the Virgin Mary in Spain and the Americas, makes this argument. Hall uncovered how the Virgin Mary is held up in many contexts as a feminine vision of peace and unconditional love with a profoundly strong power over those who worship her. Analysing Roman Catholic theology, Hall argued, is important in understanding the Virgin Mary's particularly strong power over worshippers as she is 'not God but the Mother of God. She is fully human, the vehicle through which Christ became flesh, but not herself a deity' (Hall, 2004, p. 7). Hall suggested that the Virgin Mary's resonance and power is partly explained through this humanity, as it makes her more accessible to people, as a fellow person, rather than a God. Hall's insights into the Virgin Mary's relatability could further explain why *abuelos* in *Pueblo* may have held the Virgin Mary saint statues in such profound reverence, and generated such deeply intimate personal bonds with them. This relatability is further enhanced by the particular localised versions of the Virgin Mary saint statues existing in *Pueblo*. I argue this relatability positions Virgin Mary saints as ideal candidates to fulfil the role of divine mediators and spiritual protectors, guiding people from life to death, and could explain why people in *Pueblo* increased their devotional practices as they got older.

### ***Fiestas* as Social Solidarity**

This chapter now uncovers how these saints were celebrated through annual *fiestas*. I use Mattingly's (2010; 2014) and Svendsen et al's (2018) theorisations to analyse how care-givers in *Pueblo* deliberately incorporated local *fiesta* rituals into eldercare to reap therapeutic benefits. I then carry the concepts of collective effervescence, *communitas* and liminality from the anthropology of religion (see Durkheim, [1912] 2007; Turner, 1969) into the anthropology of ageing by exploring how *Pueblo's fiestas* strengthened *abuelos'* sense of belonging and reaffirmed them as important community-members. The celebratory, multisensorial nature of the *fiestas'* processions could incite a liminal state by triggering profoundly embodied memories in people with dementia, despite their increasing forgetfulness, to be experienced as therapeutic. The seasonal, repetitive nature of *fiestas* orientated *abuelos* with dementia to the present, whilst linking them to their community's shared past. The benefits of taking a 'person-centred' approach to dementia care have been well-established (see Kitwood, 1997), yet investigating these collective religious rituals displays

the importance of taking a ‘community-centred’ approach. I thus bring insights previously explored by the anthropology of religion into collaboration with the anthropology of ageing, by arguing that community religious rituals have the capacity to generate a spiritually and collectively therapeutic role in elder and dementia care. This demonstrates the importance of approaching dementia care as not only ‘person-centred’ but also ‘community-centred’ to ensure care is contextually relevant and reaps the therapeutic advantages of the community and culture from which it comes. As Brittain and Degnen (2022) have advocated, it is crucial to explore dementia care *beyond* only private homes and institutional settings. This chapter thus furthermore demonstrates the benefits of taking an everyday, *ethnographic* approach to investigating ageing, dementia and care, that stretches beyond healthcare sites, revealing the diverse ways that collective cultural practices can form a crucially important part of elder and dementia care.

The first annual procession with a Virgin statue had the added build-up of occurring straight after the *Fiesta de Las Cruces* (Crosses Festival), another of many *fiestas* that decorated *Pueblo’s* calendar, which involved people adorning large crucifixes with flowers which were dotted about town. *Pueblo* was thus already in full-swing of *fiesta* by the time *La Virgen de la Humildad*, left her chapel to parade the streets for the procession in her honour. Below, I describe my experience witnessing the start of this procession:

As I walked towards the chapel, I could hear the thumping drums and hooting brass music drawing closer. Children ran past excitedly, holding sparkly balloons and brightly coloured plastic wind-spinners, heading in the crowd’s direction. I joined the excited hubbub gathered in the plaza outside the chapel. Men dressed in traditional-style suits with wide-brimmed hats, stood alongside women in colourful polka-dot flamenco dresses, chatting excitedly, whilst chewing on sunflower seeds, scattering the floor with their discarded shells. The uniformed town band standing outside the chapel were playing and the atmosphere was jubilant. My neighbour, closer to the front of the crowd, caught my attention and waved me over.

‘You’re here just in time.’ She pulled me into the crowd, smiling, ‘She’s about to come out!’

Minutes later, the chapel doors were flung open, and out streamed the procession. People dressed as priests, some carrying large crucifixes, or candles, others waving pots on chains, filled with strong-scented frankincense, marched alongside an array of costumed people: women in ornate dresses with veils,



priests in long tunics holding up silver sceptres, children dressed as shepherds with tea towels over their heads, all marching in line to the music.

Moments later, the crowd let out a huge cheer and the unmistakeable, towering figure of *La Virgen de La Humildad* standing tall on her ornately decorated float emerged from the church doorway, supported over great wooden beams resting on the shoulders of men in white shirts, marching in unison. The band upped the volume and blasted out a celebratory tune, whilst members of the crowd shouted '*¡Viva la Virgen de la Humildad!*', '*¡Guapa!*' and '*¡Morenita!*'<sup>7</sup> to rapturous applause. Spectators standing on balconies overlooking the plaza, threw colourful petals which spun and floated over the crowd. People were smiling, clapping, cheering and shouting at the Virgin statue, stretching out their arms to get closer to her.

The collective excitement of the *fiestas* was not only spiritual, but a collective, social experience that produced community solidarity. Many younger residents explained they were not religious, with some even describing themselves as 'anti-religious' because of Catholicism's role during Franco's dictatorship. Yet, even non-religious residents described enjoying the *fiestas* as a celebration of their community.

Collective worship rituals were famously investigated by Durkheim [1912] (2007) as social processes through which people connect as a group. Using Durkheimian analysis, participation in *Pueblo's fiestas* linked residents to the spiritual and everyday worlds of their community. For *abuelos* needing care, this solidarity across generations could offer profound comfort. Durkheim described collective participation in religious ritual as generating 'a sort of electricity', which he named 'collective effervescence' (Durkheim, [1912] 2007, p. 247). I extend this analysis into eldercare, arguing that this experience is particularly meaningful to older people, who due to physical or cognitive decline may be experiencing social isolation from their community. Through participating in *fiesta* rituals, *abuelos* channel into collective effervescence, providing a profound sense of solidarity. Existing care research has emphasised the need to approach care as 'person-centred' (see Kitwood, 1997), yet investigating older people's collective participation in these religious rituals demonstrates that care, as well as being 'person-centred' is also profoundly 'community-centred'.

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<sup>7</sup> *Morenita* translates into English as 'little tanned woman' and in Andalusia expresses the beauty of a woman with tanned skin. Residents explained this as an affectionate nickname for the Virgin. This reference to tanned skin may be indication of the Virgin saint's relatability to the people of *Pueblo*, who working in the olive plantations tend to have tanned skin from working outside.

Christian's (1972) ethnography in a highly devout region of Northern Spain, explored people's experiences of religiosity and devotional practices. He explained the Virgin Mary as a 'totem object' to Spanish people, whereby she becomes representative of the community's essence, its link between real and spiritual, and to ancestors that celebrated her before and future generations who will celebrate her after. As Durkheim wrote of a totem object 'it is the centre of all regards...the permanent element of the social life' (Durkheim, [1912] 2007, pp. 278-279). The Virgin thus becomes a totem-like mediator, generating social cohesion across different generations, and between the natural and supernatural world. As the Virgin Mary statue is animated during processions, the celebration of people's devotion stimulates collective effervescence which generates a profound sense of shared protection and care across the community, especially felt by *abuelos* and displaying the value of 'community-centred' care.

During processions the Virgin's personhood comes into closer proximity to people's everyday reality, providing people with a deeper emotional engagement with the Virgin and an enhanced sense of her spiritual protection. The statue, resting on a float and swung by those who carry her, is animated which emphasises her vitality and personhood. As Mitchell described of the Maltese *festa*, the ritual processions that animate the statue of St Paul make him 'an agent', enabling people to experience a closer social engagement (Mitchell, 2004, p. 68). *Pueblo's* residents positioned themselves as close to the procession as possible and held out their arms towards the statue to experience this intimate engagement. The Virgin Mary statue, animated through processions, is thus brought into an intimacy where she moves within the everyday world of her people.

By moving the statues away from their usual resident chapels into *Pueblo's* public spaces, the saints' spiritual protection appeared to be felt more strongly. This can be seen through the town's response to the outbreak of Covid-19 experienced by *Pueblo's* care home in April 2020, which tragically resulted in multiple hospitalisations and deaths. *La Virgen del Pilar* statue was carried and held in front of the care home in a special socially-distanced ceremony, emphasising that the Virgin saint was present and watching over the care home during this extraordinarily difficult period. The physical closeness of the statue thus appears to enhance the saint's spiritual protection, which I argue has a profound effect on *abuelos*. Brittain and Degnen (2022) highlighted the need to explore what makes communities more inclusive for people with dementia. They explained how 'when materialities and socialities are working well together, public spaces appear to become more flexible in a way that is more inclusive and dementia friendly' (ibid., p.428). In *Pueblo*, during this time of crisis, the flexible, creative deployment of the materiality of the statue by members of the public, enabled *abuelos* living in the care home to tune into this collective solidarity to feel supported both

spiritually by the saint, and socially by the community. This again highlights the need to approach care as 'community-centred' and demonstrates the importance of investigating how collective cultural practices influence elder and dementia care.

*Pueblo's fiestas* stimulate what Turner (1969) referred to as 'communitas', a deep sense of togetherness felt across *Pueblo's* community. During *Pueblo's fiestas*, everyday institutions are suspended; local public holidays are given from schools and work. On the first day of the *fiestas* for *La Virgen del Pilar*, the council fund a huge paella to be served in the town's plaza and residents eat together, with the town mayor sitting alongside *Pueblo's* citizens. Everyday normalities dissolve, stimulating a sense of 'communitas', enhancing community solidarity. Such solidarity demonstrates to *abuelos* the care existing across generations in their community.

### ***Fiestas* as Generating Belonging**

Feelings of solidarity experienced by those engaging in the *fiestas* helped generate a sense of belonging, whereby people felt connected to *Pueblo's* community, to both its people and the physical place of the town. In the introduction to this thesis, I discussed how belonging involves connecting with people, as well as to places and material objects. Edwards' (1998) explored belonging in her ethnographic work in a post-industrial town in the north-west of England. She uncovered how residents of the town forged belonging through a multitude of connections and attachments to material things, stating: '[to] belong to a locality implies that you belong along with all kinds of other things such as houses, factories, services and pasts. Belonging entails a claim on, and a connection to, these things' (Edwards, 1998, p. 161). *Pueblo's fiestas* played into residents' attachments to material things as a way to strengthen their belonging to the town and its people.

*Pueblo's* Virgin Mary statues are specific saint versions of the Virgin Mary that belong only to *Pueblo* and its land. These statues thus formed a unique and integral part of *Pueblo's* municipal identity, and through residents' profound attachment to them, fostered belonging to *Pueblo's* land and people. Christian described how Spanish saints who occupied shrines possessed their own 'territory of grace...an area over which its benevolent power seems especially manifest' (Christian, 1972, p. 44). Certain ritual practices during *Pueblo's fiestas* linked the Virgin saints to *Pueblo* as their 'territory of grace' to generate belonging in *Pueblo's* residents. May, in her theoretical analysis of belonging, defined it as 'the process of creating a sense of identification with, or connection to, cultures, people, places and material objects' (May, 2013, p. 3). In the chapels housing the statues in *Pueblo*, are objects which connect to the town's unique local collective identity. For example, there are vases filled with dried branches from *Pueblo's* many olive groves, and during the *fiestas*, small glasses of *Pueblo's* locally-produced, distinctive alcoholic drink are placed by the statues. In placing

these objects in these particular positions, and interacting with them in these specific ways, residents of the town developed attachments to these objects which materially connected residents to the locality of *Pueblo* to constitute belonging. Photographs used in *Pueblo*'s annual calendar display its distinctive mountainous physical landscape alongside images of the Virgin statues, suggesting the Virgin saints watch over *Pueblo* as their 'territory of grace' (see figure 6). This belonging to the town, expressed and experienced through attachment to these material objects, thus also constituted a shared spiritual belonging, whereby residents were endowed with otherworldly protection from *Pueblo*'s 'territory of grace'.

For *abuelos*, this sense of local spiritual protection from the Virgin saints is keenly felt as they approach the latter part of their lives. Bedroom walls in *Pueblo*'s care home are covered in images of the Virgin statues and *Pueblo*'s landscape. *Abuelos*, in positioning these objects as acts of devotion towards the Virgin Mary saints, thus generate within themselves a deep belonging to the land of *Pueblo* as a spiritually protected 'territory of grace', which protects them as they move further into older age.



Figure 6. Poster of Virgin Mary statue in front of *Pueblo*'s landscape, on a care home bedroom wall.

For *abuelos* who attended *Pueblo*'s day centre or lived in its care home, belonging to the wider community of *Pueblo* was especially important as it reduced a sense of displacement that could be felt through having moved into the care institutions and away from their old homes in the town. The home (*casa*) is deeply significant in Andalusian culture, and I noticed how people in *Pueblo* would often remark '*no hay ningún sitio como tu casa*', reflecting the English 'there's no place like home'. Despite people in *Pueblo* being highly sociable in public places, there was a

guarded privacy around people's houses, which were generally only accessed by family. This may partly explain why belonging in *Pueblo*, appeared to be largely experienced as a feeling of '*estar en casa*' ('being at home'). This reflects Antonsich's insights, reviewing work on belonging, who suggested that belonging is above all 'a personal, intimate feeling of being 'at home' in a place' (Antonsich, 2010, p. 652). *Abuelos*, in both the care home and day centre, complained of missing their old (*casas*) homes/houses in the town. Miller, in her philosophical analysis of belonging, suggested that people can derive wellbeing from belonging as it 'makes us feel good about our being and our being-in-the-world' (Miller, 2003, p. 218). She explained a basic conception of belonging as 'standing in correct relation to one's community, one's history and one's locality' (ibid., p. 218). In moving from their long-term homes in town to the new environments of the care institutions, *abuelos*' feelings of being 'at home' were at risk of rupture through their physical repositioning, and thus their wellbeing could be placed in jeopardy.

Care practices used in the care institutions thus attempted to enhance *abuelos*' wellbeing through reinstating this feeling of being 'at home' by being positioned in correct relation to their locality by reconnecting *abuelos* to the wider community of *Pueblo*. The *fiestas*, as an important part of municipal collective identity, were thus incorporated into care practices to reaffirm *abuelos*' belonging to the community despite this change in their physical environment. Staff at the care institutions thus engaged *abuelos* in activities which were integral to *Pueblo's fiestas*. For example, in the months leading to the *Fiesta de Las Cruces*, *abuelos* attending the day centre made craft flowers to decorate a large crucifix which was displayed outside. Every year they used different materials to make variations of flowers. Whilst I was there, we painted pinecones collected from *Pueblo's* forests. In previous years they used dried pasta, plastic spoons and egg boxes (see figures 7-12). During the *fiesta*, a party was held at the day centre, with the decorated crucifix displayed alongside other local markers of collective identity. Walls were decorated with trinkets and items attesting to *Pueblo's* collective identity, such as flamenco fans and instruments used to make the locally-produced alcoholic spirit (see figure 13). *Abuelos* recalled with pride how they had previously won *Pueblo's* competition for the most beautifully decorated cross. Such familiar, place-specific activities restrengthened *abuelos*' belonging to the wider community of *Pueblo*, and in doing so helped *abuelos* to feel more 'at home' within the care institutions, despite having physically moved away from their old long-term (*casas*) houses/homes in the town.



Figure 7. Craft flowers made from pasta.



Figure 8. Craft flowers made from plastic spoons.



Figure 9. Craft flowers made from egg boxes.

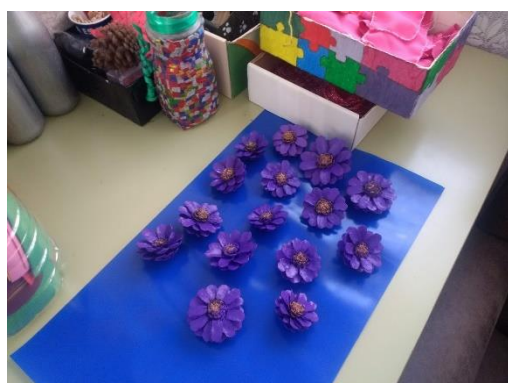


Figure 10. Craft flowers from pine cones laid out for painting at the day centre.



Figure 11. Craft flowers made from pine cones.



Figure 12. Staff member checks how many more pine cone flowers are needed for the decorated crucifix.



Figure 13. The day centre's decorated cross on display with local artifacts during Fiesta de las Cruces.



Belonging can be understood as a process, which can be generated through performances. Wright (2015) analysed how belonging is actively created through performances that involve humans, places and things coming together in certain ways. Rather than understanding belonging as a static status, Wright emphasised the importance of approaching belonging as a 'process' and advocated explorations of 'performances of belonging' (Wright, 2015, p. 392). Rituals taking place during *Pueblo's fiestas* can thus be understood as performances, that draw people, things and places together to generate belonging. During the *fiestas* of *La Virgen del Pilar*, the care home, which was situated near her resident chapel, was welcomed to its own visitation with the statue. Staff accompanied residents to this visitation, where they were invited to kiss the statue's hand and speak with her directly. During these *fiestas*, a procession paraded down the street where the care home was located and paused in front of it to sing devotional songs. Residents who could, sat outside the care home awaiting the procession's arrival, others clustered around windows to watch. The street where the day centre was situated was too narrow for the procession to enter, so the procession paused at the top of the street and the float carrying the statue was turned to look towards the day centre and give her blessing. Through people moving and interacting with the statue in these specific, carefully rehearsed ways, within the particular environment of *Pueblo's* streets, the procession can be understood as a powerful performance of belonging.

Mitchell's (2010) work analysed devotional practices towards Catholic statues in Malta. He explored how statues in Malta were performed with through certain ritual practices that generated spiritual presence, whereby the statues become embodiments of the saints they represented who could, in and of themselves, channel spiritual power. He described how people in Malta physically interacted with the statues, by carrying them, and talking, praying, touching or gazing at them. Through these interactions and ritual performances with the statues people would feel their spiritual power and presence. These ethnographic insights are helpful in analysing the way people interacted and performed with the Virgin Mary saint statues in *Pueblo*. Through the ritual performance of *Pueblo's* Virgin Mary saint statues being carried and paraded through the streets of the town in a procession, they were understood to be spreading their powerful spiritual protection throughout the community. The particular stops the procession makes to acknowledge the care home and day centre highlight how the Virgin Mary's healing powers are considered particularly important to the lives of *abuelos* and demonstrates her role in elder and dementia care. *Abuelos* may have been experiencing a feeling of ruptured belonging, through their displacement from their long-term homes to their new lives in *Pueblo's* care institutions. However, through their integral participation in *Pueblo's fiestas*, *abuelos* were reaffirmed as important community-members and their belonging rejuvenated through these collective ritual performances.

Belonging is localised to the place and wider community of *Pueblo*, but even further to the town's distinct neighbourhoods, giving the feeling of belonging a closer intimacy. Antonsich's (2010) analysis of belonging as a deeply personal, intimate sense of being 'at home' in a place resonates with this more proximate belonging that people in *Pueblo* felt to their neighbourhood community. This can be seen through people's stronger attachments to their neighbourhood's specific Virgin Mary saint statue. *La Virgen de La Humildad* rests in the upper neighbourhood chapel, and *La Virgen del Pilar* in the lower neighbourhood chapel. Several houses in both neighbourhoods had icons of their distinct neighbourhood Virgin saint set into their walls (see figure 14). My neighbours in the upper neighbourhood explained that although they were devoted to *La Virgen del Pilar*, and celebrated her *fiestas*, being from the upper part of town they emphasised it was *La Virgen de La Humildad* whom they were most devoted to. 'Because she's our neighbour', my neighbour explained. 'It is her I see every Sunday at mass. It is her that we know will watch over us up here.' As May explored in her theoretical examination of belonging, the way people feel about the space they occupy is influenced by 'the relationships they have with the people in that space and by the 'cultural content' of that space' (May, 2013, p. 5). The upper neighbourhood was more deprived than the lower neighbourhood, and there was some animosity amongst my neighbours towards the lower neighbourhood. They recounted how the council had privileged the restoration of the lower neighbourhood's plaza as it generated more money from tourism, and they felt the upper neighbourhood was neglected. There thus existed a closer sense of belonging, that the Virgin statues represented, to people's own neighbourhood alliance, as this felt even closer to home. The devotion to one's neighbourhood Virgin saint was thus more personal and intimate and thus her protective powers were felt more strongly by those living in her locality.



Figure 14. Icon of Virgin saint set into a house in Pueblo.



One example demonstrating this closely intimate neighbourhood belonging was 86-year-old Luisa, who had moved into *Pueblo's* care home situated in the lower neighbourhood a year earlier, from her life-long home in the upper neighbourhood. Her bedroom walls in the care home were covered in photos of the upper neighbourhood's *La Virgen de la Humildad*. She had cut-outs from local magazines and photos tucked behind the falls alarm on the wall above her bed (see figure 15). She showed me around her bedroom enthusiastically:

‘And here is *La Virgen de La Humildad* from last year's processions. Beautiful!’ she said, beaming, pointing out one of the magazine cut-outs stuck on the wall.

‘You see I'm from the upper neighbourhood,’ she said to me, lowering her tone of voice. ‘And I know my dear Virgin, my *Morenita*, felt betrayed that I had come down here.’ A look of remorse came over her, ‘But what could I do? I couldn't keep living there. I couldn't manage that big house alone anymore, and all that shopping up the hill from the supermarket. It was too much... But I felt terrible at first. Of course, I love Pilar [*La Virgen del Pilar*], but it's not the same.’

Luisa's guilt since moving from the upper to lower neighbourhood, and her displays of loyalty towards the upper neighbourhood's Virgin saint, shows how people felt the Virgin saints were part of their localised neighbourhood's collective identity. Their belonging and feeling of being ‘at home’ in a place, was thus made more personal and intimate through devotional practices towards their neighbourhood's own specific Virgin Mary saint statue.



Figure 15. Photos of Virgin Mary statue tucked behind a falls alarm.

For older generations, many of whom had never moved house, or only after marriage, a close sense of belonging to their neighbourhood was felt strongly. When a resident died, depending on which neighbourhood they were from it would be the upper or lower chapel's bells which would chime, and many *abuelos* could distinguish this difference between bell chimes. When a man who had been living in the care home passed away, the chapel in the upper neighbourhood chimed for him, as despite spending his last years of life in the care home in the lower neighbourhood, having lived all his life in the upper neighbourhood his was still inherently connected to the collective identity of this part of town. The Virgin Mary saint statues thus, generated a sense of belonging, both to *Pueblo* as a whole, but more intimately and closely to the neighbourhood people were from. This highly localised, intimate sense of belonging, and smaller 'territory of grace', appeared to be felt particularly strongly by *abuelos*.

For many *abuelos*, however, the sense of closeness and belonging to their community could have been reduced by their inability to access *Pueblo's* streets, both in daily life and during *fiestas*. Bissell et al (2019) and Miller (2003), in their explorations of belonging, however, highlighted how belonging can be 'worked at' and created. So, belonging could be deliberately worked at and built for *abuelos* who were not able to physically access *Pueblo's fiestas*. This can be seen through analysis of the broadcasting practices of *Pueblo's* local media networks. *Pueblo*, despite only having 10,000 inhabitants, like other Andalusian towns had its own active radio and television networks, which I refer to as *TelePueblo*. These show unedited live coverage of *Pueblo's fiestas*. When I visited *abuelos* at home, I noticed how commonly these local channels were put on. I became friends with Diego, the camera operator for the local TV station. Chatting to him over a beer one night, he stressed the importance of *TelePueblo* for *abuelos*:

'Sometimes I get fed up when I have to wake early at the weekend to go record another ceremony. Or that time of year when the *fiestas* are on and everybody is off work and enjoying holidays and I have to be on the street all day and night to record yet another procession. But what keeps me going is thinking that I'm doing something that is so valuable for the *abuelos*. They're our main audience. I remember one year I was in the upper plaza filming the *feria* and an *abuelita* [little old lady] came up and kissed me and said, 'thank you so much for recording the *feria*, because I had a hip operation last year and I couldn't leave my house, but seeing it all on TV made me feel like I was there.' 'It made me so happy,' Diego recounted looking wistful. 'So now, when it's 6am on a Saturday and I'm feeling resentful dragging myself out of bed, I think about that *abuelita* and it gives me motivation.'

Diego also explained how, as a media network for a small municipality, it is possible to be flexible and adapt content and showing times to fit with viewers' needs, most of whom are older people:

'We can be very flexible. Say, if an *abuela* rings me up to ask what time we're showing a procession, I'll say 'What time would you like us to show it?' and she might say 'Well around 4pm would be great' so I'll say 'No problem!' and we'll run it then. These older generations are our main audience, so we want to put things on when they want to watch them.'

Despite the town's relatively small population, having its own media networks gives it scope for flexibility which facilitates greater accessibility. By showing live coverage of *fiestas* and being flexible to local people's needs, it facilitates *abuelos*, who can no longer attend the *fiestas* in-person, to participate and generate that sense of belonging to their community.

### ***Fiestas* as Inciting Embodied Memories**

Investigating the role *fiestas* play towards *abuelos* with dementia, I noticed that *fiestas* appeared to influence memories and incite feelings of familiarity in people with dementia. The *fiestas* and all that goes with them: the ceremonies, processions, fun-fair rides, lights, incense, decorations, singing, dancing, and costumes invoke a deeply multisensorial experience in participants. Bull and Mitchell's (2015) edited collection investigates the potential of combining cognitive/neuro-anthropology with performance studies, and the anthropology of the senses, to reach new understandings of religious transmission. They explored the experiential nature of religious ritual practice and its influence over the body. Rather than focusing on mental representations in religious transmission, they advocated the need to investigate people's embodied experience of ritual, approaching the body as 'the sensing body' (Bull and Mitchell, 2015, p. 4). This suggestion is helpful in analysing the *fiestas* in *Pueblo* in relation to the bodily, sensorial experience of those participating. It is particularly useful in exploring the effects of such ritual practice on those *abuelos* who, due to cognitive impairment or dementia, were not necessarily able to communicate through conventional verbal modes, but whose embodied engagement with the *fiestas* was more easily observable.

The annual repetition of these *fiestas* since childhood meant people described certain sensorial triggers, such as the smell of frankincense, triggering nostalgic memories of past *fiestas*. People in earlier stages of dementia, despite their struggles to form newer memories, through multisensorial aspects of the processions could still be triggered into reminiscence of their long-term memories of participating in these rituals in the past. Processions play on the multisensory body; the music, strong smell of frankincense and the striking image of the Virgin Mary statue make the

procession a persuasive and sensorially stimulating event that may imprint long-lasting memories. Below I demonstrate this through my observations of Tano, a 91-year-old man with dementia who lived near me in *Pueblo*:

As I left my house and walked down the street this morning, I'd seen the usual sight of Tano wandering up to his garage, situated at the end of our street. I'd seen him many a time marching up to his garage, opening the door, entering for a few moments, then leaving and locking the garage door behind him. His tendency was to then wander back down the street, but stop and turn back halfway down. He would then return to the garage and check it was locked, sometimes he might end up opening it again, and checking inside, before again closing and locking the door. He would then start heading back down the street, before turning around and repeating the whole process. His wife would get frustrated with him when he said he was going to the garage 'You've already checked it twice this morning,' she'd say, but she could not stop him heading out multiple times throughout the day, sometimes for hours at a time...

It was Tano's repetitive ritualised behaviour that I witnessed in action again today. But this time his ritualised behaviour was fitting to his surroundings. The procession was due to pass through my street, so I'd decided to watch it from my house. Crowds were gathered running up the street awaiting the procession's arrival. The procession began its march down from the top of the street...At the lower end of the street I saw Tano, turning up the street, garage keys in hand. I knew where he was likely to be heading. But on seeing the crowds, he stopped in his tracks. As the procession marched down the street, I saw him stand to the side amongst the crowd and observe the approaching procession. As the procession drew closer, he doffed his hat and I heard him shout '*Viva la Virgen!*', he then clapped along with the music, remaining amongst the crowd.

The deeply multisensory, embodied experience of ritual can cause participants to enter into what anthropologists have coined a 'liminal state' (Van Gennep, [1909] (2004); Turner, 1969). People with dementia could be brought into this liminal between state through previous memories of having participated in the *fiestas* temporarily bringing them into the current moment of collective celebration. People, like Tano, with early-stage dementia, who struggle to form newer short-time memories but can recall long-term memories, can benefit from this liminality. Entrance into this

state may occur through participation in the multisensorial ritual of the procession triggering deeply embedded long-term memories, which have formed from bodily participation in these rituals throughout lifetimes, transporting *abuelos* with dementia into the present moment of collective celebration through memories of the past. Such rituals thus become an important way of connecting people with dementia to their community.

I discussed care-givers' attempts to stimulate what Svendsen et al (2018) called 'magical moments' in people with dementia. These were moments when the person connected with their surroundings. The liminal state, triggered through the multisensorial familiarity of the procession, seemed to incite a 'magical moment' in Tano. The multisensorial procession triggered Tano to break from his loop of forgetful behaviour in checking and rechecking the garage door, enabling him to enter into a liminal state of presence. Despite his short-term forgetfulness, he could enter this state through his long-term embodied memories of past participation in processions, transporting him into the 'magical moment' of collective community celebration. As Goldsmith explained, people with dementia participating in religious ritual 'just *know* what they have to do' (Goldsmith, 2002, p. 145). The repetitive multisensorial nature of *Pueblo's* *fiesta* rituals can be therapeutic for *abuelos* with dementia; the triggering of long-term memories means they can channel into the collective liminal state of this ritual practice and connect to this meaningful community celebration.

During *Pueblo's* *fiestas* memory also connects people to their shared historical and spiritual past. This can be particularly meaningful for *abuelos*, who are coming to the end of their lives, as it can provide a reminder of participating in these rituals with their relatives who have since passed away. People described how processions triggered nostalgic memories of watching them with family years ago. This forms a connection to the spiritual world of their ancestors alongside the spiritual world of the religious saints.

Processions celebrated a shared Catholic historical memory. During *Pueblo's* *Semana Santa* (Holy Week/Easter) processions, Catholic stories are re-enacted. *Abuelos* spoke with genuine sorrow about the procession recreating Christ's betrayal, and with jubilation about the procession performing his resurrection. This can play a reminiscence role to *abuelos* to generate a sense of belonging to a shared religious history. Mitchell, describing Catholic Maltese processions, explained how through this annual re-enacting of past events, they remain 'a continuous presence', which creates a 'concertina-ing of time' (Mitchell, 2009, p. 61). This 'concertina-ing' of time occurred through *Pueblo's* *fiestas*, which were repeated annually in line with specific seasons. This could orientate people with dementia to the present, yet also provide a reminiscence of the past. It could also have an especially powerful effect on *abuelos* approaching end-of-life, by highlighting the

temporal and connected nature of time, nostalgically connecting them to their past relatives, community's shared history, and spiritual world which, as believers, they awaited.

It is important, however, to recognise that for many *abuelos* with dementia the *fiestas* had become inaccessible. For families, this was often taken as a sign of significant deterioration in loved ones' memories and could be extremely upsetting. For such family care-givers, *fiestas* could serve as a painful reminder of changes in their relative. Claudia, who looked after her 88-year-old mother with Alzheimer's Disease, described how her mother had lost interest in the processions and disengaged from prayers to the Virgin statue, which she had performed avidly throughout her lifetime. Claudia recalled taking her mother to a visitation with the Virgin statue, describing how her mother had refused to wait in the queue to enter the chapel and appeared to have forgotten the close relationship she had once shared with the Virgin saint. She understood this as evidence that her mother had declined so much that she was no longer the person she once was. Claudia explained how the town's *fiestas* had now taken on a sad tone. Not only because she was no longer able to attend as she had to stay at home to look after her mother, but because even when she watched them on *TelePueblo*, the memories of having previously enjoyed the *fiestas* with her mother gave her a profound sense of loss.

For others with dementia *fiestas* could be disorientating. José, who I discussed in earlier chapters, was an 85-year-old retired shepherd and olive farmer, in the early stages of Alzheimer's disease. José spent his free time '*en la calle*' ('in the street'), socialising with other men of his generation. I would often pass him in the large plaza in the upper neighbourhood, sitting on benches chatting to other men or playing bowls. José had participated in the *fiestas* keenly throughout his lifetime. However, one afternoon during a *fiesta* the *feria* (funfair) was occupying the plaza where José would normally socialise, causing it to overflow with a hectic mix of people, stalls and loud music. I described, in chapter three, how that afternoon I ran into José who was looking completely lost and barely seemed to recognise me, saying he had forgotten how to get home. It is possible that the chaotic change of everyday circumstances caused by the *fiestas* had been disruptive to José's usual routine of socialising with friends in the plaza and had contributed towards him becoming disorientated. This shows how the rupture to the everyday of the *fiestas* also had the capacity to be potentially disorientating to people with dementia, who may rely on routines to substitute for memory deficits. The meanings of the *fiestas* are thus dependent on every individual's unique contextual experience. Although this chapter has focused on the therapeutic capacities of *Pueblo's fiestas* to elder and dementia care, it is important to recognise that such effects are not universal and are deeply subjectively experienced.

## Conclusion

This chapter has used ethnography to delve into spiritual and collective realms of dementia care. Through exploring *abuelos* interactions with *Pueblo*'s Virgin Mary saint statues, and their participation in collective *fiesta* rituals, I have revealed that such social cultural practices form a deeply meaningful part of community elder and dementia care. I began with an exploration of *abuelos*' interactions with the statues, uncovering how the statues possess personhood and fulfil the role of spiritual protectors. The statues play into people's interdependent sense of personhood to become Virgin saints who act as kinship care-givers. This kinship care-giver role is especially meaningful to *abuelos*, who have lost family over the course of their lifetimes. I analysed how the Virgin Mary saint statues, as powerful ubiquitous religious symbols, can continue to be recognised by *abuelos* with dementia, providing stability amongst the confusion that dementia can bring. Care becomes a 'moral laboratory' (Mattingly, 2010; 2014) in which care-givers perform experimentations, using these symbols to harness 'magical moments' (Svendsen et al, 2018) in those they care for. I discussed how the nature of prayers can provide a steady repetitive thought-pattern in people with dementia which can be experienced as comforting. I also argued that ritual practices towards the Virgin saints for spiritual guidance are especially important to *abuelos*, as they prepare for end-of-life and entrance into the spiritual world.

I then used Durkheimian analysis to explore how the *fiesta* rituals generate 'collective effervescence', inciting social cohesion and intergenerational solidarity to produce a strong sense of community. I explored how the Virgin saints, represented through the statues, act as mediators across generations, and between everyday and spiritual worlds. Through these collective practices, the Virgin saints' spiritual other-worldliness is brought into people's everyday lives. This is experienced as especially comforting to *abuelos*, whose spiritual protection from the community and Virgin saints is reinforced, demonstrating the value of 'community-centred' elder and dementia care. I discussed how *fiestas* form a break from people's everyday lives, generating 'communitas' (Turner, 1969) through collective celebration, strengthening sense of belonging. As the Virgin statues are paraded through the streets during the processions, they map out their spiritual protection over *Pueblo*. The *fiestas* form a uniquely local celebration, drawing on municipal symbols of collective identity to generate belonging. This is particularly important to *abuelos* in care institutions, who may be suffering from feelings of displacement. Staff at these institutions encourage *abuelos* to participate in the *fiestas* to generate this sense of belonging and reaffirm *abuelos*' community-membership. Such feelings of belonging are also felt towards individual neighbourhoods, increasing intimacy. Local media networks facilitate sense of belonging by ensuring the *fiestas* are accessible to *abuelos* who cannot attend.

I then discussed the role of memory in the *fiestas* in relation to dementia care. During the *fiestas*, the multisensorial collective action triggers a 'liminal' state (Van Gennep, [1909] 2004; Turner, 1969), which some people with early-stage dementia who still hold long-term memories, can access. This state is generated through the repetitive multisensorial *fiesta* rituals triggering their long-term memories of participating in the rituals throughout their lifetimes. This liminal state can cause people with dementia to experience 'magical moments' (Svendsen et al, 2018) during the rituals. These embodied past memories thus bring them into the present moment.

I also outlined how the seasonal, repetitive nature of *fiesta* rituals generates a 'concertina-ing' of time (Mitchell, 2009, p. 61), which brings a shared spiritual history into the present. This is particularly important for *abuelos*, who have lost loved ones over time, and are reminded of the connectedness of past to present, and spiritual to everyday. I finally highlighted how every person's experience is subjective and whilst the *fiestas* can be therapeutic to some people with dementia, for others they can be experienced as distressing through highlighting ruptures in memory, or experienced as disorientating by interrupting established routines. Meanings of rituals are thus subjective across individual contexts.

By investigating how meaning is generated around *Pueblo's* Virgin Mary saint statues and *fiestas* I have revealed that community religious rituals have the capacity to generate a spiritually and collectively therapeutic role in elder and dementia care. This brings findings from the anthropology of religion into the anthropology of ageing to demonstrate the importance of approaching elder and dementia care as not just 'person-centred' but 'community-centred', ensuring care is contextually relevant and reaps the therapeutic aspects of the culture and community from which it comes. Exploring the benefits of collective ritual participation for older people is particularly relevant now, as we negotiate new forms of socially-distanced care under the Covid-19 pandemic. This chapter demonstrates how ethnography can provide a useful tool to explore how localised cultural practices can be harnessed to create communities where older people and people with dementia feel valued and able to participate in civic life. It thus more broadly demonstrates the benefits of taking an *ethnographic* approach to investigating ageing, dementia and care, that journeys beyond healthcare sites to reveal the diverse ways that collective cultural practices can form a crucially important part of community elder and dementia care.



## Chapter Six: Power Relations and Exploitation in Care Institutions

This chapter uncovers power relations and exploitation within *Pueblo's* care institutions. It reviews theories of institutional power developed by Foucault and Goffman, applying these to *Pueblo's* care institutions. It also explores how these power relations impact on *abuelos'* belonging. It portrays how the care institutions' physical environments can restrict belonging. Following this, it investigates how working conditions devalue care work and exploit staff. This leads into a depiction of restrictive care-giving practices I witnessed in *Pueblo's* care institutions. Everyday use of haphazard restraints reduced the personhood of people with dementia whilst increasing risk of harm. I then describe how these institutions operate through routines which both empower and disempower people with dementia. I analyse how cognitive exercises, a regular activity at both institutions, subscribed to Euro-American notions of successful ageing which explain cognitive training as fighting off dementia to sustain individualist personhood. Yet when these exercises were implemented in *Pueblo's* care institutions, medicalised perceptions of dementia interventions clashed with local understandings, through which *abuelos'* forgetfulness had always been managed through family interdependency. Everyday care within *Pueblo's* care institutions could thus be experienced by both *abuelos* and staff as exploitative. However, whilst some care techniques were experienced as degrading by some, for others the same strategies were experienced as empowering. This reveals the subjectivity of how dementia care is experienced, demonstrating the challenges of standardising formal dementia care in institutions.

### Theories of Power within Care Institutions

Wrists wrapped with bandages and tied onto wheelchair handlebars...people placed in straight-backed chairs and pushed against tables...furniture positioned to block people's paths...eyes kept shut from heavy doses of medication...doors locked with no way out...

The reflections scattered above depict incidents I witnessed during fieldwork in *Pueblo's* care institutions. These were not isolated cases but the normalised reality of day-to-day life for many people with dementia living within these institutions. How were such care practices experienced by those receiving and giving them? Are they inherently degrading? Or given the advanced stage of dementia of many care-receivers, are they, in attempting to avoid harm and protect, empowering? Participant-observation at *Pueblo's* day centre and care home gave me an insider's perspective into the care taking place within the walls of these institutions. In this chapter, I investigate the power relations within these institutions, focusing on seemingly degrading care forms that I observed. I also explore how belonging is related to power. Belonging, as constituted through processes of inclusion and connection, is also, paradoxically, made through exclusion and disconnection. However, I recognise that whilst for some certain care practices were experienced as disempowering, for others these same practices were experienced as empowering. This displays the subjectivity of dementia care experience, revealing the challenges of standardising institutional dementia care.

Healthcare institutions have long been the subject of power investigations in social sciences. Care homes, where occupants usually take permanent residence, exert control and alter individual

freedoms, thus making them interesting sites to unpack power relations. Foucault and Goffman have investigated power in healthcare institutions. Although their focus was on psychiatric institutions, the inmates they described were residing semi-permanently and usually involuntarily, and therefore their analyses have relevance to my exploration of care institutions. However, as *abuelos* in *Pueblo's* care institutions were living, or attending the institutions indefinitely, it is important that I investigate how their theories of power link with belonging. In this section, I apply Foucault's and Goffman's theories to my ethnographic data to explore power relations within *Pueblo's* care institutions.

Foucault's [1976] (2008) concept of 'biopower' explains how regulatory forces transform the individual body into a 'docile body'. Within institutions, Foucault [1965] (2001) explained how large populations are controlled through this bodily regulation. Brijnath and Manderson (2008) used the Foucauldian concept of biopower to analyse dementia care. They found family care-givers to relatives with dementia in India were tasked with 'bodywork' through which they practiced care that enacted biopower to control the relative's demented body to prevent it from threatening the social body of society. In *Pueblo's* care institutions, staff could be understood as tasked with 'bodywork' whereby care enacted biopower to ensure the institution ran effectively. In chapters one and five, I found helpful Antonsich's analysis of belonging as 'a personal, intimate, feeling of being 'at home' in a place' (Antonsich, 2010, p. 644). Given that *abuelos* were permanently residing in, or attending, the care institutions, it is important that I unpack how this biopower that privileged the structural running of the institution, impacted on *abuelos'* personal, intimate feelings of belonging in a place. In this chapter, I thus explore how biopower was enacted and experienced by staff and *abuelos* within these institutions, and how this structural force impacted on *abuelos'* personal, intimate feelings of belonging.

Foucault [1965] (2001) unpacked western understandings of family within psychiatric institutions, explaining how under liberal economies, care of the sick was entrusted to the family over the state. Foucault explained asylums as microcosms recreating normalised structures of conventional society, thus emphasising family as care-givers. In *Pueblo's* care institutions, family metaphors were omnipresent. Residents at the care home and attendees of the day centre were referred to as '*abuelos*', grandparents, thus connecting them to an imagined kinship network. Given local emphasis on the value of kinship eldercare and the prevalence of anti-institutionalisation discourses, it is possible that care institutions by adopting familial metaphors are attempting to replicate family relations to legitimise the social responsibility and control of the institution over its members. Such understandings of family, Foucault theorised, were why asylums functioned through power relations that replicated 'Family-Child relations' (Foucault, [1965] 2001, p. 274). In later discussion I unpick how certain care practices towards *abuelos* by staff, such as scolding, restraint

use, encouraging child-like activities, and cultivating schoolroom dynamics, replicated this family-child relationship, producing a parental authority of staff over *abuelos*.

Understandings of work and morality in western society, Foucault explained as stemming from Quaker mentalities that defined work as possessing holy importance. He suggested this was why asylums were structured around rigid, work-like routines, which 'detach the sufferer from a liberty of mind', understood as triumphing reason and control over madness and uncontrol (Foucault, [1965] 2001, p. 247). I later explore how routine is used in *Pueblo's* care institutions, highlighting *abuelos'* experiences of detachment and subjugation. I also explore however, how routine can be beneficial for people with dementia, as its familiarity fills in memory deficits. I thus argue that although Foucault's theory still applies in many cases, detachment through rigid work routines differs for people experiencing memory loss, as the lack of need to think due to routine can be empowering. Goffman also explored work as a form of control within psychiatric institutions, referring to formalised task-based activities in institutions as 'work therapy' (Goffman, [1961] 2017, p. 90). In *Pueblo's* care institutions, timetabled, task-based activities were conceived as work-like. At the day centre, *abuelos* were made to sit for two hours daily to complete cognitive exercises, which I discuss later. Such formulaic prescription of task-based activities reflects a 'work therapy' ethic.

Goffman also theorised 'institutional display' as performances directed towards outsider visitors of institutions. Such displays attempted to cultivate an image to reduce outsiders' concerns about the institution being involuntary. He highlighted how public events were used to 'allow outsiders to see that everything is all right on the inside' (Goffman, [1961] 2017, p. 104). I later explore this performativity within *Pueblo's* care institutions, focusing on the care home's Christmas play. I reveal how this event's objectives were aimed at producing an image of the institution as caring over genuine concerns for *abuelos'* wellbeing.

### *Belonging and Power*

I have explored, in chapters one, three and five, the varying ways that dementia and elder care practices in *Pueblo* strategically harnessed belonging to enable *abuelos* to strengthen meaningful connections to people, things and places. However, despite being experienced by many as a positive feeling of being 'at home' in a place, which could facilitate wellbeing, belonging inevitably could also constitute exclusionary feelings of 'not-belonging'. Antonsich highlighted this duality in belonging, explaining how belonging involves two opposing sides 'the side that claims belonging and the side that has the power of 'granting' belonging' (Antonsich, 2010, p. 650). He referred to Probyn's (1996) conceptualisation of 'longing' as demonstrative of the presence of 'not-belonging' that exists in opposition to belonging (Probyn, 1996, cited in Antonsich, 2010, p. 652). Wright supports this

assertion in her theoretical investigation of belonging, highlighting how the opposite of belonging may be exclusion, which can result in 'isolation, alienation, loneliness, dis-placement, uprootedness, dis-connection, disenfranchisement or marginalization' (Wright, 2015, p. 395). The presence of 'displacement' and feelings of social alienation and marginalisation resonates with the experiences of many *abuelos* who described to me, with deep sadness, their experiences of moving from their long-term homes into *Pueblo's* care home. I have emphasised throughout this thesis the importance of the '*casa*' (house/home), in Andalusian culture, and how a feeling of '*estar en casa*' ('being at home') plays an important part in generating belonging. Given that moving into *Pueblo's* care home, or even regularly attending *Pueblo's* day centre, physically restricted *abuelos* from being in their long-established home environment, it is also important to explore how entrance into these care institutions may have led to a rupture of belonging in *abuelos*.

Through moving into care institutions, *abuelos'* everyday social routines were disrupted and they became at risk of social exclusion and alienation. It was commonplace, particularly in *Pueblo's* care home, to hear *abuelos* continually expressing a profound and distressing longing for the people, things and places relating to their old routines that had existed prior to moving into the care home. Such attachments can be understood as ways through which *abuelos* had previously found meaning and belonging in their lives. These attachments may have facilitated empowerment and agency. Such connections to people, things and places, could be turned to and harnessed in times of crises. Gammeltoft (2018), through her evocative descriptions of ethnographic case studies in Vietnam of women experiencing personal crises, highlighted how people can experience agency through belonging. She analysed how, through belonging, people embed themselves into social webs with others, to gain meaning and make sense of their lives. This belonging can thus be drawn into to provide meaning to help people be resilient when faced with hardship. Having moved into the care home, *abuelos* distressed expressions of longing for these old ties could be understood as a restrictive feeling of having been cut off from their agency through a powerful rupture to their long-established belonging. In this chapter I thus explore relations of power in *Pueblo's* care institutions and how these were inherently linked into, and impacted on, belonging.

### **The Physical Institutional Environment**

I now explore how care institutions' physical environments impacted on belonging. I have described how *abuelos* frequently complained of missing their old homes and described immense loss experienced in first entering the institutions. Those attending the day centre, who still resided at home, described missing old daytime routines. Even *abuelos* who had lived in the care home for years, complained it never felt '*como estar en casa*' ('like being at home'). Given, as I have already

explored, that an important part of belonging in *Pueblo* was formed through an intimate feeling of being 'at home' (see Antonsich, 2010), this physical move from their long-established home environment into the care institutions could rupture *abuelos'* feelings of belonging.

The buildings housing the institutions had previously served different functions. The day centre was previously a pre-school, evidence of which remained dotted throughout the building. On initially visiting I had problems finding it, as despite being founded seventeen years ago, '*guardería*' ('pre-school') was still etched into its marble entrance sign. The bathroom toilets were low as they had been designed for young children. With my occupational therapy background, I was aware of the problems many older adults have in transferring on/off toilets of standard adult height. It was therefore, unsurprising that, although raised toilet seats and rails had been fitted, many frailer *abuelos* struggled to get on/off the toilets due to their awkward height. This repurposing of a building designed for something else demonstrates how eldercare appeared a kind of 'afterthought' of the state.

*Abuelos* complained that the day centre was too '*institucional*' ('institutional') and did not feel '*acogedor*' ('homey'). In its physiotherapy gym, equipment was worn, and several items were broken and left unrepaired for months. The day room was sparsely furnished with riser-recliner armchairs and a television giving a blurry image. The walls had however been decorated with photos of the Virgin statues, crucifixes from the *fiestas*, and crafts made by the *abuelos*, which gave a warmer feel. When I began volunteering in December 2018, I noticed Christmas decorations, but these remained up until the following Christmas. This neglect to update the physical environment, gave the day centre a stagnant atmosphere, which accentuated the sense of a timeless drift that is often attributed to dementia and older age. The day centre was nevertheless, always kept tidy and cleaned daily by the housekeeper, Sandra, and understood as her responsibility. The overall physical environment however, felt neglected and the day centre lacked features that made it home-like, instead containing symbols that marked it as institutional.

The care home was an ex-nunnery and could house almost ninety *abuelos*, with the majority of bedrooms shared between two and some single rooms. The floors were split into a women's, men's and mixed floor for *abuelos* with cognitive deterioration. There was a large assembly hall with a stage, stained-glass windows, tables and chairs, where regular activities occurred. Originally designed as the nunnery's chapel, the hall's high ceilings meant it was hard to communicate with *abuelos* due to sound reverberation, which was particularly challenging for hard of hearing *abuelos*. However, other *abuelos* commented that they appreciated the '*santidad*' ('holiness') of this room, and enjoyed Sunday mass which a priest conducted here weekly.

The building featured long, winding corridors, creating a maze effect that was easy to get lost in (see figure 1). An *abuela*, in the early stages of Alzheimer's disease, described:

'It's so difficult to find your way around! These long corridors, it feels as though they're never going to end! Often I'm in my room and somebody wanders in thinking it's their own!'

Long corridors were especially problematic for *abuelos* with dementia to navigate, and there were frequent incidents of *abuelos* getting lost, leading to heightened confusion, whilst upsetting others they disturbed. Although rails had been fitted, frail *abuelos* still struggled with the long distances required to move from room to room. *Abuelos* complained the corridors contributed towards an 'institutional-feel':

'It depresses me getting up in the night to use the toilet and having to walk so far down that long corridor. It makes you feel like you're on a hospital ward.'

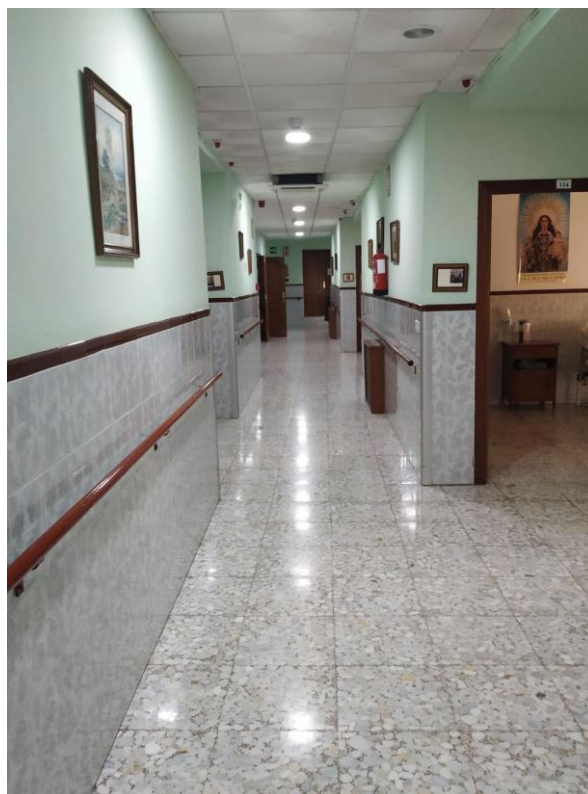


Figure 1. A corridor in Pueblo's care home.

This institutional-feel exaggerated *abuelos'* feelings of dis-placement, rupture, and longing for their previous, long-term homes, which prevented them from belonging through feeling 'at home' in the care institutions. The care home was cleaned by a housekeeping team. However, due to the number of *abuelos* who were given assistance with toileting at the same time, the bathrooms

emitted a strong smell when *abuelos* were being toileted. The smell travelled the length of the corridor, and lacking windows, lingered, causing complaints, whilst exacerbating embarrassment of those being attended to. Such practices contrasted strongly with the intimacy and privacy that *abuelos* had previously experienced in their long-term homes.

Another issue consistently raised was shared bedrooms. Of almost ninety beds, only twenty were in their own bedrooms. All other bedrooms were shared and there was a waiting list to be allocated an individual room. Within these bedrooms two beds were placed within close range of one another (see figure 2). There was frequent upset amongst *abuelos* sharing bedrooms, with conflicts over daily activities like what to watch on television. Shared bedrooms were allocated on timing of admission and convenience to the institution, with little consideration of who may get on, and changes to bedroom occupants only made when conflicts escalated. This reflects research by Calkins and Casella (2007) who found older adults in residential care overwhelmingly preferred private bedrooms. Furthermore, Davies' (2017) ethnography of a care home found that no-one sharing a bedroom referred to the institution as 'home'. Given the importance and privacy constructed around the '*casa*' ('house/home') in Andalusia, sharing a bedroom could be experienced as a violation of that privacy and thus again impinge on *abuelos* being able to experience belonging through preventing them from feeling 'at home' in the care home.



Figure 2. A shared bedroom in Pueblo's care home.

Sharing rooms also presented infection risk, particularly when *abuelos* with dementia accidentally picked up items belonging to their roommates. In 2020, when the care home's conditions underwent media scrutiny after a Covid-19 outbreak (see afterword), shared bedrooms were

criticised for infection risk. Care institutions' physical environments thus presented issues for *abuelos*, impacting their daily lives, sense of belonging, and safety.

## **Working Conditions**

Working conditions at these institutions devalued care work. Within both institutions staff complained about their timetable, wages and conditions. Carers' pay was low, at approximately five euros an hour, similar to 'unskilled' jobs like working as a cashier or factory-worker. A few younger carers had social care qualifications, but the majority had learnt through experience. Working in such institutions was thus deemed undesirable for social mobility. Adding to devaluing perceptions of care work were training deficiencies. I was initially shocked by manual handling I observed at the day centre compared to what I had learnt as 'safe' practice as an occupational therapist (OT) in the UK. I regularly observed techniques such as pulling people up by their arms, using bear hug lifts, and haphazard physical restraints. I was also surprised by the lack of formal division between staff roles. The director, housekeeper and physiotherapist all assisted carers with the lifting/transferring, toileting and feeding. In the care home divisions between formal roles were clearer. For example, cleaners or cooks never assisted with care tasks like manual handling.

During my year at the day centre, one training session occurred, which took place at 19:00, after closure. It was unpaid but staff were obliged to attend. The training was a three-hour lecture from a woman from an external company that ran staff training sessions at varying organisations. I attended the session alongside staff, after an afternoon shift and found my eyes closing during the tedious lecture. The training coordinator had never worked as a carer and read entirely from notes. Safe manual handling pictures were shown, with no physical practising of techniques. After the lecture we were awarded certificates and *Pueblo's* mayor and the local TV crew arrived. Photos were taken of staff with our certificates and the mayor and day centre's director were filmed citing the day centre's benefits. The event reflected Goffman's 'institutional display', in that it cultivated 'an 'appropriate' image of the establishment' (Goffman, [1961] 2017, p. 102), rather than genuinely improving practice skills.

Working timetables also devalued staff. Carers at the care home worked twelve-hour shifts, causing tiredness. The day centre carers operated on a siesta-timetable with two-hour lunch breaks. Siesta-timetabling is used widely in Spain as it allows employees to rest during the hottest hours of the day when in summer temperatures can exceed 40°C. Increasingly however, there have been demands to overthrow siesta-timetabling as campaigners call it outdated when people are now likely to live further from work and have air-conditioning. At the care home, the psychologist, social worker and OT worked under siesta-timetables. In both institutions staff complained this created a sense of



working all day, as the extended lunchbreak meant working later, despite starting early in the morning. For example, at the day centre, Miguel, who did the pick-ups/drop-offs, started at 8:00, but did not finish until 19:00. His working day spread across eleven hours, although he only worked and was paid for nine. It was particularly difficult for staff living far away. Iris, the care home OT, lived thirty-minutes' drive away and had a three-hour siesta break which she spent at home, meaning she commuted four times daily.

Holiday allowances staff also criticised for being dated and inflexible. In Andalusia, traditionally employers offer holidays to their staff for the entire month of August or July, due again to the extreme heat of summer months. Staff at both institutions had to take holiday as a month-block in July or August. This meant during July and August additional summer staff, who were less experienced or familiar with *abuelos'* needs, had to be employed and staff numbers were reduced. This exacerbated staff feeling overworked throughout the rest of the year, when no holidays could be taken. The day centre closed on public *fiesta* days, which meant some holiday days were dotted throughout the year. However, I noticed extreme fatigue amongst staff as a result of working eleven months without significant time off:

I was helping Miguel [a carer] lift the last of the *abuelos* into the van. As he bent down to lift Rosita's heavy legs over the ridge of the van door, he let out a pained groan, dropping her legs and reaching for his lower back.

'Argh, my back is so sore,' he moaned.

'Hmm,' I responded, 'having to do all the pick-ups and drop-offs everyday your back must suffer.' Miguel then leaned in close to me and whispered,

'You want to hear the word me and Alberto [the driver] use to describe this feeling?'

'What?' I asked,

'*Abuelado*' he replied, jokingly, '*Abuelado* is when you just can't take any more *abuelos*'

Miguel and Alberto had created a word by adding the generic past participle ending '*-ado*' to the word '*abuelos*'; the result was '*abuelado*'. Its meaning implied they were tired of time with grandparents/older people; the English equivalent would be something like 'grandparented out'. Given the working conditions, I was unsurprised at this creation. Staff complained of back and joint pain, tiredness and stress. Julia, a carer at the day centre, explained she had started seeing a private

therapist as she felt so drained from work that she was suffering anxiety. Care institutions, in formalising elder and dementia care, devalued care work causing staff to suffer.

### **Restrictive Care-giving Practices**

Devaluing formalised eldercare through poor working conditions may have contributed towards the controversial care-giving practices I witnessed in *Pueblo's* care institutions, due to staff exhaustion and training deficits. I frequently observed staff reprimanding people with dementia for their forgetfulness:

I was chatting with José [an *abuelo*], and asked him what he'd had for his lunch. He furrowed his brow, appearing deep in thought.

'Do you know I have no idea,' he said, looking perplexed.

I felt guilty for having drawn attention to his forgetfulness, so was about to change the subject when, Camila [a carer], having overheard our conversation, shouted across the room.

'José! You had lunch an hour ago! How do you think we're going to let you out of here when you cannot even remember what you just ate?!' Her tone was scolding, and those seated nearby turned to watch.

'I don't know, *mujer* [woman]. I don't know,' replied José in a small voice, shaking his head, 'My head isn't right anymore. I'm only good for being shot.' He looked mournfully at the floor.

Some staff criticised *abuelos* for forgetfulness in ways that caused distress or embarrassment. This happened frequently by certain staff; it was rare a week passed when I did not see some teasing towards *abuelos* with dementia by at least one staff member at either institution. Some staff however never engaged in these interactions and appeared more considerate of dementia symptoms. These staff, rather than highlighting *abuelos'* memory deficits, would show empathy or use distraction to reduce distress.

Certain care staff also scolded *abuelos* with dementia if they engaged in unusual behaviours. 58-year-old Lorena had early-onset dementia and could only engage in minimal verbal communication. She usually held a vacant expression and did not appear fully aware of her surroundings, although she showed moments of more lucidity. Below is an example of care staff reprimanding Lorena:

It was *merienda* [afternoon tea break] and everybody was sat around tables with coffee cups and napkins in front of them. Sandra [the housekeeper] was pushing the tea trolley around the room placing pastries onto the napkins. She had just placed a pastry in front of José [an *abuelo*] when Lorena suddenly swooped across the room from where she'd been seated and grabbed the pastry off José's napkin.

Julia [a carer], on seeing this, marched over to Lorena and snatched the pastry out of her hand, slamming it on the table in front of José. She shouted into Lorena's face.

'Stop that! Stop it!' She yelled, whilst tapping Lorena forcefully on the arm. She then grabbed Lorena and led her across the room before pushing her down into a chair.

Incidents of staff violence towards *abuelos* with dementia were uncommon but I did witness direct violence from this carer, Julia, in which she actually physically tapped or pushed the *abuela* hard on at least two occasions. Both times it was Lorena whom Julia was violent towards. I considered raising it with the director but had seen her witness this behaviour herself and not rebuke it. I had also thought about talking directly to Julia, but felt unsure how to. Once, after witnessing Julia shouting at another *abuela* with dementia, I must have been staring as Julia snapped at me:

'You can look at me like that if you want, Chloe, but you don't have to come here every day! You would be the same if you did!'

I averted my eyes and muttered about not meaning to look at her like that and that I knew she had a very hard job.

Julia's behaviour towards *abuelos* at times appeared severely objectionable. Although I witnessed others scold *abuelos* with dementia and be forceful or careless in manual handling, it was Julia that I observed behave like this more frequently and with more forcefulness. Julia was in her late fifties and had been working at the day centre for fourteen years. During afternoons, it would often just be Julia and I on shift and we would chat. She complained that she hated her job and suffered from backpain, stress and anxiety. She explained she was looking after her husband who had recently recovered from cancer. Every weekend she drove one-and-a-half hours to visit her daughter to provide childcare. Although Julia's care-giving practices were abusive, they could be

partly understood within the challenging context she was working under. Exploiting staff through devaluing care work, thus may have contributed towards insensitive or abusive care-giving.

Some staff also taunted people with dementia. Macarena was an *abuela* at the care home in her eighties with advanced dementia. She only engaged in minimal conversation, which was often incoherent. Her husband visited daily and when he arrived, she would get up from wherever she was sitting and walk towards him. One afternoon, as staff brought *abuelos* into the dining room for lunch, two young carers were gossiping together about a friend whose partner had had an affair. As one of them laid the table in front of Macarena she started teasing:

‘Macarena, did you know that Ángel [Macarena’s husband] has a new girlfriend?!’ the young carer said, laughing.

‘Yes, Ángel’s not coming to see you this afternoon,’ the other carer joined in teasingly, ‘because he’s with his new girlfriend!’

It was difficult to know if Macarena had understood what they were saying, but she was staring intently. The carers continued laying the other tables, and after a few minutes, one of the carers came back to Macarena and placed her hand on her shoulder saying, ‘We’re just joking, Macarena!’

Given her difficulties in communicating, it seemed cruel to engage Macarena in this joke. I observed such teasing of people with dementia at least several times monthly at both institutions. When I questioned staff about this, they tended to become defensive and respond that they were only joking. Although teasing may have been intended as a way of relating to *abuelos*, it seemed to demonstrate a lack of understanding of dementia. This lack of understanding, combined with staff being overworked, resulted in care-giving practices which disempowered care-receivers with dementia in *Pueblo’s* care institutions.

### *Use of Restraints*

The most shocking revelation I witnessed on fieldwork was the frequency with which physical restraints were used on people with dementia in *Pueblo’s* care institutions. In this section, I investigate restraints as a form of dementia care, seeking to understand people’s experience of both using restraints on others and being subjected to restraint use. By the end of my first week attending the day centre, I had already witnessed several incidents of physical restraints being used on *abuelos* with dementia. I was especially surprised that, given I was an outsider, staff did not hide restraint use from me, suggesting it was normalised. This reflects Estévez et al’s (2017) research who found

physical restraints were prevalent in 84.9% of the long-term care institutions they investigated in Spain. Normalising physical restraints as acceptable care-giving techniques in care institutions, may partly explain the resistance of Andalusian families to send their relatives to such institutions. I wondered if using physical restraints on people with dementia made care more disciplinary as an attempt to formalise it. I was curious about how such care forms influenced agency and personhood in people with dementia. Reflecting on Brijnath and Manderson's analysis of care work as enacting Foucauldian biopower, they explored how care-givers engaged in 'bodywork' which 'prevents the demented body from threatening the stability of the social body' (2008, p. 608). *Abuelos* with advanced dementia who exhibited disruptive behaviours, such as wandering, shouting or aggression, posed a threat to the smooth running of *Pueblo's* care institutions. Staff thus may have relied on physical restraints to control the bodies of *abuelos* with dementia to ensure the stability of the institution.

Carers would order *abuelos* to do certain tasks, like getting washed or dressed, and scolded them when instructions were not followed or sometimes threaten restraints as punishment. This reflects Foucault's theorisation that formal institutions centre around 'Family-Child relations' (Foucault, [1965] 2001, p. 274). Physical restraints were used in *Pueblo's* care institutions, to control the bodies of people with dementia and to threaten punishment to enforce certain behaviours, and thus could be interpreted as a manifestation of staff's 'parental authority' (Foucault, [1965] 2001, p. 274). This was legitimised through references to safety, just as the disciplining of infants is considered necessary parenting. Power relations manifesting through this parental authority between staff and *abuelos* thus legitimised restraint use in care institutions, which restricted the agency of people with dementia.

Restraint use in *Pueblo's* care institutions usually appeared haphazard. Given I was observing formal care settings, I was surprised at the regulation deficit regarding restraint use. Estévez et al's (2017) research highlighted the lack of national legislation in Spain regarding physical restraint use in care institutions which are based on underdeveloped regional laws providing only vague stipulations allowing restraint use to protect from harm. Application of restraints is therefore left to staff discretion. One example of haphazard restraint use was using furniture to restrict *abuelos'* movements. After *merienda* (afternoon tea break) at the day centre, Miguel and Alberto escorted *abuelos* home in the van. Usually, just Julia and I would be left responsible for the remaining twelve or so *abuelos*. No formal activities occurred in the afternoons, and many *abuelos* would sleep in their armchairs. For others, however, restlessness set in, which seemed particularly to affect those with dementia, some of whom would pace about. Julia explained that all *abuelos* must remain in the day room so we could see them. However, for those with dementia who wandered, keeping them in one

room was problematic. Rosita, who had advanced dementia, hallucinated more vividly in the afternoons. She would moan, cry, get up from her armchair and pace about, sometimes disturbing other *abuelos*. To prevent Rosita from moving, Julia used furniture to physically restrain her. She would physically escort Rosita into a straight-backed chair and push her tightly against a table so she was unable to move. Or, when Rosita was trying to stand up from an armchair, Julia would drag another armchair, sometimes holding a sleeping *abuelo*, in front of Rosita, to block her in. Rosita would often become more frustrated and grunt as she attempted to get up unsuccessfully. When I asked Julia why she did not let Rosita move about, she explained it was for safety.

Discussions by staff about *abuelos* walking or ‘wandering’ were framed around risk and safety and thus actively discouraged. Safety-focused discourses around risk in *Pueblo’s* care institutions legitimised physical restraints as an acceptable technique to prevent *abuelos* from walking. Graham (2015) highlighted how movements of people with dementia have been pathologised as ‘wandering’ to justify restrictive care practices. Although I understood the need to protect *abuelos*, given the extremity of restrictions the physical restraints involved, I was surprised they were not more carefully measured or formalised. There were no written care plans or risk assessments for *abuelos* detailing behaviour management strategies or when restraint use may be necessary, although the care home did seek permission from family before restraint harnesses were used (see below).

Restraint techniques appeared haphazard and, despite continued references to safety, were potentially dangerous. I witnessed some haphazard physical restraints have adverse consequences. One example was when I observed care staff using objects to physically force open the hands of Lorena, who had rigidity as a result of dementia:

Staff were using a children’s foam ball, which they had forced into Lorena’s tightly shut hand to open it up. After half an hour or so, Lorena suddenly started choking and her face turned bright red.

Camila [a carer] ran across the room and shoved her fingers into Lorena’s mouth to retract the brightly coloured foam ball which was now in pieces as Lorena had put it in her mouth to chew on it. Camila frantically searched for the foamy pieces in Lorena’s mouth, whilst Julia [a carer] thumped Lorena hard on the back. Fortunately, Lorena’s choking subsided and her face started to turn back to its original colour. Everybody breathed a sigh of relief and nothing more was said about the incident.

This use of haphazard physical restraint put Lorena in life-threatening danger. As Strout (2010) found through her review of restraints in psychiatric institutions, complications often occur as a result of physical restraint use. Such complications more likely occur if restraints are unregulated and done in a haphazard, non-formalised manner, as in *Pueblo's* care institutions.

In the care home, although restraint use was frequent it was more regulated. On my first visit to the care home, I noticed that on the *deterioro cognitivo* (cognitive deterioration) floor many *abuelos* had harnesses strapping them into their seats (see figures 3 and 4<sup>8</sup>). Iris, the OT, explained that the home had to obtain consent from residents' families before such equipment was used, and that it was only used when assessed as absolutely necessary due to disruptive behaviour. Staff explained disruptive behaviour as anything that interrupted the smooth running of the care home, such as interrupting group sessions, or wandering, particularly when *abuelos* entered others' bedrooms. Or behaviours that put *abuelos* themselves or others at risk, such as aggression or violence. If an *abuelo* was seen engaging in this behaviour regularly they were considered for a restraint harness. Iris explained that the harness restricted movements in a safe way to avoid the person hurting themselves or others, and that it was a last resort to ensure safety. I never witnessed the *abuelos* I had observed wearing restraint harnesses at the start of my time at the care home without one; thus, it appeared that once consent had been granted the harness was used indefinitely.



Figure 3. Restraint harness (front).



Figure 4. Restraint harness (behind).

The care home had thus formalised the practice of certain physical restraints, by using professionally-designed restraint equipment with permission gained from family. However, this still

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<sup>8</sup> Images were taken from the company website that produced the restraint harnesses used in *Pueblo's* care home.

did not guarantee the safety of the person wearing the harness. Below is an example of an *abuela* with advanced dementia becoming agitated wearing the restraint harness:

Teresa [an *abuela* with advanced dementia] was in the activities group looking somewhat unhappy when she suddenly started shouting. Iris [the OT] wheeled her to the far corner of the room to avoid her disrupting the group and gestured for to me to follow.

Iris grabbed a ball and started throwing it to me and then to Teresa. Initially Teresa joined in with the game, but she quickly became agitated again and wailing, threw the ball to the floor. She then repeatedly tried to get up from the wheelchair, but the restraint harness kept forcefully pulling her body back down. With each failed attempt Teresa became progressively more frustrated and wailed louder, whilst pulling at the blue material of the harness with her fingers. Meanwhile, Iris was speaking softly to her to try and calm her down, 'Teresa, what's the matter, sweetie hmm?... Let's play with the ball.' But Iris's soothing words were only met with more agitation. Teresa kept pulling and pulling at the harness, wiggling and pushing her weight about, causing the wheelchair to rock back and forth violently until it toppled over.

Fortunately, Teresa was not injured, but it did make me question the safety of the restraint harness being so widely used within the care home. Why was this harness being used as a risk prevention strategy when it could increase risk? Was the safety discourse around the use of these harnesses concerned about *abuelos'* safety or that of staff? How did the wearing of these harnesses affect *abuelos'* sense of personhood?

Harnesses appeared to cause discomfort and agitation to the person forced to wear it. Strout's (2010) research into restraint use in psychiatric institutions highlighted trauma caused from being physically restrained. Observing Teresa's agitation rapidly accelerate as she tried to fight against the harness, her trauma was palpable. Even regulated use of physical restraints thus still presented as harmful. Furthermore, the obvious visibility of the restraint harness meant that others seeing an *abuelo* wearing the harness knew they were 'disruptive' and likely to have cognitive impairment. It therefore physically distinguished and stigmatised *abuelos*, which could be degrading to their sense of personhood.



Medical restraints were also used regularly to modify behaviours of those with dementia exhibiting challenging behaviours. Both institutions administered antipsychotic medication: older typical and newer atypical antipsychotics. This medication was prescribed to certain *abuelos* as an emergency treatment to reduce challenging behaviours. When *abuelos* were given antipsychotics after expressing disruptive behaviour I could see them calm down. However, they also became heavily sedated and unable to engage in activities for hours afterwards. The overuse of antipsychotics on people with dementia in care homes has been raised in international media as presenting serious risks (Pattanayak and Pattanayak, 2012). It was reported by the US Department of Health and Human Services that 24% of people with dementia in care homes were prescribed antipsychotics to modify their behaviour (US Congress, 2012). When I asked the day centre's director why antipsychotics were used to manage challenging behaviours, she claimed it was safer than using physical restraints. She explained that they had to be prescribed by a doctor and were given as a last resort. The dosage of medication given to *abuelos* was regulated through a medication chart, which was kept on record and checked by doctors during regular medical reviews. For *abuelos* considered most 'disruptive', antipsychotics were given daily as part of their routine. The use of medical and physical restraints, although legitimised through safety discourses, seemed somewhat aimed at reducing staff demands and disruption to the institution's routine, rather than at *abuelos'* welfare. Restraints could increase risk and exaggerate distress to *abuelos*, physically and mentally disempowering people with dementia. Such care practices restrict individual choice and agency. Through this deprivation of agency, the elevation of individual identity and personhood are deprioritised to ensure the smooth running of the institution.

### **Routines and Activities**

Marisol, the day centre's director, emphasised the importance of routine in dementia care as a memory prompt. She ensured that everyone with dementia at *Pueblo's* day centre maximised their activity engagement through a stringent routine of timetabled activities. Describing the influence of routine on his wife Iris Murdoch, who suffered from Alzheimer's disease, Bayley claimed 'routine provides a substitute for memory' (Bayley, 1997, cited in Davies, 2017, p. 42). The care home also followed routines, which they understood as beneficial to *abuelos* with dementia. I now explore how formalised routines operated and were experienced. Many *abuelos* spoke enthusiastically about routines, reciting the day's plan proudly. Routine provided familiar, comforting responses to questions like 'What are we doing?' which forgetful *abuelos* repeatedly asked. Routines facilitated remembering and provided reassurance to reduce confusion in people with dementia, and thus could be experienced as empowering.

Institutional routines, however, could also be experienced as disempowering as their fixed nature reduced the person-centredness of care, overlooking individual preferences. José was 85-years-old, in the early stages of Alzheimer's disease, and had spent his life as a shepherd and olive farmer. Since retiring, José spent his time '*en la calle*' ('in the street'), or frequenting bars; used to the personal freedom to do as he pleased. He struggled when he began attending the day centre to follow a timetable set by others that consisted largely of indoor activity. During cognitive exercises, which took place seated around tables, he became agitated:

'I can't sit still for so long!' José protested getting up and moving away from the table, 'My bum hurts! I want to go outside. You can't keep me shut up in this place all day!'

Staff explained José's behaviour as a temporary 'settling in' period. Observing José's first weeks at the day centre was like watching him being 'broken in'. His protestations were initially constant, refusing to participate in timetabled activities, complaining that he wanted to go outside, pacing, and demanding to be released. As time passed, José's agitation decreased and he slowly accepted his situation. However, although he sat with other *abuelos* during activities, his participation was limited and he looked withdrawn and resentful. This sense of withdrawal due to resistance to fixed routines seemed applicable to many *abuelos*. Foucault suggested that strict institutional schedules caused inmates to 'detach' from 'liberty of mind' (Foucault, [1965] 2001, p. 247). When I suggested taking José for a walk instead of the sit-down cognitive exercises, staff insisted he complete the exercises as they were a timetabled therapeutic intervention.

Davies' (2017) ethnography of a care home in the UK offers some interesting points of reflection, which although taken from a differing cultural setting, can be helpful to contemplate in relation to my observations in *Pueblo's* care institutions. Davies' insights are particularly helpful as she had previously been a registered nurse before moving into anthropological research. Davies had worked as an agency nurse filling in many shifts at understaffed care homes in the UK, and was thus able to bring a practice-focused understanding that helped her capture the perspectives and needs of care home staff. Her ethnography explored the everyday lived experiences of staff and residents living in a large-bedded care home in the UK. She found that care practices within the care home required an ongoing balancing act between the individual needs of residents and the needs of the institution, which were dictated by the care home's manager and staff. Care assistants who had been in their posts at the care home for a long time, she explained, were extremely reluctant to change long-standing routines and working methods. I observed a similar sense of reluctance to change old routines amongst care staff at *Pueblo's* care institutions. Given the challenging working

conditions, that I depicted above, of care staff in *Pueblo's* care institutions, it is easy to understand this apparent reluctance from some staff to change long-established routines that could potentially increase their already overstretched workload. Institutional routines could thus appear to be inflexible, reflecting staff wishes and capacities, rather than adapting to *abuelos'* differing, individualised needs. The unchanging activities could thus restrict *abuelos*, through institution-led rather than person-centred routines.

Activity groups were central to both institutions' routines. At the day centre activities were the same every day and consisted of physiotherapy, cognitive exercises, crafts, and physical exercise, with no formal activities in the afternoon. In the care home, the OT, Iris, and psychologist, Mari, were responsible for running the activities programme. Activities timetables were displayed around the building, listing a wide-range of activities, such as exercise, music therapy, relaxation and cognitive stimulation (see figure 5). However, the activities timetabled rarely matched those that occurred.

HORARIO		LUNES	MARTES	MIÉRCOLES	JUEVES	VIERNES	FIN DE SEMANA
9:00 a 10:30 h	Grupal		* ¡BUENOS DÍAS! * T.O.R	* ¡CUÁNTO TE QUIERO! * CUÉNTAME			
10:30 a 12:30 h	Grupo A	* GERONTOGIMNASIA * RELAJACIÓN	* PROGRAMA DE ESTIMULACIÓN DEL LENGUAJE, MEMORIA, PSICOSTIMULACIÓN, MONTESORI, ESTIMULACIÓN CON NUEVAS TECNOLOGÍAS	* INTERVENCIÓN GRUPAL EN PLANTA	* PROGRAMA DE ESTIMULACIÓN DEL LENGUAJE, MEMORIA, PSICOSTIMULACIÓN, MONTESORI, ESTIMULACIÓN CON NUEVAS TECNOLOGÍAS	* PROGRAMA DE ENTRENAMIENTO EN H.H.S.S Y DINÁMICAS GRUPALES * MISA * CINE-TERAPIA * TALLER DE DINÁMICAS DE GRUPO	* TALLERES OCUPACIONALES (sábados): manualidades, dinámicas, actividades cognitivas
	Grupo B	* PROGRAMA DE MANTENIMIENTO FÍSICO Y MEJORA DE LAS ABVDs * MASAJES CON RODILLOS * RELAJACIÓN * MUSICO-TERAPIA * PROGRAMAS DE SALIDAS 	* PROGRAMA DE ESTIMULACIÓN COGNITIVA Y SENSORIAL, MEJORA DE LAS CONDICIONES MENTALES 	* TALLER DE INFORMÁTICA, ADAPTACIÓN A LAS NUEVAS TECNOLOGÍAS * PAI: REUNIÓN EQUIPO 	* PROGRAMA DE ESTIMULACIÓN COGNITIVA Y SENSORIAL, MEJORA DE LAS CONDICIONES MENTALES 	* TÉCNICAS DE RELAJACIÓN * PROGRAMA DE SALIDAS  	* RELACIONES PERSONALES * MISA: FAMILIA -TV * TELEVISIÓN Y RADIO * VISITAS Y SALIDAS CON FAMILIA * PASEOS POR EL CENTRO * OCIO * PRENSA * LECTURAS * VISITAS * PASEOS 
GRUPO A: residentes con elevado deterioro cognitivo (Psicóloga y Terapeuta Ocupacional)		GRUPO B: residentes con deterioro cognitivo leve y funcionamiento intacto (TASOC)			GRUPAL: todos los residentes		

Figure 5. The activities timetable displayed around *Pueblo's* care home.

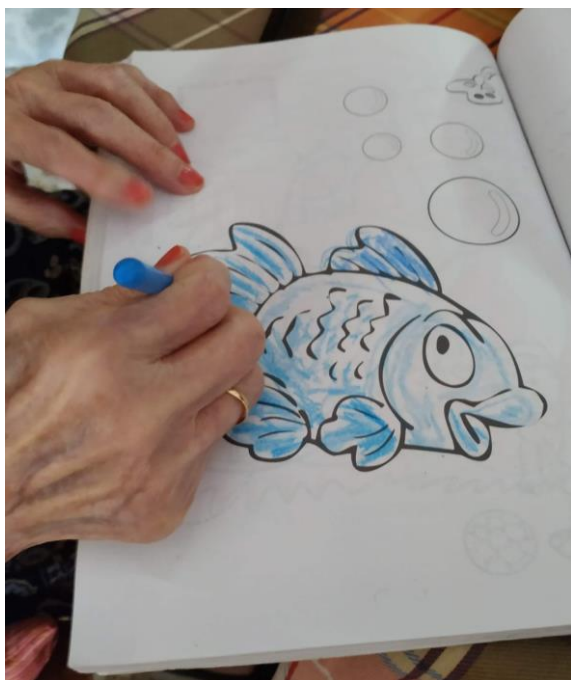


Figure 6. An abuelo at Pueblo's care home colours in a picture.



Figure 7. An abuelo at Pueblo's day centre colours in a number worksheet.



Figure 8. A display of colouring-in activities completed by abuelos at Pueblo's care home.

During sit-down activities, worksheets were photocopied from children's colouring books (see figures 6-8). Although many *abuelos* enjoyed these activities, there was a significant minority who did not. For example, at the care home, Alejandro, despite continually refusing to participate, was repeatedly brought into the activities group, but as he used a non-self-propelling wheelchair, he could not leave. When I asked him once why he was not completing the worksheet he angrily replied:

'Because it's for children! I know how to count and write! I ran my own shop for years! Many people here may be foolish enough to enjoy this, but not me. I don't want to be here. I was brought in against my will!'

As an older person, with a lifetime's knowledge, being made to engage in activities designed for children impinged on Alejandro's agency and self-esteem which may have damaged his sense of personhood. The infantile nature of some activities offered thus encroached on some *abuelos'* dignity, leaving them feeling humiliated and disempowered.

Activities at the institutions often neglected the needs of *abuelos* with dementia. Activities at the care home were held in its assembly hall, either as a circle group activity, like chair exercises, or tables were put out and *abuelos* given worksheets. Activities at the care home were usually attended by roughly the same group of *abuelos*, about half of whom were women without severe cognitive impairment who participated enthusiastically. The rest were largely people with dementia, who were either encouraged into the group, or if they were in a wheelchair, wheeled in by staff involuntarily.

Group activities were difficult for those with advanced dementia to follow as they included verbal/visual instructions. Although Iris and Mari would sometimes try to include those with dementia by addressing the person directly or prompting them to participate by, for example, lifting up their arms during chair exercises, their participation remained extremely limited. However, their presence and being able to watch the activity provided some stimulation, whereas many *abuelos* with dementia, who tended to exhibit disruptive behaviours, were excluded from activity groups completely. The cognitive engagement required by the activities was usually unsuitable for most *abuelos* with dementia and was aimed at *abuelos* without significant cognitive impairment. Iris and Mari would often ask these *abuelos* what activities they wanted to do and base decisions on their wishes. These cognitively functional *abuelos* thus had more control over the activities than those with dementia.

Davies' (2017) ethnography in a UK care home similarly found that activities organised by staff were aimed much more towards those residents who did not have significant cognitive impairment or dementia. She observed how people with dementia were only invited or encouraged by staff to take part in the activities on offer occasionally. Davies highlighted how, despite reduced cognitive function, research suggests that 'people with dementia can gain immense pleasure and satisfaction from structured activities' (Davies, 2017, p. 115). She thus criticised the lack of activity engagement by staff to residents with dementia, and advocated that care homes do more to include people with dementia in structured activities. The exclusion of residents with dementia from organised activities in care homes thus appears to be an issue that is reflected in care homes beyond the context of Andalusia.

Including *abuelos* with cognitive impairment or dementia, who were not able to engage with the activities in *Pueblo's* care institutions appeared more performative than functional, and could be interpreted through Goffman's [1961] (2017) 'institutional display'. Activities groups were frequently interrupted by visitors, and for visitors to see a large activities group cultivated the image that activities were inclusive. For those visiting *abuelos* with dementia who were in the activities group, visitors got the impression that their relative or friend was participating, even if their participation was limited. The activities timetable, including a range of activities which never took place, was displayed all over the care home. This again could be interpreted as institutional display, cultivating an image of the care home activities as rich, varied and inclusive, whilst hiding the reality that activities were limited and exclusive, serving the interests of a minority of the institution's population.

One example of performativity was the care home's Christmas play. Goffman [1961] (2017) explained Christmas celebrations within psychiatric institutions as an example of theatrical institutional display. For two months prior to the Christmas play morning activities were replaced by rehearsals. There were only ten *abuelos* who had lines to read, and these rehearsals focused solely on those *abuelos* practising, whilst others watched. During an on-stage rehearsal a week before the play, the care home's director was invited to watch. Sonia, the resident playing the Virgin Mary, suffered from chronic obstructive pulmonary disease, making her breathing laboured. During this rehearsal she struggled to articulate her lines and took gasps between sentences. The director, on hearing Sonia's performance, whispered something in Iris' ear. After the rehearsal, Iris informed Sonia that they would find somebody else to play the Virgin Mary. Sonia protested that she could do a better job and would make sure she took more oxygen before the performance to help her breathing. Her protests did not avail, however, and she was removed from the cast. Iris then sought out a new Mary, but no-one else volunteered. She pleaded with various *abuelas*, finally insisting another *abuela* took the role, who reluctantly agreed only if the lines were reduced. Excluding a willing *abuela* and forcing a reluctant *abuela* to participate demonstrates how the play's objectives were more focused on presenting a smooth performance than on *abuelos'* engagement.

On the day of the performance, participating *abuelos* were dressed in costume. As many had mobility issues, getting onto the stage was challenging and took over an hour. *Abuelos* were then required to practice their lines, so those participating had to sit in their costumes, offering little warmth, on the draughty stage, for over two hours. *Abuelos*, weary after climbing onto the stage, moaned of being cold, and some were shivering. This demonstrates how performative value was prioritised over the basic comfort of *abuelos*. The play was filmed by the local TV station. The

importance of performing well and cultivating a respectable image of the institution appeared to be the Christmas play's key objective.

Despite the activities offered, there was still boredom amongst *abuelos*. At the day centre activities occurred in the morning, but after lunch there were no formal activities, other than a brief coffee break. The television in the lounge would be left on, but the image was blurry and sound almost inaudible. José would get increasingly restless, constantly clock-watching, and pacing about. I tried to distract him by encouraging him to chat. Had there been some organised activity during the afternoons it may have helped him settle. In the care home there were formal activities in the morning and afternoon during weekdays. However, the OT only attended one Saturday monthly and other than when she came, there were no activities over weekends. *Abuelos*, like Isabel, who regularly attended activities complained about this:

‘The week passes so quickly as we have Iris and Mari here to entertain us. But at the weekends, it’s such a different atmosphere, I get so bored and the days pass really slowly.’

Goffman described life in mental institutions as a ‘dead sea in which little islands of vivid encapturing activity appear’ (Goffman, [1961] 2017, pp. 69-70). He explained activities’ insufficiency as causing deprivation. At *Pueblo*’s care institutions, the lack of adequate meaningful activity caused many *abuelos* to experience boredom leading to feelings of dejection.

### *Cognitive Exercises*

Every morning at the day centre, I helped staff lay tables and chairs into four differing ability groups, as though preparing a school classroom. Seated at these tables *abuelos* completed two hours of cognitive exercises (see figure 9). Proclaimed as specialised dementia interventions, these were used at both institutions. Cognitive exercises took the form of paper worksheets, which were sometimes handwritten, but usually printed from websites which claimed to have been produced according to scientific evidence demonstrating them as effective in slowing cognitive decline. The worksheets consisted of basic numerical or word-based tasks (see figures 9-12).





Figure 9. A group of abuelos at Pueblo's day centre completing cognitive exercises.

*¿Si necesitas comprar medicamentos, a dónde vas?*

*a.) A la panadería   b.) A la farmacia   c.) A la carnicería*

If you need to buy medication, where do you go?

*a.) To the bakery   b.) To the pharmacy   c.) To the butcher's*

Figure 10. A representation of one of the word-based tasks, with translation.



Figure 11. Abuelos completing cognitive exercises at Pueblo's care home.



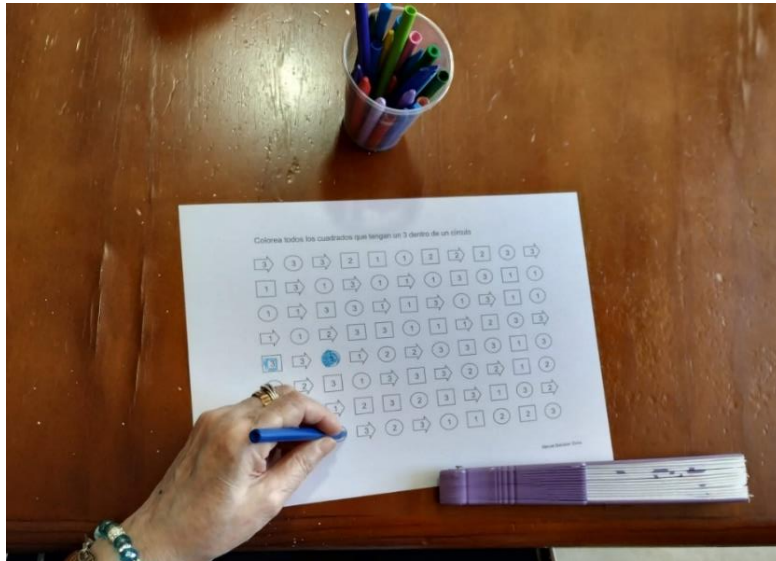


Figure 12. An *abuela* at Pueblo's care home completes a cognitive worksheet which reads 'colour all the squares that have a 3 inside a circle'.

Each table was given worksheets corresponding to ability with a carer supervising. On the two higher ability tables, the carer distributed the worksheets and went through each task as a group, discussing the answers together before *abuelos* wrote the correct answer down. The highest-level table also completed dictations, where the carer read a text aloud which *abuelos* copied down. On the lower-level tables, worksheets contained simpler tasks, such as colouring in a picture or tracing a dotted line. *Abuelos* on these tables could not all communicate verbally, so would be continually supported by the carer to complete their worksheets. The lack of orientation to the activity from *abuelos* with more severe cognitive impairment made the cognitive exercises seem somewhat meaningless. Lorena, for example, who had early-onset dementia and was unable to verbally communicate, struggled with the worksheets. Carers would wrap their hand around hers and complete the answers for her, which seemed to contradict the cognitive stimulation philosophy. After two hours carers would collect the completed worksheets. These were given to *abuelos'* families annually to demonstrate work accomplished. Given staff would have often completed worksheets on *abuelos'* behalf, this recording system provided further evidence of Goffman's [1961] (2017) 'institutional display' rather than a genuine attempt to monitor progress. It demonstrates how these sites were 'made' into respectable care institutions and given clinical legitimacy through engaging in practices that reflected global medicalised understandings of cognition, ageing and dementia.

The other cognitive exercises the day centre conducted used a computer programme. This software was designed to provide cognitive stimulation to people with neurodegenerative

conditions. The programme is recommended by the *Consejería de Salud de Andalucía* (Ministry of Health Andalusia) as a suitable dementia intervention. Its website claims it has been designed based on scientific research, including a systematic literature review by García et al (2017) which found computer-based cognitive interventions had moderate effects on cognition, anxiety, and small effects on depression in people with dementia. However, the study noted issues with external validity and the need for further research to clarify findings.

Every *abuelo*, apart from those considered to have too advanced dementia to benefit, spent thirty minutes weekly using the computer with support from a carer. The programme consisted of questions with images, and the user had to select the correct multiple-choice answer via touch-screen. For example, '*¿En qué estación estamos?*' ('What season are we in?') and the user would select a season (see figure 13). The programme would cite whether they had answered correctly. However, often, and particularly for those with cognitive impairment, the carer would select the correct answer, invalidating the activity's purpose. The performance of each *abuelo* was recorded to track progress. A print-out of their statistics would be put into each *abuelos'* file at the end of the year.



Figure 13. A representation of a screen of the cognitive simulation software programme, used by the day centre, with translation.

The care home also used written cognitive exercise worksheets, downloaded from the same websites as the day centre. However, they were given sporadically depending on what other activities were available. Those with more advanced cognitive impairment did not participate. The OT and psychologist positioned *abuelos* around tables in groups to complete the worksheets, although unlike the day centre they did not formalise groups on cognitive ability. Instead, the OT went around with a bundle of worksheets, distributing individual worksheets she deemed suitable

for each *abuelo*, and assisting them whenever needed. These sessions usually lasted roughly an hour and a half. The care home did not use computer-based cognitive exercises.

The cognitive exercises were received with mixed responses by different *abuelos*, but a common reaction was resistance. Many *abuelos* perceived the exercises as monotonous and draining ‘work’:

Blanca [an *abuela*] was resting in her usual armchair under a woollen blanket with her eyes closed. The blanket was moving up and down under the heaviness of her breath.

Camila [a carer] marched over to Blanca and tapped her on the shoulder, causing her to stir.

‘Come on Blanca! You know it’s time for the computer now!’ Camila said assertively. Blanca opened her eyes a little, and on seeing Camila, quickly closed them again, muttering under her breath.

‘No, no please! Not today! I’m so tired!’

‘Blanca You say that every day! Come on! It won’t take long,’ Camila tutted, pulling the blanket off Blanca’s body and assisting her out of the armchair.

Reluctance to engage in cognitive exercises was common. Staff usually had to coax and cajole *abuelos* into participating. Frequent moans were heard from the tables at the day centre as *abuelos* became drained from the two-hour long cognitive exercises. Staff too would sigh and check the time, seemingly wishing the minutes away. Goffman [1961] (2017) discussed how institutions used ‘work therapy’ to control behaviour. The coercive persuasions of staff to encourage *abuelos* into the cognitive exercises, and their protestations, suggest they perceived the exercises as undesirable ‘work’.

Understanding cognitive exercises as ‘work’ may partly explain why many staff, *abuelos* and relatives referred to the day centre as ‘*cole*’ (‘school’). The sit-down nature of the written cognitive exercises conducted at tables every morning, with a carer correcting the groups in a teacher-like manner, was reminiscent of a school classroom. Running into 86-year-old Clotilde one weekend, when she waved goodbye, she shouted cheerfully ‘See you at school on Monday!’ Other *abuelos*, like José, on being given worksheets would groan and say ‘I was never good at school’. These differing attitudes suggest cognitive exercises were perceived as ‘work’ and imply that enjoyment

was dependent on *abuelos'* experiences and attitude towards school. This echoes Orr's (2010) research into dementia assessments, who found people's experiences were influenced by their educational and class backgrounds. Like the standardised assessments, these cognitive exercises were thus not neutral interventions but were experienced through *abuelos'* cultural and class dispositions.

Understanding cognitive exercises as 'work' or 'work therapy' reflects global discourses around dementia care that subscribe to the 'successful aging' paradigm<sup>9</sup> and individualised personhood. This paradigm, which has been critically deconstructed by Lamb (2014; 2000; 1997), takes a specific approach to ageing which places importance on *individual effort* to maintain independence in older age. This approach emerged from western modernity, the development of contemporary neoliberal ideals of individualist personhood, freedom and self-governance against a demographically ageing population constructed as a burden (Lamb Robbins-Ruszkowski and Corwin, 2017). It promotes individual effort, self-control and body-maintenance through engaging in practices such as exercising regularly, eating healthily and maintaining productive lives to resist ageing. Health becomes 'ascribed', as individuals 'work hard' to be healthy (Scheper-Hughes and Lock, 1987, p. 25). Cognitive exercises reflected this 'successful aging' approach, claiming that through regular engagement in monotonous, challenging maths and word games one could prevent the effects of ageing, staving off cognitive decline and dementia to maintain an individualist personhood. The use of cognitive exercises in this context shows how care homes are effectively being made into meaningful institutions of care through the everyday practicing of this international approach to ageing and dementia. Relatives frequently praised the institutions for these cognitive exercises, understanding them as an important part of formalised dementia care. Subscribing to this global discourse which prescribed cognitive exercises as part of dementia care, provided care institutions with clinical legitimacy, enhancing their reputation.

This global discourse of dementia care and the successful ageing paradigm however also faced tense contestation in the locality of *Pueblo's* care institutions. Such contestations can be understood through what Appadurai (1990) referred to as 'disjunctures', where the influx of an entirely differing approach to economic and social life brought about through global neoliberalism sparked against a long-established local outlook. A disjuncture occurred when these cognitive exercises, which subscribed to the global paradigm of successful ageing and an individualist sense of personhood, were implemented within *Pueblo's* local context and differing worldview, under which older people's forgetfulness had always been managed through the interdependency of family

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<sup>9</sup> The 'successful aging' paradigm is sometimes referred to under differing labels, including 'active aging', 'healthy aging', 'productive aging', 'vital aging' and 'aging well' (Lamb, Robbins-Ruszkowski and Corwin, 2017, p. 1).

networks. Although some *abuelos* enjoyed engaging in these cognitive exercises, particularly those few who had spent more time in formal education, the vast majority not only did not enjoy the exercises but found them distressing. *Abuelos* frequently complained and resisted being made to partake in them:

‘That’s it! I’ve had enough of this,’ said José [an *abuelo*], flinging down his pencil and pushing the piece of paper across the table. ‘I’ve worked all my life in the countryside! I’ve never been to school! I don’t understand this! I can’t do it!’

‘You must do it José!’ said Julia [a carer], passing the worksheet back to him. ‘That’s why you’re here. To learn, to get better.’

The majority of *abuelos* had spent little time at school and many were illiterate. Women from *Pueblo* of this generation were unlikely to have been to school; men were more likely to have had basic schooling, but many had been sent to work on the olive plantations from late childhood. The cognitive exercises were thus often not understood by the *abuelo* completing them, causing distress. The institutions however, were trying to do the ‘right’ thing in implementing these cognitive exercises according to global dementia care understandings, despite the contestations they were affronted with.

*Abuelos* had never used computers and found the programme particularly confusing. Orr (2010) similarly found that older people experienced cognitive assessments as infantilising and alienating during clinical dementia assessments in the UK, whilst Brijnath (2011) found a cognitive dementia assessment used in New Delhi to be of limited usefulness due to the low literacy of older people being tested and the irrelevance of the assessment questions to local context. Spencer, Krefting and Mattingly (1993) in analysing OT assessments also highlighted the dangers of testing people outside of cultural contexts, as this could result in observations of their strengths being missed. José, for example, may not perform well completing a maths-based cognitive exercise worksheet, but if calculating the hours of labour it would take to harvest a certain number of olive trees he would likely perform much more effectively. These studies were however investigating cognitive assessments and thus were one-off tests, so were not repeated daily as were the cognitive exercises at *Pueblo*’s care institutions. However, the ignorance of cultural context and unrelatability of the tasks were also present in the cognitive exercises. The cognitive exercises thus became sites of daily contestation for many *abuelos*.

*Abuelos*’ attempts to disengage from these exercises could be interpreted as a struggle to relate to the cultural outlook and sense of personhood that the worksheets represented. The

individualistic, self-disciplined rationale of the cognitive exercises used by *Pueblo's* care institutions reflected an international neoliberal approach to ageing and personhood. Yet these cognitive exercises, and the work ethic and ideology they ascribed to, clashed with the entirely different worldview of this rural Andalusian community, where *abuelos'* forgetfulness had always been managed through interdependent family networks. This demonstrates how global biomedical ideas become selectively adopted in institutional contexts in Andalusia to give these sites clinical legitimacy as institutions of formal dementia care. The institutions themselves however, are also local contexts making themselves into legitimate care institutions through their own care practices. In attempting to enact international dementia care interventions through implementing these cognitive exercises, the contestations occurring in these institutions cannot be reductively analysed as a global versus local dichotomy, but rather a complex interaction of diverse local and global influences being played out in everyday formal care practices in this particular context.

## Conclusion

This chapter has opened the doors of *Pueblo's* care institutions to reveal how such institutions can both exploit and empower people with dementia and those who provide their care; revealing the complex processes of power that are generated through institutional dementia care. It began with a theoretical discussion of Foucault and Goffman's theories around power and care. I then explored how power relations were integral to, and impacted on, experiences of belonging in *abuelos*. I described how the physical environments of the care institutions, impacted by funding shortfalls, produced an institutional-feel which *abuelos* contrasted with a deep sense of longing for their old homes where they had lived prior to moving into the care institutions. Given the importance of, and privacy guarded around the '*casa*' ('house/home') in Andalusia, and how belonging was generated through a feeling of being 'at home', the institutional environment, and violation of privacy it necessitated, contrasted with the intimacy of *abuelos'* old homes. This therefore encroached on *abuelos'* capacities to feel 'at home' and experience belonging in the care institutions. I next explored the power mechanisms at play for those working within these institutions. The low pay, long hours and minimal holidays formalise work in care institutions as undesirable. Staff suffered fatigue, stress and anxiety and felt devalued. I portrayed how staff being overworked and lacking training, led to this devaluing exploitation being transferred through abusive care-giving practices onto *abuelos*, which especially impacted those with dementia. I described observations of the frequent use of haphazard restraints in *Pueblo's* care institutions, which produced disempowering and dehumanising care forms, that reduced *abuelos'* agency and sense of personhood, and exposed them to augmented risk of physical and psychological harm.

I then described how *Pueblo's* care institutions operated through structured routines that formalised care. The repetition of structured, regular routines empowered some people with dementia, through facilitating familiarity which enabled them to remember more easily. However, the fixed routine could conversely also be experienced as disempowering, through forcing certain activities favoured by the institution onto *abuelos*, reducing the person-centredness of care and overlooking individual preferences. I revealed how some activities were interpreted as infantilising, which impinged on *abuelos'* dignity and reduced autonomy and personhood. The limited activities at both institutions also meant boredom was experienced frequently by *abuelos*, which for those with dementia especially could result in increased restlessness.

Cognitive exercises were used in both institutions and subscribed to a global paradigm of successful ageing and independent, individualist personhood. This paradigm advocates individual hard-work and discipline to resist dementia symptoms and improve cognition to retain individualist personhood. Yet when these exercises were implemented in *Pueblo's* care institutions, I witnessed how a 'disjuncture' (Appadurai, 1990) occurred as this global notion of independent, individualist personhood and resisting dependence, clashed with local people's long-established understandings of forgetfulness in older age as managed through interdependent family networks. I observed this through *abuelos'* confusion, frustration, agitation and resistance when made to engage in these exercises. However, the institutions themselves are also local contexts making themselves into clinically legitimate formal care institutions through their own daily care practices. Therefore, resistance to the cognitive exercises cannot be interpreted through a simplified local versus global dichotomy, but rather should be understood as a complex intersecting of diverse influences occurring through everyday formal care practices in *Pueblo*. Care institutions can thus be sites of diverse forms of power, both empowering and exploiting people with dementia and those who provide their care, whilst also becoming sites of resistance; revealing the complexity of power relations that underscore institutional dementia care. This demonstrates the deeply subjective nature of dementia care experience, thus displaying the challenges of standardising formal dementia care in institutions.

## Chapter Seven: (Re)Creating Kinship and Community through Formal Dementia Care

This chapter explores how, as dementia care formalises in Andalusia, people (re)create kinship and community through care. It uncovers community-making processes within *Pueblo's* care institutions, demonstrating how institutions get made through everyday practices. This contradicts assumptions of care institutions as inert, to show such institutions as dynamic sites of meaning-making where power, relationships and values are constantly (re)produced. Solidarity develops amongst *abuelos*, who become citizens of care institutions. These institutions are permeable and form central parts of *Pueblo's* community, maintaining *abuelos'* sense of belonging. Community-making is not, however, experienced equally. I discuss how dementia, gender and class intersect with belonging. Community-making is also experienced by carers who, working under challenging conditions, generate solidarity. Solidarity is especially valuable amongst migrant carers who, living far from their native homes, strive to establish belonging in Andalusia. Formal carers sometimes form kin-like relationships with care-receivers. In care institutions, *abuelos* living together also formed kin-like relationships, and the informality of institutions facilitated close relationships to develop between staff and *abuelos*. Live-in carers also described how the intimacy of living together bonded them to care-receivers. For migrant carers this reduced isolation and facilitated cultural exchange. Attestations to kinship through formal care could, however, result in carers experiencing feelings of duty, obligation and guilt. Formal care was experienced subjectively, with not all carers experiencing positive relationships with care-receivers. This chapter demonstrates how, despite the formalisation of dementia care in Andalusia, people strive to (re)create kinship and community to attain human connection through care.

### (Re)Creating Community within *Pueblo's* Care Institutions

The click-clack of domino tiles filled the air, interrupted now and then by shouts of '*¡Venga ya!*' ['Come on!'] or '*¡Te toca!*' ['It's your turn!'], as men competed with one another, huddled about tables in the lounge of *Pueblo's* care home.

Moving downstairs, clusters of women had positioned their chairs together in the corridor and were chatting, discussing other *abuelos*, the up-and-coming processions, and general goings on...

Moving through *Pueblo's* care home, it occurred to me that the buzz of social activity I was observing was not dissimilar to the bustling '*vida en la calle*' ('street life') of the town lying outside its walls. This raised various questions: 'What do *abuelos* enjoy about life here?', 'How do they make their lives meaningful within these institutions?' and 'What kind of relationships do they develop?' I now explore how solidarity and community are (re)created within *Pueblo's* care institutions, transforming them from formal institutions into spaces of belonging and community. This contradicts commonly-held assumptions of formal institutions as ahistorical, stable, inert contexts, to show how care institutions get made through everyday social practices. These practices transform care institutions into dynamic sites of meaning-making where power, relationships and values are constantly (re)produced. I follow Robbins' 'anthropology of the good' to explore how people 'organize their personal and collective lives in order to foster what they think of as good' (Robbins,



2013, p. 457). I uncover how, as elder and dementia care rapidly formalise in Andalusia, people strive to (re)create kinship and community to experience meaningful human connection through formal care. I begin by describing how care institutions (re)create a microcosm of *Pueblo's* community. I uncover how solidarity was formed amongst *abuelos* living together within care institutions. Care practices, like regular community meetings, provide space for *abuelos* to voice rights. I question how engagement in such civic-like duties repositions people with dementia in care institutions, using Barlett and O'Connor's (2010) analysis of people with dementia as 'active citizens'.

Care institutions (re)created *Pueblo's* social liveliness, to form a microcosm of community life. Much of *Pueblo's* everyday social life, like other Andalusian towns, occurred in the street (see chapter two). During milder months, residents would sit on the street on fold-up chairs chatting. Outdoor bar terraces spilt into the street, where men drank and played dominoes. Life in care institutions (re)created '*vida en la calle*' ('street life'). Rather than sitting in front of their houses, *abuelos* in the care home positioned chairs outside their bedrooms in the long corridors. They called to passers-by, just as *Pueblo's* residents would shout to neighbours in the street. *Abuelas* in care institutions positioned their armchairs in circles and gossiped, sometimes bringing sewing or knitting whilst they chatted. Men also sat together and filled the men's lounge with competing dominoes games. The way *abuelos* interacted within communal spaces in *Pueblo's* care institutions could thus be interpreted as a microcosm of *Pueblo's* active street life.



Figure 1. Male *abuelos* at *Pueblo's* care home play dominoes.

Community-making was further enhanced through *abuelos* engaging in acts of camaraderie. For example, as staff gathered up *abuelos* to participate in the activities groups at the care home, several *abuelos* would assist them in recruiting others. Esperanza, who regularly attended the groups herself, encouraged reluctant *abuelos* to participate:

‘Come on *cariño* [darling], Esperanza urged Carlota, an 89-year-old *abuela* with dementia who rarely left her bedroom. ‘You’ll feel better getting out of this bedroom and doing something with the day.’

‘I feel too tired!’ Carlota protested, rubbing her eyes, which were red and watery. Esperanza put her hand on Carlota’s back and rubbed it soothingly. Carlota started crying quietly and Esperanza continued comforting her, saying softly ‘Don’t cry *cariño*. You’ll be OK. You’re just tired today’. After Esperanza had sat with Carlota for over twenty minutes and missed the start of the group herself, Carlota agreed to go. During the group, Esperanza sat beside Carlota and held her hand throughout.

Initiatives of kindness like the one above, demonstrate how *abuelos* supported one another. Other compassionate acts included mobile *abuelos* pushing those in wheelchairs to escort them to wherever they needed to go. During mealtimes at the day centre, Clotilde would sit next to Rosita, who dribbled uncontrollably, and would wipe her face with a napkin. In the care home, Felipe, who had dementia, would often get lost within the corridors, and I frequently observed other *abuelos* helping him back to his bedroom. Such gestures of kindness demonstrate the solidarity existing amongst *abuelos* living within *Pueblo’s* care institutions. I also observed *abuelos* helping staff at the care institutions. *Abuelos* helped with light chores like laying the table, watering plants, or sweeping the floor. When I asked Esperanza why she was assisting staff with cleaning she replied:

‘Because it makes everyone feel better when it’s clean. And the cleaners have so much to do, while I’m sitting about all day. It’s no bother for me to help’

Esperanza’s response shows a sense of solidarity towards staff and other *abuelos*, but also implies she took pleasure in helping and feeling useful. Solidarity experienced by *abuelos* was thus multifaceted and complex. *Abuelos* wanted to help others and took pleasure in this, giving themselves use and purpose.

*Abuelos*, rather than being passive, disempowered care-receivers, were actively involved in generating caring environments. Care institutions attempted to support *abuelos’* needs by asking them for care evaluations, and many *abuelos* expressed opinions about what should be changed. At

both institutions, *abuelos* frequently complained to staff about things they were unhappy with, if for example they had not liked a certain food, or were unenthusiastic by the activities on offer. However, although care institutions sought evaluations regarding certain aspects of care, such as menu choice, the institutions' directors refused to negotiate on other unpopular care interventions, like cognitive exercises. Care evaluations from *abuelos* were thus still limited by the institutions.

Providing space for opinions to be voiced, the care home held monthly community meetings, which were open to all. The description below details one such meeting:

It was a hot July morning and a group of *abuelos* were gathered around a table in the care home's assembly hall. The air was dense and stuffy. Folding fans were being flapped up and down by *abuelos* whilst sipping glasses of water. The meeting was facilitated by Aitana, the care home's director, who was asking *abuelos* if there was anything important they wished to bring up.

'*Gazpacho*,' Isabel called out, 'the last few days we've not had any. It's so hot! We need a glass of *gazpacho* at lunchtime'

'Yes!' Fran raised his hand in agreement, 'We should be having *gazpacho* with every meal during summertime, not just now and then.'

'Of course, no problem,' Aitana nodded and scribbled down a note. 'I will speak to the kitchen today. *Gazpacho* with every meal...anything else?'

'Pedro [another resident],' Fran spoke up again, 'He can't go on like this, he's harassing the *chicas* [girls- referring to care staff], it's not fair the way he talks to them...He's even pestering the *señoras* [*abuelas*] now too. It's disgusting!'

'Thank you, Fran, for bringing this up,' Aitana responded, 'We're aware of this problem...We've already spoken to Pedro and explained we're moving him into a different bedroom.'

Isabel's assertion of the need for *gazpacho* may seem minor, but having choice over food preferences enabled *abuelos*' control over basic components of their lives. Davies' (2017) ethnography in a UK care home uncovered how lack of food choice left residents feeling disempowered. Having an allotted time/space to discuss everyday issues was important in allowing residents to feel valued and in making the institution into a home, which people belonged to, and had rights over. The community meeting also provided a space for *abuelos* to connect with, and look

out for one another, which strengthened their sense of belonging by embedding them into the social fabric of the care home. As Antonsich (2010) raised in his work analysing the concept of belonging, feeling 'at home' is not only an individual matter, but a social one. Fran in voicing his concerns over the way Pedro, an *abuelo* known for exhibiting sexualised behaviours towards female staff and *abuelas* (see chapter four), shows how *abuelos* looked out for one another. Fran, although not directly affected by Pedro's behaviour, was troubled by it upsetting others. Such protective actions attest to the solidarity existing amongst *abuelos* which enabled the generation of a collective belonging to the care home as a community. Gammeltoft (2018), in investigating belonging through ethnographic case studies in Vietnam, drew wider conclusions about the complex ways belonging allows people to connect with one another and in doing so, find meaning and direction in their lives. She explained how, through belonging, 'people weave themselves into larger social collectives, attaining moral positions as members', which allow individuals to expect protection and support from others within these collectives (Gammeltoft, 2018, p. 89). Fran, in raising this issue and showing his concern for others, was occupying a moral position which embedded himself into the care home as a community. Bartlett and O'Connor (2010) advocated moving debates on from Kitwood's (1997) emphasis on person-centred care, towards seeing people with dementia as 'active citizens' constructing their own care. This understanding of *abuelos* as active citizens of care, asserting their desires for change, and experiencing belonging to the care home as a community, appears present in the meeting above. However, certain aspects of care remained non-negotiable, and thus this citizenship was partial with only *some* aspects of care open for discussion.

Furthermore, community meetings were usually poorly attended, by around ten to fifteen *abuelos*, out of the eighty-seven living in the home. They were typically attended by the same vocal and cognitively-able *abuelos*. Fran, for example was one of the youngest *abuelos*, and although he had physical health issues, he was cognitively functional, wrote poetry and participated keenly in social events. Those with dementia who participated in community meetings tended to be brought in by staff without fully understanding its purpose, seemingly to fill numbers. Although the director invited everyone's input, she must have known such attempts to be futile when asking *abuelos* who were unable to verbally communicate. This implies evidence of Goffman's [1961] (2017) 'institutional display' (see chapter six), indicating the meetings were more about appearing to be giving *abuelos* voice, without genuinely seeking inclusive ways to do so. Therefore, it was usually more cognitively functioning *abuelos* who dominated agendas, whilst *abuelos* with dementia were left without input.

### **Care Institutions as Part of *Pueblo's* Community**

Visiting the care institutions, I never felt separated from *Pueblo's* community. They were not isolated institutions, but formed integral parts of *Pueblo's* community. Meeting people and explaining about my research, everyone I spoke to knew about the care home and day centre. Quirk, Lelliotta and Seale (2006) through their ethnography of UK psychiatric wards found that, unlike Goffman's [1961] (2017) analysis of institutions as 'total', modern-day institutions were 'permeable'; patients maintained contact with the outside world. Investigating *Pueblo*, I found its care institutions were not only 'permeable', but formed an integral *part* of its community. I begin this section by discussing how the institutions' physical locations ensured they remained publicly accessible, reflecting their centrality to community life. I then describe how both institutions participated regularly in intergenerational community events which established the institutions as parts of the community.

The care home was situated beside the town hall in the town centre, whilst the day centre was five-minutes' walk away. Some *abuelos*, without severe mobility needs, were permitted to leave the home freely and, due to its central location, could spend time in nearby shops, cafés and parks. For those unable to go out safely alone, the OT and psychologist organised regular trips out within the activities programme (see chapter six). As the majority of the care home's *abuelos* had lived in *Pueblo* their whole lives, it was not unusual when out with *abuelos* for them to bump into people they knew. These care institutions, situated in the centre of this close-knit community, fostered familiarity in people with dementia, who despite moving from their long-established homes into unfamiliar institutions, remained firmly within *Pueblo's* community. When discussing with *abuelos* plans for the four-star hotel on the edge of town to be converted into a luxury care home, they expressed astonishment:

'I can't imagine why anyone would want to live there! It's so far from the shops and things,' Carmen exclaimed.

'It's because it's not for people from *Pueblo*,' Isabel asserted.

'Yes,' Esperanza nodded, 'I'm sure most people in *Pueblo* couldn't afford what he's [the hotel's owner] going to be charging...I expect he's hoping to bring in rich people from out of town.'

The prospect of this new private care home, which the owner was aiming at prosperous outsiders, was not appealing to *abuelos* in *Pueblo's* only current care home, as for them, a huge advantage of the home was its position and involvement with *Pueblo's* wider community.



Figure 2. *Abuelos sit in a local park, as part of the care home's activities programme.*

The care home was easily accessible and visitors were allowed at any time. Marta visited her mother-in-law with advanced dementia daily. If her mother-in-law joined the activities group, she attended too, helping the staff running it. Other visitors came frequently, popping into the home whenever they were in town. One visitor, 81-year-old Elvira, described her contentment at the home's location:

'That's one of the great things about the care home. It's right in the centre of town and so close to everything. Whenever I go to *Mercadona* [the supermarket] on my way home, I pop in and visit Sergio [her cousin who lives in the care home]. It's so easy.'

The care home during the day was thus filled with visiting friends and relatives. This was wholly unlike the UK care home investigated by Davies' (2017) ethnography, which was off a road that was only accessible by car and lacked public transport links. She described its remote location as causing social marginalisation to residents. Contrastingly, in *Pueblo's* care home, people visited frequently, meaning *abuelos* were not marginalised from the wider community.

Visitors were keen to assert the frequency of their visits, which, given the historical resistance to institutional care in Andalusia, may have been to defend against imagined judgement from others. This echoes Yamamoto-Mitani, Aneshensel and Levy-Storrs' (2002) findings, who found relatives of people with dementia with sentiments against care homes were more likely to visit frequently if the person was eventually admitted into one. Visitors, whom I spoke to about my

research, would stress how frequently they came, as Eva, who regularly visited her brother, commented:

‘I know he’s in here [the care home] but I haven’t abandoned him, I visit every day. The only day I don’t come is Sunday because my brother visits then. But he always has someone coming to see him.’

At the day centre, *abuelos* who were not brought in the van, were escorted by relatives. The high volume of visitors in *Pueblo*’s care institutions thus demonstrates how entrance of a person into a care institution does not stop kinship care-giving. Family care-givers continued caring for relatives in the care home and day centre. Visiting relatives described providing care with more energy now that the care institution had removed the bulk of essential care, as Eva expressed:

‘Now I really enjoy spending time with him [her brother]. I can read to him, show him photos, I take him out...Before when he was home, I was so focused on doing the basics, like getting him washed and fed that I couldn’t spend quality time with him.’

This demonstrates how institutional care worked alongside kinship care-giving. The care institutions were far from Goffman’s [1961] (2017) notion of ‘total institutions’, and formed highly valued parts of *Pueblo*’s community.

The importance of *Pueblo*’s care institutions to the community is also demonstrated through their involvement in intergenerational community events. Events such as *La Semana de los Mayores* (Older People’s Week), *Churros para Merendar* (Teatime Churros) or *Noche de Flamenco* (Flamenco Night) were dotted across the town’s calendar. Events took place at the care institutions or locations around town, with *abuelos* escorted by staff. *La Semana de los Mayores*, was a region-wide event, and in *Pueblo* was celebrated through a three-course lunch at a restaurant for anyone over 65-years-old and was attended by *abuelos* from the care institutions and those living in town.

Events were promoted throughout town and broadcast on local media networks. Tano was a 91-year-old man with dementia, whom I visited with his wife weekly. Tano frequently complained that his brother Pablo had been moved by his daughter into the care home. Tano had lived two doors down from his brother for most of his life, describing it as deeply upsetting that his brother no longer lived nearby. Tano’s wife explained:

‘We’d always watched *TelePueblo*, but we do even more since Tano’s brother moved into the care home. Because often there are events going on and they

show them there. The other day, some girls from the school came into the care home to dance, and we could see Pablo in the audience. It's reassuring to see him there. We can't visit him often as the care home is down the hill...it's comforting for Tano to see his brother is alright.'

Local broadcasts show how, despite *abuelos* living within care institutions, their regular participation in community events was known. This ensured they remained visible across the community. Events were not restricted to *abuelos* from the institutions and their family but included those who did not personally know anyone in the institutions. Intergenerational events, involving children from the local school, were common at both institutions. Below I detail one such event at the care home:

Today, school children were participating in the activities group. We escorted the *abuelos* into the hall to sit in a huge circle, leaving one chair free between each of them.

About twenty-five children poured into the assembly hall, accompanied by their teacher. Mari, Iris [the psychologist and OT] and I introduced ourselves to the group. Then Iris handed around pieces of folded paper to each child. The pieces of paper gave descriptions which referred to each *abuelo* in the group, for example, '*She has blue eyes, wears glasses, enjoys knitting and has thirteen grandchildren*'.

Mari then instructed the children to open their pieces of paper and find the *abuelo* it referred to. The children hurried about the room, speaking with as many *abuelos* as possible, asking them questions about their lives.

Slowly the empty seats besides the *abuelos* filled up with children, many of them launching into conversation with their new neighbours. Eventually the entire room was paired up and the children and *abuelos* went to sit at the tables and complete a craft activity together, making autumn leaf decorations and pinning them onto the windows (see figure 3).





Figure 3. Autumn leaf decorations produced from an intergenerational activity at Pueblo's care home.

*Abuelos* spoke enthusiastically about these events for weeks afterwards. The deliberately fostered connection of the care home to the school shows how intergenerational links were retained between *Pueblo's* older and younger citizens. Rather than care home admission representing loss of community, community was (re)created within the institution. *Pueblo's* care institutions, through participating with community residents across generations, were understood as respected and integral *parts* of its community.

These events, organised seasonally, provided rhythm to community life and orientated *abuelos* to the time of year, which was grounding for those with dementia. *Pueblo*, situated within a mountain-range, experienced extreme seasonal temperature changes. Most *abuelos* had worked on the *olivos* (olive plantations) that dominated *Pueblo's* landscape. During the olive harvest, temperatures drop and people typically cook *migas*, a heavy dish made from soaked bread, garlic, chorizo and olive oil. The care home's head chef organised *abuelos* to participate in making *migas*. Carmen, an 84-year-old *abuela*, had grown up on an olive plantation. As the smell of *migas* floated down from the kitchen she whispered excitedly:

'That smell reminds me of harvest. That was the only time of year my sisters and I got to join the men outside in the *olivos*. It was hard! But there's nothing like eating a huge plate of *migas* after you've been out all morning working.'

Carmen had early-stage dementia, and would sometimes get disorientated, repeatedly asking for the day or time. Yet cooking this autumnal dish appeared to trigger her long-term, place-centred memories, which reorientated her to the current season. Clarke and Bailey's (2016) qualitative research with people with dementia living within rural and semi-rural areas in the North of England, investigated how physical environment impacted on people's experiences of dementia. They highlighted the lack of research exploring how place can enable resilience in people with dementia. Speaking to people with a recent diagnosis of dementia, they found that familiarity with places could be supportive and bring 'a sense of continuity and stability' to participants with dementia (Clarke and Bailey, 2016, p. 444). They also revealed how 'changes within natural rhythms of the days and seasons in the countryside' had a positive influence on their participants by bringing 'interest and reassurance' into their everyday lives (ibid.). Bringing these insights into comparison with the example of Carmen can be illuminating. Although Carmen was not living in her long-term home, as she had been moved to the care home since her diagnosis of dementia, this sense of being reassured by a specific, place-centred activity that orientated her to the current season did appear to be experienced as comforting. By planning activities based on seasonal rituals, care institutions in *Pueblo* attempted to orientate *abuelos* with dementia to the season and rhythm of community life to facilitate a sense of familiarity, reassurance and comfort. This example shows how care practices within *Pueblo's* care institutions were deeply embedded in local knowledges of seasonal municipal rituals that helped generate profoundly community-centred forms of dementia care.

In chapter five, I explored how care institutions were involved in *Pueblo's* religious *fiestas*, which formed a crucial part of municipal collective identity and belonging. These *fiestas* were dotted throughout the year to celebrate Catholic events like the *Fiestas de las Cruces* (Crosses Festival), *Semana Santa* (Easter/Holy week) and the *fiestas* in honour of the town's Virgin Mary saints. During these celebrations *Pueblo* came to life; the town was decorated with brightly-coloured lights, bunting and banners, and huge processions paraded through the streets. Both care institutions incorporated *fiestas* into their activities' programmes. At the care home, in the weeks before the *fiesta* for the Virgin Pilar, *abuelos* made flower wreaths in her honour. During the *fiesta*, the care home was assigned its own visitation with the Virgin, and staff accompanied *abuelos* to lay the wreaths at the statue's feet. Whilst at the day centre, from January to May *abuelos* prepared craft flowers to decorate an ornamental cross for the *Fiestas de las Cruces*. Potential feelings of loss from entering the care institutions could be reduced through *abuelos'* integral participation in the *fiestas* which reaffirmed them as respected community-members, and sustained their belonging to *Pueblo*. Therefore, rather than feeling isolated through their new lives in care institutions, *abuelos* were reaffirmed as active, integral members of *Pueblo's* community.

During *fiestas*, processions paraded through the streets, making special stops where the care home and day centre were located so that the Virgin Mary saint statue, carried on a processional float, could send her spiritual protection over the institutions. *Abuelos* spoke with fervent enthusiasm about this part of the procession. The organisation of the processional route to include the care institutions demonstrates how these institutions, far from being isolated, were highly valued institutions that demanded the respect of a personalised visit from the popular Virgin Mary saint statues. *Abuelos* living their lives within these institutions, through their integral participation in the town's *fiestas*, were thus reaffirmed as valued members of the community and their sense of belonging was strengthened.

### Unequal Access to Community in *Pueblo's* Care Institutions

Access to community-making processes however varied individually. Adopting Robbin's (2013) 'anthropology of the good' risks romanticising collective social processes, masking subjective experiences. In this section, I demonstrate how individual subjectivities affect collective social processes by discussing how dementia, gender and class intersected with community-making and belonging within *Pueblo's* care institutions.

Some *abuelos* with dementia were segregated from community-making processes by staff and other *abuelos*. *Abuelos* with advanced dementia were physically segregated by being allocated bedrooms on the *deterioro cognitivo* (cognitive deterioration) floor, making up over a third of the institution's population. This physical separation of dementia in care homes is represented in the Spanish animation film *Arrugas* (2011). The protagonist, Emilio, a recent arrival to a care home, lives in fear of being transferred to the top floor, occupied by residents with advanced dementia (see figure 4).



Figure 4. Scene from the Spanish animation film *Arrugas* (2011), Emilio's roommate Miguel explains to him that the top floor of the care home is occupied by those who have '*perdido la cabeza*' ('lost their minds').

*Abuelos* expressed negative feelings towards the *deterioro cognitivo* floor. Isabel, an *abuela* without cognitive impairment, explained:

‘We don’t see people up there. They stay on their floor...They’re *atontados* [slow/scatter-brained] so they can’t join in the activities.’

Staff explained this segregation was due to differing care needs. There were some *abuelos* with dementia on other floors, but if their behaviour was deemed ‘disruptive’, they would be moved to the *deterioro cognitivo* floor. Staff occasionally did one-to-one activities with *abuelos* on this floor, but only sporadically. Goffman explained stigmatisation occurring when people are cut off from society (Goffman, [1963] 1986). In *Pueblo*’s care home, people with advanced dementia were physically segregated, marginalising them from the community.

People with dementia were also given fewer opportunities to access the wider community. Regular outings were organised at the care home. Although these included some *abuelos* with dementia, others deemed ‘disruptive’ were excluded. This is shown in the example below regarding Ascención, an *abuela* with early-onset dementia:

Mari and Iris [the psychologist and OT] were gathering *abuelos* to take out. Ascención, seeing the huddle of people in the entrance hall, asked where they were going.

‘To *Mercadona* [the supermarket],’ Esperanza [another *abuela*] replied, ‘then we’re going to the park’

‘Oh great! I’ll join you!’ replied Ascención enthusiastically.

‘Ascención!’ Iris jumped in, overhearing their conversation, ‘You have things to do here. You have to stay behind I’m afraid.’

‘What things?’ Ascención replied defensively. ‘I don’t have anything to do!’

‘Yes, you know, you have the urm...cleaning to do, Mari, doesn’t she? Mari, why don’t you show Ascención that cleaning that needs doing?’ Iris said, giving Mari a knowing look.

‘Yes, you have lots to do!’ Mari agreed, ‘Come with me, Ascención, I’ll show you what needs doing,’ hastily grabbing Ascención’s arm and leading her away.

Later I asked Iris why Ascención could not come and she explained that Ascención was difficult to manage. She recounted how Ascención had been out with them previously and spoken to members of the public inappropriately, and that once she had walked off and they had almost lost her.

Ascención was only 60-years-old and physically fit, but had been diagnosed with early-onset dementia. The psychologist explained how early-onset dementia affected the frontal lobe, resulting in disinhibited behaviours. Ascención was a bubbly, outgoing character who was well-liked throughout the home. She was almost always cheerful and frequently burst into song or told dirty jokes. Although Ascención was popular, *abuelos* who exhibited such ‘disinhibited’ behaviours were rarely allowed out. This reflects findings from Brittain and Degnen’s (2022) research, who found that care-givers to people with dementia feared social judgement from others when accessing public spaces which were less predictable than private homes or residential care settings. Thus, although the care home provided a community where their unusual behaviours were tolerated, accepted or even appreciated, it restricted them from access to *Pueblo*’s wider community.

Although barriers existed for people with dementia, some staff actively included them in community-making. One *abuela* with dementia, Josefa, would repeatedly rub the walls with her hands as though she could see dirt. One of the cleaning staff would give Josefa a cloth, which she explained she did so that Josefa would feel she was cleaning effectively. This transformed Josefa’s unusual, dementia-led behaviour into the everyday practice of cleaning. Kontos’ (2005) ethnographic observations in a care home explained how people with dementia retain an ‘embodied selfhood’, through daily corporeal primordial behaviours in which they express themselves. She highlighted how through bodily gestures, such as pulling a necklace over one’s clothes or clapping along with music, one could recognise embodied selfhood in people with dementia. She advocated dementia care practices that gave life to such expressions. The cleaner, in giving Josefa a cloth, could thus be understood as encouraging Josefa’s embodied selfhood expression. This small gesture recognised Josefa within the care home’s community, reaffirming her personhood. It demonstrates how it was not solely *abuelos* but also staff who enabled community-making.

Staff cultivated conditions that encouraged people with dementia to engage with their surroundings. For example, Angela was an 89-year-old day centre attendee with advanced dementia who rarely spoke; however, she sometimes responded to certain cues. Sandra, the day centre

housekeeper, clearing away lunch would say to Angela 'How was it?', which prompted a seemingly automatic response in Angela, who would reply 'Very good'. Sandra explained doing this as she felt it was important to 'bring her into reality'. Svendsen et al (2018) conducted an ethnography at a care home for people with dementia and found care staff strived for 'magical moments', which were 'moments in which the person with dementia responded, albeit slightly, with a nod, a movement, or a verbal sound' (Svendsen et al, 2018, p. 28). Sandra, in attempting to stimulate an everyday response from Angela seemed to be striving for a 'magical moment'. Mattingly (2014) explained how family care-givers to chronically ill children coped through experimenting within 'moral laboratories' of care. Care-givers, faced with complex moral choices, attempted to cultivate the experimental conditions required to enable the care-receiver fulfilment. I combine Svendsen et al's (2018) 'magical moments' with Mattingly's (2014) 'moral laboratories'. Staff at *Pueblo's* care institutions experimented within 'moral laboratories', attempting to create the conditions to enable 'magical moments' to occur in people with advanced dementia, so they could connect to the community around them.

Community access was also regulated by sociable *abuelos* without cognitive impairment, some of whom would exclude those with dementia. Cliques were formed, with *abuelos* sitting together and gossiping about others. Activities groups involved schoolyard politics which marginalised those with cognitive impairments. Isabel, an *abuela* without cognitive impairment, acted as ring-leader to a group of *abuelas* who sat together during activities. When an *abuelo* with dementia tried to sit beside them, Isabel placed her hand on the seat and told them it was saved. Cliques gossiped about *abuelos* showing signs of cognitive decline. Davies' (2017) ethnography of a UK care home similarly found residents lacked understanding regarding cognitive impairment. By critiquing other *abuelos'* cognition, those without cognitive impairment reinforced subgroup solidarity, displaying how membership of this community was exclusive and dependent on superior cognitive function and attesting to the 'hypercognitive ideology of human worth' (Post, 1995, p. 90). This values cognitive capabilities, thereby devaluing people with dementia. Sometimes gossiping *abuelos* would even imply *abuelos* with dementia were in their state of health due to moral misgivings. Below I detail Isabel gossiping about another *abuela*, Teresa, who had advanced dementia:

'She's from a difficult family. Everybody knows her husband was a drunk and always having affairs. It's no wonder she's ended up like this...I think her family were happy to be rid of her when she got put in here. She never gets any visitors from anyone, not even her daughters.'

Isabel's comments imply Teresa's family relations somehow connect to her dementia. Understandings connecting dementia to family and morality echo Cohen's (1998) insights from his ethnography of families in India, suggesting lack of family care towards an older relative can result in their forgetfulness. Isabel's comments attest to the complex ways broader societal and generational changes that affect older people and kinship feed into local dementia understandings. Such judgement from other *abuelos* thus further stigmatised those with dementia, marginalising them from community life.

People with dementia did not however always accept marginalisation and fought to maintain their positions as community-members. 82-year-old Mercedes formed a subgroup of three women who attended the day centre and sat at the highest cognitive function table during cognitive exercises. Mercedes had a dementia diagnosis but only experienced mild memory loss, sometimes muddling up days/times. One morning she remarked it was Monday, which another *abuela* corrected saying it was Friday. Mercedes responded, 'Oh yes, of course,' looking unsurprised as though it had been a slip of the tongue. Such attempts to hide memory loss can be understood as 'covering', whereby people hide deficits to avoid stigma (Goffman, [1963] 1986, p. 102). Such 'covering' enabled Mercedes to retain her membership of this subgroup of higher functioning *abuelos*. This demonstrates Beard's (2004) assertion that people with dementia deliberately deploy techniques to maintain community status, whilst illustrating Bartlett and O'Connor's (2010) claim that people with dementia are not passive care-recipients, but active citizens forging their own community identities.

Others, who had been well-respected community-members prior to dementia onset, because of the close-knittedness of *Pueblo*, remained valued community-members through 'double biography' (Goffman, [1963] 1986, p. 78) negating their stigmatised/spoilt public identity. For example, Pepe was 78-years-old and attended the day centre since dementia onset after a stroke. He was unable to verbally communicate and sometimes acted violently. Pepe was well-known throughout *Pueblo* for his work in the *cofradía* (religious brotherhood). During his violent outbursts, I was surprised that other *abuelos* did not criticise him as they would others who acted violently due to dementia, and instead repeated how wonderful a man he had been before the stroke, recounting his *cofradía* work. Within small communities like *Pueblo*, a double identity can thus be formed in people with dementia, through which prior well-respected identities prevent stigmatisation, meaning newer dementia associated behaviours are more easily accepted or forgiven.

I argue that rather than being protected by old identities, others were accepted through their *newer* identity *post*-dementia. For example, Ascención's daughter described her as having

always been reserved. However, since dementia onset, she had become disinhibited, frequently telling dirty jokes, touching or tickling people and singing loudly. Her daughter, deeply saddened, felt unable to manage this behaviour and Ascención was moved into *Pueblo's* care home. However, within the care home she was much-loved and accepted, *abuelos* enjoyed her disinhibited behaviours, encouraging her to sing and laughing at her jokes. This overcomes Beard's (2004) explanation of people with dementia attempting to preserve old identities, instead showing how people with dementia can gain new identities to be accepted in entirely different ways to identities prior to illness. Although Ascención's new characteristics were not accepted by her family and *Pueblo's* wider community, within the care home she became a well-liked community-member.

Community-making access was also gendered. Women outnumbered men in both care institutions. At the day centre there was only one regular male attendee, José, who struggled to settle into life at the institution. José was an 85-year-old retired shepherd and olive farmer in the early stages of dementia. As a man of his generation, José was accustomed to having the autonomy to go where he pleased. It was therefore difficult for José adjusting to day centre life, restricted to a small indoor space, surrounded by women. He frequently complained and would pace about demanding to be released. Day centre activities were aimed at the female majority and thus José was reluctant to participate in activities like knitting or craftwork. If staff had time, they would play dominoes with José, or male staff would take him out in the van. However, José remained disconnected from the group, largely ignoring *abuelas* and making continued rebuffed attempts to seduce younger female staff (see chapter four). He thus failed to form functional relationships with *abuelas* or staff; remaining an outsider.

At the care home, the majority of *abuelos* were women, but there was a significant male minority. Other than the cognitive deterioration floor, gender was segregated by men's and women's floors. Activities occurred in the assembly hall on the women's floor where genders mixed. Although all *abuelos* were invited to participate in activities, women dominated. Men tended to organise activities amongst themselves, like playing dominoes in the male lounge. Speaking to a group of male *abuelos* about why they did not participate in the activities programme, Carlos, a resident in his 60s, who had physical disabilities, explained:

'Because those groups are for *mujeres viejas* [old women] and *tontos* [fools]...I prefer to do my own thing. I go out sometimes for a coffee with Fran [another male *abuelo*], I play dominoes...I like spending my time how I choose.'

Carlos highlights how the activities programme was influenced by gender and cognitive status. Men without cognitive impairment disregarded activities groups. However, as there were



other male *abuelos*, they could form subgroups within the care home and thus experienced belonging and sociability, despite not participating in formal activities.

Although women went on supervised outings, they would never leave the care home unaccompanied, whereas there were about five/six men who regularly went out independently. The care home thus reflected gendered community boundaries of this generation, in that women remained in the domestic sphere and only men accessed the public sphere (Driessen, 1983). This appeared to be accepted as I did not observe women expressing wishes to go out other than on organised outings. Male *abuelos*, assessed by staff as safe to go out unaccompanied, left when they pleased to meet with friends or family, enabling maintenance of their previous social networks. Women contrastingly, depended on the limited timetable of staff-organised outings or visitors, and thus on moving into the institution lost more control over maintaining previous social networks. Gender therefore significantly impacts community-making experiences of *abuelos* in *Pueblo's* care institutions.

*Abuelos'* class backgrounds also influenced community-making and belonging in care institutions. The majority of *abuelos* had not spent any/much of their childhood in formal education, and many were illiterate. The regular cognitive exercises comprised of written worksheets, conducted at both care institutions, were therefore frequently a cause of distress amongst *abuelos* as they clashed with their class backgrounds and cultural dispositions (see chapter six). Being forced to engage in activities that subscribed to an entirely different worldview to their own, many *abuelos* felt socially isolated which impinged on their sense of belonging. The minority of *abuelos* from wealthier backgrounds that had spent significant periods in formal education, completed the cognitive exercises more enthusiastically. Esperanza, who had worked as an administrator, said she enjoyed the cognitive exercises as they reminded her of the wordsearches she completed in her free time. However, this minority of more educated *abuelos* complained about the infantile nature of many other activities on offer. *Abuelos* at the care home, such as Alejandro or Juan, who had worked as a shopkeeper and banker respectively, complained that activities like colouring-in were childish. Negotiating activities that were inclusive to the diversity of *abuelos* within the care institutions was thus complicated as *abuelos'* sense of belonging and community were experienced differently.

### **(Re)Creating Community Amongst Care Workers**

Community within formal care was also dependent on staff. Carers within care institutions and working as home carers, although facing challenging working conditions, strove to (re)create community for resilience. I interviewed women working for both *Pueblo's* publicly-funded homecare service and as *cuidadoras internas* (live-in carers), paid privately by families or agencies. Many were

migrants from developing countries, forming 'global care chains' that are reconfiguring globalised kin-relations (Hochschild, 2012). Although many families had previously relied on live-in migrant carers for eldercare, none of the families I knew were employing a migrant carer willing to participate during fieldwork. I therefore contacted an NGO in Málaga with whom I conducted interviews with migrant care workers.

Paid carers across all settings reported challenges at work. However, a protective factor that facilitated resilience was the employment of carers' own kin to work alongside them. In *Pueblo's* care home, Belén, a 25-year-old carer described how she attained her job through her sister:

'I did a little *enchufe* [nepotism] to get the job. My older sister, Lisabet, was working here already, and when a position arose, she told me about it and the director called me that day. They didn't have to bother advertising the post, they just gave it to me...It's easier for them having us both working here because we're sisters so we work well together...And it's good for us because when we're put together the shift is better.'

People referred to *enchufe* positively, bragging about how they had earned themselves, friends or family opportunities. The *enchufe* described by Belén benefited her sister and enabled her to better manage the work. Ibarra (2013) highlighted how Mexican migrant care workers in California negotiated with clients to find jobs for their own family, which created better working conditions for themselves. Working alongside family gave carers resilience to cope with challenging working conditions.

Care work thus frequently spread through kin networks. Patricia, a middle-aged woman in *Pueblo* who I interviewed about the care of her late-mother who had dementia, described how she and her siblings had paid live-in carers to help when her mother's care became too difficult to manage. The live-in carers they employed were all young South American women. She found the first carer through an agency, but from then on, whenever a carer left, they would recommend a friend who took over. Carers thus deliberately navigated care settings they worked within to find opportunities for their own contacts.

For migrant carers, in unfamiliar cultural environments, finding work for kin was valuable as it made an alien environment more familiar. Daniela, a middle-aged Colombian woman who had migrated to Andalusia four years previously, described how she had found work as a live-in carer to Nuria, a woman in her eighties with dementia in a small *pueblo*. Daniela recalled her initial struggles settling in, describing the isolation she experienced as she knew nobody else in the *pueblo*. She

recollected the loneliness of spending every day alone with the *abuela*, who she initially felt she shared nothing in common with, recounting how they spent hours preparing meals which she found tedious. She described how her only comfort were weekly phone-calls to her daughters. After a year, as Nuria's needs increased, Daniela's daughters moved from Colombia to join her. With three of them working, they could afford to rent a house nearby, meaning rather than working as live-in carers they could rotate shifts between themselves and spend time off together. Daniela explained her daughters' presence transforming her experience so that she now felt 'at home'. Her relationship with Nuria improved as a result, and they now sometimes all went to Nuria's to cook Colombian food. Through formal carers reconfiguring unfamiliar working environments by inputting kin, they generated community, belonging and resilience to manage the job's demands.

Many formal carers described isolation due to unsociable working hours and lone-working. Migrant carers described the added isolation of being perceived of as an *extranjero* (foreigner) and experiencing prejudice. Juliana, a carer from Brazil, described caring for a woman with dementia who would get upset when she lost things and call Juliana a thief and '*sudaca*', a derogatory term to describe someone from South America. Juliana understood this behaviour was due to dementia, but recalled how upsetting it was when the woman's daughter also believed her mother's accusations were true. She blamed this on local stereotypes about South Americans being untrustworthy, which made her struggle with fitting into the local culture.

Combatting isolation migrant carers formed close relationships with one another. Environments, like the NGO migrant centre in Málaga, provided a community space. Social events took place here and the NGO offered free care work and Spanish courses, which enhanced migrants' chances of finding employment. Migrants spending time here, shared information about work opportunities and formed friendships. I spoke here with two women from the Dominican Republic who had arrived separately to Málaga, but moved to the same *pueblo* to work as live-in carers for an elderly man with dementia, rotating shifts between them. They lived together and became extremely close. Forming peer friendships reduced the isolation migrant carers experienced living in a foreign place, cultivating community and belonging.

The intimate nature of care work and its challenges also facilitated solidarity amongst formal carers. In *Pueblo's* day centre there had been almost no changes to staff since its conception. During quiet moments, staff would massage one another to soothe muscle pain from manual handling. Staff had attended one another's weddings, children's communions and family funerals. When the physiotherapist's husband became seriously ill, everyone contributed to buying him flowers and visited him in hospital. The everyday, intimate nature of care work meant a homely, informal

atmosphere formed amongst staff. As one carer from the care home stated: 'Once you've done a night shift with someone, you know them inside out'. The intimacy and everyday nature of care work thus facilitated care workers to develop solidarity and build supportive communities.

### **Complex Care Relationships**

In this section, I first explore how *abuelos* in care institutions formed caring relationships which they described as kin-like. Institutions operated informally, facilitating the development of caring relationships between staff and *abuelos*. I discuss how valuable cultural and generational exchanges occurred; whereby younger care staff sought *abuelos'* life-long knowledge. For migrants working as live-in carers to *abuelos* a cultural exchange could occur, facilitating belonging to their new foreign home. Despite challenging working conditions, I reveal how carers described their work as morally valuable. Home carers described how the intimacy of working within homes enabled a special closeness to develop. Care workers described deeply felt emotions towards those they cared for, with relationships enabling a (re)creation of kin-like connections. Portraying relationships as kin-like could however, also generate feelings of obligation and guilt. Formal care relationships were experienced diversely and whilst many reported positive connections, others recounted feelings of mistrust or being at risk.

Within *Pueblo's* care institutions, meaningful relationships formed between *abuelos*, generating community-making. In chapter six, I discussed how many *abuelos* were unhappy sharing bedrooms; however, this was not true for all. Esperanza and Carmen, both in their 80s, were allotted a shared bedroom without knowing one other. Two years later, they spent almost all their time together, with Esperanza describing their relationship as '*como hermanas*' ('like sisters'). Davies' (2017) ethnography of a UK care home described an overriding sense of loss within the institution. Although loss was present in *Pueblo's* care home, there was also a sense of gain amongst many *abuelos*, who described having found a new life, relationships and community. Beard (2004) advocated distancing from loss discourses surrounding dementia, stressing how people with dementia actively preserve old identities. Yet, in *Pueblo*, through their new lives in care institutions *abuelos* constructed novel relationships and lifestyles to find a renewed personhood, rather than simply preserving their previous sense of personhood.

Formality of care institutions was reduced by the presence of actual kin-members, blurring boundaries between staff and *abuelos*. At the day centre when permanent staff took summer holidays an *abuela's* granddaughter worked as cover staff. The presence of genuine kin-relationships within care institutions reduced the formality of care relationships, whilst in the care home there were several *abuelos* who were related. Ramona and her middle-aged son both had learning

difficulties and lived in the care home together, whilst Isa and Santiago were a married couple who moved into the care home after Santiago was diagnosed with dementia. Reproductive kinships were thus present in the care institutions reducing formality.

The informality of staff regarding their personal lives also created a relaxed atmosphere within care institutions that led to relationships stretching beyond professional boundaries. Having worked as an occupational therapist in the UK, I had learnt to be discreet about my personal life and would never reveal contact details to service-users. I was thus struck by the informality of care staff in *Pueblo*. On a morning trip out to the park with *abuelos* from the care home, a staff member whose house adjoined the park came out to pass her pet rabbit around the *abuelos*. She was not on shift and explained that if she was home and saw the group of *abuelos* in the park, she would bring her rabbit out for them to pet as they enjoyed it. She was happy spending her free time helping *abuelos*, showing that her work was more meaningful than the salary it provided, and she was happy sharing aspects of her personal life with *abuelos* without concern for professional boundaries.

Descriptions of cultural and generational exchanges between formal carers and care-receivers provide further evidence of care relationships stretching beyond formal boundaries. The extract below comes from Fatima, a middle-aged woman from Morocco who had been working as a carer in Málaga for sixteen years:

‘I feel grateful for the way we learn from one another. Many other women I know who came here from my country, if they haven’t worked here, they don’t learn the way of life...Although I came here alone, which was very difficult, it meant that I was forced to fit into the culture. Now I can speak Spanish perfectly and I understand the people here. I know their culture. Other women who have been here longer than me can barely even understand Spanish. But I had to learn on the job...I teach people here about my own culture. The man I care for now, he’s so sweet, and he really loves Moroccan food! I make him *tangia*, *couscous*, and he loves it because it’s so different to what his wife used to make him.’

Fatima migrated to Spain alone to escape a violent husband, and was extremely positive about the care work she found. She was pleased to have learnt about Andalusian culture through her job and spoke enthusiastically about teaching *abuelos* about Morocco. Other migrant carers I spoke with similarly referred to cultural exchanges occurring at work. Even Daniela, who I earlier explained was negative about her time working as a live-in carer, explained that she appreciated how much she had learnt from the *abuela* she cared for about Andalusia, and that she could not have gained this cultural knowledge without living in such intimacy in the person’s home. This

cultural exchange thus enhanced the work's value and deepened relationships between care-givers and receivers.

Generational knowledge exchanges also enriched relationships between formal carers and care-receivers. In the day centre, the *abuelo*, José, was comforted by conversations about *el campo* (the countryside) where he had worked all his life. Some staff had family-owned *olivos* (olive plantations) and asked José for advice, valuing his years of agricultural experience. Speaking with José about his agricultural knowledge was both used to calm José and genuinely appreciated by staff. Despite his limited short-term memory, José could recount long-held local agricultural knowledge. This reflects Lewis' (2013) research with Alaskan elders, who found their experience of ageing was more positive than other US elders, partly because of their connection to the community through their shared knowledge of living off the land. Such insights demonstrate how older age, rather than being purely a time of loss, is often filled with 'prowess and skill' (Degnen, 2018, p. 152). The sharing of agricultural wisdom enabled meaningful relationships to develop beyond professional boundaries that linked into a sense of belonging to *Pueblo*.

Many carers spoke enthusiastically about the importance of their job and how, in spite of society's devaluing of care work, they recognised their role as morally valuable. Daniela described how people in Colombia were better at caring for the elderly than in Spain. She felt proud to perform this important role, seeing herself as teaching important values from her own culture. Meanwhile, in *Pueblo's* care institutions and homecare service, staff frequently criticised families of *abuelos* who were not well supported. Staff described families 'abandoning' the *abuelo* and spoke with sympathy about having to now fill in the role their family should be performing. Carers thus understood their role as morally valuable, carving agency for themselves that negated their disempowering working conditions. Attestations to kin-like relationships were frequently made by staff, *abuelos* and relatives at *Pueblo's* care institutions. Using the term '*abuelos*' to describe service-users further indicates how formal carers approached their role as filling in for family. This shows how although care was formalised, care professionals attempted to recreate kin-like relationships to reduce the formality of care, enabling relationships to be experienced as kin-like and meaningful.

Several carers described how the intimacy of living together meant *abuelos* became like family to them. Fatima explained how the woman she looked after as a live-in carer became like a mother to her:

'I became very close to the woman I first cared for, Clara. She became my family. My mother died when I was very young, so with Clara I felt as though I had a mother again for the first time. And she had nobody. Her family had totally

abandoned her. So, even though she was a Christian and me a Muslim we became like mother and daughter...It was a sad thing as she had dementia so badly that eventually she became very ill, and I had to do everything for her. But I was happy to look after her and I did it from my heart...I was so devastated when she died. It was like I had lost my only family here.'

Fatima described a kin-like relationship with Clara, partly because she did not have family and neither did Clara. She explained how, in spite of their cultural differences, through the intimacy of co-residing and dependency she became like a mother to her and experienced grief when she died.

Another migrant carer, Pati, in her 20s/30s from Bolivia, similarly described a kin-like relationship developing with the man she worked for as a live-in carer. Pati explained struggling to settle into life when she first migrated and missing her family. Once working as a live-in carer to an *abuelo* she described feeling at home through intimate moments she shared with him, such as having meals and watching television together. She described looking after him 'as if he were my uncle'. Socially isolated *abuelos* and live-in carers, particularly migrant carers who frequently experienced isolation from working far from their native homes, could gain comfort from kin-like relationships formed through formal care that stretched beyond boundaries of culture and age.

Carers working for *Pueblo's* homecare service described going beyond the expectations of their job to provide additional care they felt necessary to benefit those they looked after. Carers worked unsociable hours, but in spite of this routine, described allowing extra time to spend with people they felt needed it. One carer described how she cleaned for a woman she looked after, even though it meant she ran over the time she was paid for, as she knew it really cheered her up. Others described how they called *abuelos* on their birthdays or Saint's days, even if off-shift, as they knew nobody else would. Carers also reported how *abuelos* would give them presents, like chocolates or flowers. Relationships were thus reciprocal, with care-receivers also showing care and appreciation towards care-givers.

Such acts of kindness, that go beyond carers' job descriptions, could be the result of genuine care. However, the metaphor of family that was frequently cited by formal care employers could also be interpreted as a way of raising workforce demands. De Neve's (2007) ethnographic exploration of factory-workers in Southern India revealed how factory owners used kinship terms to refer to employees. However, De Neve highlighted how working in a precarious labour-market, employers used kinship terms to generate trust and retain staff. He raised the importance of asking 'who benefits from a rhetoric of kinship' (De Neve, 2007, p. 243). In *Pueblo's* care institutions I

noticed it was the directors that emphasised the team were '*una familia*' ('a family'), and I did not hear care staff use this term themselves. I did however hear staff, across formal care settings, refer to older people as *abuelos*; I also observed *abuelos* referring to one another using this term. This could indicate that this kinship term was being used as an attempt to express genuine care and respect towards elders. However, the danger of this term was that it could raise expectations of formal care-giving to one of kin. I frequently heard formal carers going above and beyond their job descriptions to meet *abuelos*' needs, particularly live-in and home carers, who were often the only, or one of few, people who looked after the *abuelo*. Being somebody's only social connection came with a sense of responsibility for many carers and generated feelings of obligation and guilt.

Carmela, a 27-year-old carer working for *Pueblo*'s homecare service, commented:

'I know that if I don't call them on their birthday nobody else will. They don't have any real family left so it's me that has to take responsibility for things like that. If I forget I feel terrible because they don't have anyone else.'

The widely-used term *abuelo* thus did seem representative of certain challenging aspects of kinship, involving obligation, duty and guilt. It was used by care employees, but heavily encouraged by care employers. Speaking with Alfredo, the head of *Pueblo*'s homecare service he explained:

'Staff go out of their way to help the *abuelos*, because they do really care about them. I'm proud of them all for being so dedicated.'

Alfredo's words express a pride at his employees' commitment. However, they also indicate an awareness that his staff were going beyond the expectations of their role. As 'care work' there was an expectation 'to care' and this expectation, in conjunction with references to fictive kinship, were powerful tools to instil a deep sense of obligation onto formal carers that masked exploitative aspects of their work.

Formal carers thus experienced complex care relationships, stretching beyond formal boundaries, to re-create feelings of intimacy, kinship and care for those they looked after. However, terms of kinship and expectations 'to care' could be manipulated by employers to mask exploitative aspects of care work. Furthermore, experiences of care work were hugely variable and many carers did not experience connection to those they looked after. Many formal carers spoke of feeling undervalued, underpaid and suffering stress and anxiety from over-working and fatigue (see chapter six). Several migrant carers reported experiencing racism from the families and care agencies they worked for. Live-in carers reported feeling unsafe when lone-working with people with dementia who could be aggressive/violent. Thus, although many formal carers experienced meaningful and



desirable emotions and strove to carve out value in their roles, care workers still faced severe challenges and experiences varied across care settings and individuals.

## Conclusion

As traditional dementia and eldercare systems are being replaced by formal care in Andalusia, people attempt to (re)create feelings of belonging, community-making and kinship to form meaningful social connections through formal care. The chapter began by discussing community-making processes occurring within *Pueblo's* care institutions, contradicting assumptions of formal institutions as inert, to show how they are dynamic sites of relationships, values and meaning-making. I revealed how a microcosm of *Pueblo's* active street life recreates community within institutions. Solidarity developed between *abuelos* within care institutions, although this was restricted to *abuelos* who met cognitive requirements and therefore community access was regulated. *Abuelos*, including those with dementia, exerted agency within structural limits of the contexts they lived within, to become citizens of care institutions. Such agency exertion contradicts images of people with dementia in care institutions as passive care-receivers, positioning them instead as agents of their own care. However, for *abuelos* with advanced dementia resigned to the *deterioro cognitivo* (cognitive deterioration) floor, agency remained extremely restricted.

Care settings are not isolated, bounded institutions but permeable spaces, engaging in meaningful interactions across the community. Located centrally within *Pueblo*, these institutions perform key roles in intergenerational community events, which play an important part in *Pueblo's* collective identity, generating municipal pride and belonging amongst *Pueblo's* citizens. Care institutions thus form part of *Pueblo's* community, reinforcing *abuelos'* sense of belonging to the town. Access to community-making is, however, not experienced equally across *abuelos* in *Pueblo's* care institutions. I explored how diverse identities are influenced by dementia, gender, education and class backgrounds, which intersect with community-making and belonging to reveal the diversity of care subjectivities experienced by *abuelos* within these institutions.

The chapter then moved from those receiving care to those giving it, to explore how processes of community-making were also sought by care workers. I explored how carers, facing challenging working conditions, used creative techniques to rebuild kin networks, facilitating supportive environments and equipping them with resilience to cope with demanding working conditions. Building community through supportive networks was especially valuable amongst migrant carers who, having moved far from their native homes, strived to (re)create community and establish belonging in Andalusia. Long working hours and difficult conditions led to care workers seeking comfort and support from one another, facilitating solidarity and community.

Within formalised care settings, meaningful relationships were formed amongst care-receivers and givers. Living within close-quarters many *abuelos* in care institutions experienced deeply felt emotions for one another to form kin-like relationships. Despite being formal care institutions, such places in *Pueblo* generated informal atmospheres which facilitated intimate relationships to develop between staff and *abuelos*. Live-in carers described how the intimacy of living together bonded them to care-receivers, which enabled deeply felt kin-like relationships to develop. For migrant carers in particular, this reduced isolation, for them and the person they cared for, and facilitated a cultural exchange that enhanced belonging. Meanwhile the sharing of local knowledge from older care-receivers to younger care workers facilitated valuable generational knowledge exchanges. Carers describing their profession, ascribed moral valency to their roles.

Attestations to kinship through formal care relationships could however be used by employers as a strategy to mask poor working conditions. References to service-users as '*abuelos*' could raise expectations of care workers to perform beyond their job role. Mingling ideas of kinship and care resulted in care workers experiencing feelings of duty, obligation and guilt, particularly those working as home or live-in carers for whom the person they cared for often relied entirely on their support. Furthermore, formal care was experienced through diverse subjectivities across carers, with not all carers experiencing positive relationships towards those they cared for, and some migrant carers reporting racism from the families they worked for.

Andalusia, a culture known for deeply embedded histories of kinship eldercare, has not escaped the rapid social changes brought by globalisation which have reformulated kinship care patterns, transforming the very meaning of kinship itself. Borneman (2001) critiqued anthropology's tendency to dissect the organisational notions of kinship structures in search of a 'regulative idea for humanity' which masks the human need to care (Borneman, 2001, p. 43). Moving deeper into an anthropology of care this chapter has explored formal care settings, delving into ethnographic moments that highlight how relationships of care, and the meaningful emotions and experiences that such caring practices invoke, are not confined to the organisational limits of traditional kinship ties. Seismic social changes, despite having transformed the landscape of elder and dementia care, have invoked a (re)creation of kinship and community-making through formal care, stretching beyond predestined kinship relations and demonstrating the real and human need for social connection, to care and be cared for.

## Conclusion: Towards Community-Centred Dementia Care

This concluding chapter emphasises how dementia care is made meaningful through context, thus recognising dementia care as *community-centred*. It relates key insights to the core concepts of dementia, personhood, kinship and care. I reveal how Euro-American medicalised explanations of dementia in *Pueblo* are enacted through place-specific dynamics. By exploring dementia care in a close-knit Andalusian community this ethnography demonstrates how within European settings personhood remains relational and interdependent. I also uncovered personhood's capacity for spiritual, non-human aspects. This ethnography has shown kinship to develop through care, which is experienced as enabling and restrictive. It distances from existing research conservatism to show the contradictory, polysemic nature of care. I used anthropological theories to display how care-givers craft personhood in people with dementia. Above all this research demonstrates how dementia care, formed through place-specific contexts, is profoundly community-centred. I outline applications of findings, explaining how this work has deconstructed existing dichotomies within care research, unlocked learning between occupational therapy and anthropology, and advocated ethnographic investigations of dementia care that invoke a caring participant-observation to reveal the lived experiences of dementia care. Furthermore, it uncovers how everyday cultural practices seep into dementia care experience, demonstrating the need to explore how place-specific practices form meaningful components of dementia care. We need further exploration of how to make dementia care not just person-centred, but community-centred. Anthropologists, as investigators of cultural context, are well-positioned to explore this move towards community-centred dementia care.

Afternoons tended to pass slowly at *Pueblo's* day centre. After lunch the majority of *abuelos* would slumber on the reclining armchairs in the lounge. Today, however, was different, the long-anticipated *Día de la Cruz* [Day of the Cross] had finally arrived. A hectic, excited atmosphere filled the day centre as staff and *abuelos* busied about getting ready for the party which was to take place that night. Tonight, those decorated crucifixes in *Pueblo* deemed most beautiful were awarded prizes and granted the honour of being left on display for the duration of the *Fiestas de las Cruces* [Crosses Festival]. For months, *abuelos* had spent hours every day carefully constructing craft flowers from pine cones and painting them in bright colours to decorate the day centre's own ornamental crucifix. All that preparation had been leading up to this day when finally, the winners would be announced and a long weekend of celebrations was to begin.

My partner, Antonio, had joined me at the day centre to help out, as had various friends and family of staff and *abuelos*, and as a special treat we had all shared an enormous *paella* for lunch. The *abuelos* were eager to meet my partner and excitedly clustered around him, asking him endless questions.

One of the carers, Camila, had brought her two young daughters along and, after lunch, I joined them with a group of *abuelas* gathered around a long

table where the enormous crucifix had been laid flat. Camila's daughters were assisting the *abuelas* to position the felt leaves and pinecone flowers and pinning them onto the cross.

"It looks so beautiful, we're sure to win," Clotilde, a lively 86-year-old *abuela*, remarked enthusiastically.

"We've worked so hard!" Mercedes, another *abuela*, added.

"There must be over two-hundred pinecones we've painted," I agreed.

José, the only regular male attendee of the day centre, came in and inspected the cross, furrowing his brow.

"That line's not straight," he commented critically, pointing towards a slightly crooked row of pinecones. Mercedes unpinned the pinecones and José helped her reposition them to form a straighter line.

Once the *abuelos* had gone home, Antonio and I stayed with staff to finish the preparations. The huge decorated crucifix was positioned upright in the front patio. We put up an eclectic selection of decorations attesting to *Pueblo's* local collective identity, including paper flowers, ceramic plates, flamenco fans, and pretty shawls to create an impressive display, with the adorned crucifix at the centre...

That night the party took place. A crowd made up of staff, *abuelos*, family, and friends filled the day centre's front patio, spilling into the street. Lights had been strung up illuminating the striking decorated cross and ornate display. Tables had been laid and covered with plates filled with olives, *Manchego* cheese, *chorizo*, *jamón* and *tortilla*. Alberto, the husband of Marisol, the day centre's director, was moving through the crowd offering around cups of *vino dulce* [sherry].

A ringing cut through the air as Marisol clinked her glass and the music was switched off. She stood on a stool and addressed the crowd.

"I've just heard from the judging panel," she called to the attentive crowd. "Our cross has been awarded third place! Well done everyone! Especial thanks to our *abuelos*! This is for them," and she raised her glass.

The crowd broke into applause. Clotilde, standing near me, was clapping and commented smiling, “Next year we’re going to win it!”

The description above, based on my field notes from the celebrations held at *Pueblo’s* day centre for the *Fiestas de las Cruces* (Crosses Festival) (see figures 1-5), provides an illustrative example of how dementia care was made meaningful in this context through profoundly community-centred care. Meanings of care are shaped by individual preferences, as rightly embraced by person-centred approaches, but crucially these meanings are also moulded by the social relations through which people experience everyday life. *Abuelos* at the day centre dedicated hours to constructing hundreds of pinecone flowers for the *fiestas*, yet despite *abuelos* frequently complaining about other activities on offer, I witnessed continued enthusiasm around participating in this project, which accelerated as the *fiestas* drew closer. Clotilde, at the party expressing her ambitions to gain a higher-ranking prize at the following year’s contest goes to show how *abuelos* were deeply motivated to participate in this annual celebration. Many *abuelos* with dementia who struggled to remember day-to-day goings on, still understood the festival’s importance, and would recount long-held memories of preparing for this *fiesta* since childhood. Even some *abuelos* with more advanced dementia were seemingly still able to recognise the iconic decorated crucifixes that filled *Pueblo’s* streets during the *fiestas*. The day centre’s party was not a singular event of a lone care institution, but integrated into the town’s public calendar, with *abuelos’* family, friends and day centre staff attending alongside other members of the public who were participating in this community celebration.



Figure 1. Staff and friends at day centre prepare cross display for Fiesta de las Cruces.



Figure 2. Staff member pins up a flamenco fan as part of day centre's cross display.



Figure 3. Author and her partner arrange paper flowers for day centre's cross display.



Figure 4. People gather for day centre's Fiesta de las Cruces party.



Figure 5. Author poses in front of day centre's cross display.

This thesis, through revealing the ways place-specific rituals in Andalusia are creatively incorporated into dementia care, suggests the need for a shift from individualistic approaches, towards explorations of dementia care as profoundly community-centred. The presence of *abuelos*, relatives, friends and residents together generating the merriment of the crosses celebration shows how, despite dementia care's ongoing formalisation in Andalusia, people strive to (re)create kinship and solidarity to seek meaningful connections through community-centred dementia care.

Anthropologists, as investigators of cultural context, are well-equipped to explore the cultural practices that shape this community-centred care.

Such celebratory community rituals however, are easily romanticised and another critical revelation of this thesis is the exposure of the complex power relations underpinning dementia care. Having participated as an active ethnographer, regularly attending the day centre over months, I was aware of, behind the scenes, staff members' sense of obligation, and in some cases reluctance, to participate in the above event which took place outside of their regular, contracted working hours. The children of care staff member, Camila, may have been warmly received by those *abuelas* they helped to decorate the cross, but Camila, juggling childcare with work, had been obliged to bring the children as preparing for the event took many hours and ran over her timetabled shift that normally allowed her to collect them from school. Although food and drinks were supplied in ample at the party and many staff members appeared to revel in the celebrations, their presence was expected yet not rewarded with extra pay. Marisol's speech praised her 'caring' staff, and thanked them for months of hard work preparing the celebrations for '*nuestro abuelos*' ('our grandparents'). However, references to staff as 'caring' and using kinship terms, like '*abuelos*', also obscure feelings of obligation, and the demanding, or even exploitative, working conditions of care staff, under the mask of kinship care narratives. Such narratives of kinship and care in Andalusia have long-embedded meanings tied into a historic expectation to provide self-sacrificing care to older people.

This thesis thus makes a wider call to anthropology to unpack its theoretical explorations of power and analyse the complicated ways through which power and care are intricately connected. As shown through the vignette above, *Pueblo's* care institutions, rather than being isolated 'total institutions' (Goffman, [1961] 2017) where people with dementia become 'institutionalised', also form vital components of *Pueblo's* wider civic life. These institutions are 'made' into sites of care through incorporating locally meaningful, place-specific cultural practices, which transform them into spaces of belonging and community. Powerful forces which set limits and restrictions are paradoxically also forms through which people act out love, affection and care.

This concluding chapter will continue by critiquing how insights emerging through the chapters of this thesis apply to core concepts this research grapples with- dementia, personhood, kinship and care- explaining how this research carries debates forward. Following this, I highlight applications of research findings, discussing how these insights help deconstruct reductive dichotomies that continue to endure in much dementia care research. I advocate using the methodological approach I have taken to encourage interactions between occupational therapy and anthropology, using a practical and *caring* participant-observation that is capable of revealing



complex processes of power in care. Finally, I focus on the practical applications this research provides to help move dementia care forward towards a care that is culturally conscious and community-centred.

## Key Insights into Dementia, Personhood, Kinship and Care

### *Dementia*

A key insight this ethnography has revealed is how within Andalusia, Euro-American internationally propelled medical explanations of dementia as disease were profoundly mediated through local, place-specific understandings. *Pueblo's* care institutions informed the local population about the prevention and management of dementia as a disease. In September 2019, *Pueblo's* day centre held events for *Día Mundial de Alzheimer* (World Alzheimer's Day), a global awareness-raising campaign. I helped staff set up information tables in the town centre filled with stickers, sweets, craft badges made by *abuelos*, and information booklets about Alzheimer's and other forms of dementia (see figure 6). I walked about town holding sheets of stickers and when I stopped passers-by, many commented of friends or relatives diagnosed with dementia, with one man even saying, 'half of *Pueblo* has dementia'. International narratives explaining dementia as a disease were thus widely accepted in *Pueblo*.



Figure 6. Information tables set up in *Pueblo's* town centre, raising awareness of Alzheimer's and other dementias on World Alzheimer's Day, 21<sup>st</sup> September 2019.

Despite acceptance of such explanations, I observed how international medicalised understandings of dementia were shaped through place-specific discourses around ageing, care and family. One example of this comes from discussions shared with Marisol, the day centre's director. Generally, she spoke within psycho-biological parameters of dementia and supported medicalised interventions. However, she also cited non-medical, localised explanations, for example when discussing the early-onset dementia in the youngest *abuela* at the day centre, Lorena:



‘Lorena’s from a difficult family. One of her brothers has been in prison. Another committed suicide...It doesn’t surprise me she’s ended up like this. She’s got three kids and doesn’t look after them now obviously, but apparently, she never showed any interest in them before either. They’re from *Pueblito*<sup>10</sup>, people from that town have always been odd. People say it’s the town’s location, next to the lake, that water is said to make people crazy.’

This non-scientific explanation of Lorena’s condition from the day centre’s director suggests she understood social factors, such as family relationships and environment, as influencing dementia onset. I heard many stories about the lake water affecting people’s mental health and cognition; people related it to dementia and to high local suicide rates. Dementia understandings in *Pueblo*, although grounded in wider Euro-American medical explanations, were still shaped by local, place-specific understandings.

Medicalised approaches to dementia care that led to institutional care were also filtered through local care narratives. Throughout this thesis I present how many families in *Pueblo* strove to keep relatives with dementia out of care institutions, constructing complicated rotational care patterns to prevent this. Even when dementia progression meant institutional care became unavoidable, formal care was frequently combined with high-input from families, both through the day centre acting as ‘*un punto medio*’ (‘a midpoint/compromise’), and through the permeability of *Pueblo*’s care home that ensured *abuelos* remained integrated within the community. Medicalised and formalising approaches to dementia care were thus thoroughly mediated through local, place-specific narratives that set eldercare provided by family networks as the dominant norm.

Brijnath’s (2014) ethnography of dementia care in India found local understandings of modernity causing forgetfulness in elders due to family neglect, identified by Cohen (1998) and Lamb (2000), had been reformulated into modern-day acceptance of international biomedical explanations. However, rather than being entirely uncritically accepted, these international explanations were mediated through local understandings:

‘Dementias, in addition to being neurobiological pathologies, are also mediated by cultural filters which shape individual and social realities, articulate the languages of distress, and influence how illnesses are created, embodied, maintained and treated’ (Brijnath, 2011, p. 632)

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<sup>10</sup> This is a pseudonym for a smaller town that neighbours *Pueblo*.

Yahalom's (2019) ethnography of dementia care in Teotitlán, Mexico, also demonstrated how medical understandings of dementia were well-known, but filtered through cultural understandings that shaped social care dynamics. He explained how Alzheimer's disease and age-related forgetfulness were accepted as medical conditions but associated with capitalistic, non-traditional lifestyles. My ethnography resonates with these anthropological findings from non-western contexts and reaffirms that such place-specific cultural filters are also present in European settings like Andalusia. Medical knowledges are frequently uncritically defined as 'global', and socio-familial relations as 'local'. However, this global/local dyad has been widely critiqued in anthropology for uncritically setting up a bounded division between two indefinable conceptual sites (see Grewal and Kaplan, 1994; Tsing, 2005). Rather than conceptualise dementia care under this broad-brush global/local binary approach this thesis has displayed the complicated ways through which transnational psycho-biological knowledges can be reshaped through place-specific community practices and relationships within a specific context.

This work thus relates to previous ethnographies from diverse locations exploring dementia care that reveal how despite widespread acceptance of medicalised explanations of dementia as disease, such understandings are interpreted through place-specific knowledges. I suggest that dementia understandings across contexts are deeply influenced by medicalised discourses diffused through the Euro-American healthcare establishment and professional training, but that these are still profoundly shaped by place-specific, local dialogues that inform and influence people's understanding of dementia and its care. Having investigated people's lived experiences of dementia care in a European context which is also a small, close-knit community, with a strongly held municipal collective identity, this ethnography continues to break down the fervently critiqued west versus the rest divide that continues to endure despite attempts to overcome it (Bloch, 2011). The flawed nature of this divide is thus further highlighted through this research adding to a rich selection of ethnographies of dementia care that reveal how biomedical and socio-familial perspectives can play out in similar ways across diverse parts of the globe.

Another critical insight is the contribution this ethnography makes towards anthropological and health and social care research that reveals the subjectivity of this diversely experienced condition and the multiplicity of ways it is cared for. Long-term ethnographic fieldwork reveals the day-to-day lived experiences of people with dementia and their care-givers. This research has thus avoided both alarmist public healthcare crisis narratives around demography, and oversimplified presentations of people with dementia that can be inadvertently disseminated through the person-centred care movement by focusing on a static personhood. This ethnography instead recognises dementia's diversity, as a condition that embodies the good, bad and ugly, along with immeasurable

spaces in-between. This diversity is matched by dementia care forms which are inevitably ‘vexed, multiple, and often contradictory’ (Duclos and Sánchez-Criado, 2019, p. 162). I now revisit examples of *abuelos* discussed that give insight into the diversity of dementia and dementia care experience.

José, the 85-year-old retired olive farmer and shepherd, has popped up throughout this thesis. He was looked after through a rotational care system formed by his nieces and nephew, the relationships of which he held in deep reverence. Fitting José’s care into their busy lives, the commitment and love of José’s nieces and nephew towards him was unquestionable. This does not understate, however, the severity of José’s distress and anger at his family’s decision to send him to the day centre. Gardening in the patio, looking at photos of animals, or gaining attention from young female carers, could distract José from his darker, more bitter moments, but this was not always possible. Sometimes José’s frustration built into an overpowering anger that resulted in a dangerous refusal to eat or drink. José’s frustrations grappling with these new care forms, contrary to his predecessors’ generation, combined with the commitment shown to him by his family to ensure the majority of his care was provided by them, demonstrate the deeply contradictory experiences of dementia care.

Ascensión, at 60-years-old, had early-onset dementia and provides another contrasting example. She was well-liked at the care home as she was extremely sociable, often making crude jokes which were sometimes criticised for being in bad taste. On one occasion, she burst into a formal meeting between an *abuela*, their family and social worker. Ascensión, having grabbed a balloon from an activity group going on upstairs, proceeded to bop it on the heads of everyone in the meeting whilst loudly singing a vulgar song. After a brief pause, the group erupted into laughter. This example shows how even people with dementia engaging in interactions that diverged from socially acceptable norms, had the capacity to reach productive and even therapeutic interactions. In this case, Ascensión’s socially inappropriate song, sung with enthusiasm and brashness, broke the ice of a sombre meeting. Despite the tolerated reception of Ascensión’s eccentric behaviour, she was not permitted to attend outings as her erratic behaviour could upset members of the public and she was thus limited to the confines of the care home. Ascensión’s husband and daughter visited regularly and would apologise for Ascensión’s behaviour, insisting that she never would have behaved like this before and expressed deep sadness at her transformation. Ascensión’s example demonstrates how somebody’s individual experience of dementia can be relatively positive, but can still severely restrict their autonomy and be upsetting to care-givers. Dementia and its care are thus deeply subjectively experienced and can include conflicting aspects for the person with dementia and their care-givers.

Rosita provides an entirely different example. When we first met, she could engage in conversation, although it tended to be somewhat incoherent. As fieldwork progressed, Rosita started becoming increasingly frustrated and shouting at staff. One outburst caused a fall which left her badly bruised. Rosita was prescribed additional medication to be taken when deemed necessary, which staff and family resorted to frequently, meaning she often appeared heavily sedated. Staff persistently tried getting her to walk, but she started requiring two people to support her, when previously she had walked independently. By the time I left *Pueblo*, about thirteen months after first meeting Rosita, she was in a wheelchair and unable to do anything without support. She made small utterances but conversation was not possible. Her daughter became tearful when talking about Rosita's decline, describing how upsetting it was to observe such rapid deterioration.

This sad example shows how dementia was still experienced by some people and their care-givers as deeply distressing. This demonstrates the 'limits of optimism' of the personhood movement (Leibing, 2017, p. 209), by which Leibing appears to be referring to the person-centred care movement. By avoiding horror story narratives and positively focusing on how the person was *pre-dementia* onset, the person-centred care movement can inadvertently devalue the current reality of those who have or care for dementia who experience its progression as devastating. This ethnography has thus, through everyday engagement, revealed the diverse and multiple realities of people's experiences of dementia and its care. This facilitates a more honest and open portrayal that neither demonises nor romanticises the diversity of dementia and dementia care experience.

### *Personhood*

This ethnography has demonstrated the need for research to diverge from understandings of personhood centring around the individual, towards a more relational interdependent personhood that is formed through social interactions within specific contexts. Even in European settings like *Pueblo*, personhood is shown as deeply social and interdependently constructed. As Buch highlighted, dementia has gained interest from social anthropologists largely because 'senility challenges fundamental Euro-American assumptions about the centrality of rationality and conscious subjectivity to human personhood' (Buch, 2015, p. 281). It forces us to widen narrow Eurocentric definitions of personhood and recognise ourselves as fundamentally dependent social beings, whose personhood is formed through the people and community we come from.

In *Pueblo*, particularly within care institutions, some dementia care approaches were based around individualised understandings of personhood, perceived as responding effectively to psychological dementia interventions which reflected Lamb's (2014) successful ageing paradigm critique. Interventions, such as cognitive worksheets and physio chair exercises, focused on *abuelos*

maintaining their physical and cognitive capacities, were ultimately aimed at preserving independence according to an individualised form of personhood. However, for *abuelos* of José's generation, where elderly cognitively-impaired relatives had always been unequivocally supported by kinship networks, a disjuncture occurred when they were expected to engage in dementia care interventions that subscribed to the successful ageing paradigm, with its focus on maintaining independence. As Lamb (2014) critiqued, even in the US and western countries considered highly individualistic, such emphasis on independence in older age was problematic, given the inevitability of human ageing and decline. In *Pueblo*, like his peers, José had always lived with extended family and contributed towards the family's living; this interdependence on the extended kinship network was expected. José, having seen his sister-in-law care for his mother and aunt in older age, expected the same of younger generations of women in his family towards him as he grew older. Disjunctures were demonstrated through José's anger at being made to engage in such interventions that he felt were irrelevant. His personhood had always been deeply linked into his wider kinship network, with high value placed on interdependency. Individualistic approaches requiring self-disciplined interventions to stave off ageing's effects and maintain independence, understood as one of the most desirable traits of 'successful' older age, were therefore misplaced on him. Care institutions approaching dementia care through individualised personhood understandings, thus in practice could cause conflict when applied within specific contexts.

This relational, interdependent personhood was revealed in chapter three, where I described how families in *Pueblo* generated complicated rotational kinship care strategies to ensure relatives with dementia remained within extended family networks, despite no longer being able to look after themselves independently. I used Svendsen et al's (2018) conceptualisation of 'practices of substitution' to reveal how families looking after relatives with dementia understood themselves as filling in the personhood that was no longer expressed by their relative, such as Ana, who, with her sisters, cared for her mother with advanced dementia. Ana continued updating her mother on family news, showed her photographs of relatives, and decorated her room with relics of the Virgin saint whom her mother had worshiped pre-dementia onset. Her mother was unable to verbally communicate but Ana continued engaging in these practices of substitution to ensure her mother's personhood was upheld. Her mother's personhood was thus deeply relational with Ana's. Such examples show how people's understandings of themselves were far from what has been claimed as 'western' individualised conceptualisations of personhood. As Leibing (2017) critiqued of individualised personhood focused approaches:

‘If we are really to view the person with dementia as a ‘person’, this must include acknowledging both needing care and providing care as central to many people’s experience of what it is to be human’ (Leibing, 2017, p. 214)

By approaching the gold standard of ageing as achieving ‘permanent personhood’ through eternal independence (Lamb, 2014) whereby people avoid dependence on others, we stipulate a highly individualised personhood which masks the interdependence and relational nature that exists in all people, but that dementia reveals more starkly. This ethnography, by showing the diverse experiences of those receiving and giving dementia care has displayed a deeply human interdependence, demonstrating a need to move from personhood as individualised towards acceptance of more relational, interdependent forms of personhood that vary across contexts.

Alongside demonstrating personhood as inherently relational, this ethnography has also revealed how spiritual and non-human entities have the capacity for personhood. In chapter five, I described how *Pueblo*’s Virgin Mary saints possessed personhood through people’s social, embodied interactions with the statues that represented them. *Abuelos* spoke about the statues using feminine pronouns, gave them playful nicknames, made eye contact, spoke to them directly and kissed them. Through these interactions the statues came to exist as real embodiments of the Virgin saints. For *abuelos* with dementia or approaching end-of-life in particular, these relationships were critical through the spiritual protection and comfort they offered. This ethnography has thus built on previous work in the anthropology of religion around the personhood of Catholic statues (see Mitchell, 2010; Whitehead, 2013). I have transported this work into an anthropology of ageing by analysing how the personhood of these holy figures provided *abuelos* with spiritual protection to adopt a kinship care-giving role. This shows further how we need to diversify our understandings of personhood to recognise how personhood can stretch beyond the human and into spiritual realms. Such non-human personhood can be protective in dementia and elder care, particularly given the existential contemplation that may occur as people reach latter life stages. This suggests a need for more investigations exploring spiritual personhood across dementia and elder care.

### *Kinship*

I approach kinship as an encompassing term concerning relatedness, including relationships, connections and emotions towards others. I follow Borneman’s (2001) critique of previous anthropological analyses of kinship structures focusing on reproduction, and investigate kinship beyond family structures, exploring the human need to care and be cared for. A striking example of kinship extension beyond reproduction in *Pueblo* was the widespread use of the term ‘*abuelos*’. This term, translating into English as ‘grandparents’, was used to describe older people. Having worked

across UK healthcare settings where older people using services would be referred to as ‘service-users’, ‘patients’ or ‘residents’, the use of this informal family term struck me as significant. By using this family term within *Pueblo*’s care institutions, the distance of formal care structures was reduced. Staff recounted tales of *abuelos* who had been ‘abandoned’ by their family, explaining themselves as filling in kinship, generating pride in their role despite challenging working conditions. I use the local term ‘*abuelos*’ to refer to older people throughout this ethnography to enable recognition of a kinship that goes beyond reproductive relationships, revealing how kinship can be found in diverse relationships.

I also explored how care workers expressed deeply felt emotions towards those they cared for. Live-in carers explained how the intimacy of living together bonded them to the person they cared for. For migrant carers, adapting to new cultural contexts, this intimate relationship could serve as particularly meaningful. Several migrant carers described how this bond reduced both their own, and the *abuelo*’s social isolation, facilitating a cultural exchange that enhanced their sense of belonging to Andalusia. Meanwhile, *abuelos* living within care institutions described how living in close-quarters with others led to intimate kin-like relationships. Staff working long hours under challenging conditions also developed an intimacy and solidarity with one another. These examples suggest that kinship is intricately linked to relationships of care.

Taking kinship as an encompassing term that emphasises relationships of care rather than reproduction can be enabling, yet can also mask restrictive demands placed on low-paid formal carers. Family and kinship terms being equated with care and affection can hide the reality of obligation such relationships entail. Referring to older people being cared for as ‘*abuelos*’, given the local emphasis on the moral importance of kinship eldercare, may have set standards of care as beyond the expectations normally required of low-paid employees. Such expectations could cause care workers to feel obliged to adopt the role of family in those they cared for. In chapter seven, I depicted how care workers, as primary care-givers to socially isolated *abuelos* living alone, met additional demands that would normally be expected of kin, such as calling them on special occasions, buying them presents or doing other unpaid tasks. Hourly rates did not cover these additional tasks, however, as care-givers experienced meaningful relationships with *abuelos*, formed over daily long-term engagement, inevitably they felt responsibility to fulfil these tasks that went beyond their job description.

Similarly, for biological kin the romanticisation of kinship could mean that demands became excessive. This was particularly the case for middle-aged women in *Pueblo*, held as matriarchs of kinship care. In chapter four, I discussed how, although many women described this caring role at

the centre of their kinship networks with pride, they were tasked with a heavy responsibility that often resulted in overload. This ethnography has thus explored the contradictory, conflicted and contested nature of kinship and its connection to care. Although kinship can be profoundly meaningful and enabling, it can also be romanticised, equated with a sense of self-sacrificing, infinite care-giving, and thus cause excessive demands to be placed on those deemed as kin.

### *Care*

Engaging in long-term participatory research which delved into everyday lived experiences of dementia care this ethnography has attempted to distance from the ‘conservatism’ of existing care research that investigates from uncritical perspectives (Duclos and Sánchez-Criado, 2019, p. 155). Instead, I have shown the diverse and contradictory meanings of care across subjectivities. In chapter three, I revealed the diverse forms of kinship care that families creatively strategised to support relatives with dementia, depicting the complex patterns of rotational care that ensured relatives avoided going into institutions. For some *abuelos* this was experienced as enriching as it allowed them to spend time with multiple relatives, whilst others complained they felt ‘homeless’ rotating between various households. For care-givers, the rotational system could be liberating, enabling engagement in additional ongoing commitments, whilst others complained rotations were disruptive.

Discussing care and spirituality in chapter five, I revealed how *Pueblo*’s vibrant *fiestas* became meaningful components of dementia care, with care institutions integrating *fiestas* into their activities programmes. Others expressed sadness around these events, as their relative’s newfound disinterest contrasted starkly with the person they had been pre-dementia. I explored clinical dementia care interventions, like the cognitive exercises discussed in chapter six. Although some *abuelos* enjoyed these, with several reporting they were learning and referring to the day centre as ‘cole’ (‘school’), many experienced them as alienating. This thesis, by providing rich ethnographic detail, has displayed the contradictory nature of dementia care; following Buch’s advocacy it portrays a ‘polysemic understanding of care’ (Buch, 2015, p. 277).

This research reinforces previous anthropological insights showing how fundamental care is to human experience (see Kleinman, 2012) and advances theoretical concepts from anthropological works that link care to personhood. I used Mattingly’s (2010; 2014) explanation of ‘moral laboratories’ in conjunction with Svendsen et al’s (2018) conceptualisation of ‘magical moments’ in dementia care-giving, to reveal how care constitutes personhood. Combining these theories in my analysis of dementia care in *Pueblo*, I explored how care-givers would experiment within ‘moral laboratories’ of care by trying different activities to stimulate ‘magical moments’ in those they cared



for. Equipment from their moral laboratories were deeply embedded into place-specific cultural practices, such as utilising municipal spiritual rituals as tools to incite magical moments. Care-givers to people with dementia thus become moral experimenters, attempting to create the right experimental conditions to harness magical moments and craft personhood in those they looked after. These moral experimenters are highly adept to their specific social environments, ingeniously crafting place-specific cultural practices into their care to craft magical moments and constitute personhood. The thesis thus widens theoretical debates into the complex relationship between personhood and care.

This ethnography, through detailed everyday engagement within a care home and day centre has also critically unpacked the notion of ‘formal care institutions’. Despite historically-rooted resistance to eldercare institutions in *Pueblo*, with families often expressing fears of relatives becoming ‘institutionalised’, going inside such institutions I learnt they were not stable, inert contexts, but places that get *made* through the social and power relations of everyday practice. As both an occupational therapist, focused on exploring how meaning is created through day-to-day activities, and an anthropologist attuned to the wider forces of power underlying social interactions, I have been able to uncover the complex processes through which these care institutions are made through everyday practice. In chapter seven, I displayed the myriad of ways these care institutions are made into spaces of community and belonging, where caring relationships are developed and maintained, across both *abuelos* and staff acting out their lives within them. An important insight of this thesis is thus that it demonstrates how formal care institutions are imagined and *made* through everyday practices of care, transforming them into places where people experience feelings of profound belonging and community.

A further overarching insight of this ethnography is its demonstration of dementia care as deeply social and relational, formed through local cultural practices from the community wherein it is performed. Previous research into dementia care focuses on Kitwood’s (1997) advocacy for ‘person-centred care’, which is sometimes also referred to as the ‘personhood movement’. Although this approach marked a radical step forward from long-standing dehumanising images of people with dementia, person-centred care approaches can also exhibit some problematics of the ‘successful ageing movement’ critiqued by Lamb (2014). Attention on ‘person-centred’ care, which emphasises a focus on the person somebody ‘once was’ pre-dementia can inadvertently propel a static vision of personhood that emphasises only the previous person without dementia, rather than acknowledging their current personhood with dementia. Leibing (2017) has highlighted the limits of optimism through this focus on a nostalgic image of personhood pre-dementia, and advocates recognising people’s need for care as central to human experience. The person-centred care focus,

in conjunction with narratives around successful ageing which deem dementia as a failure to 'age well', can thus inadvertently deny recognition of dependency and need for care as fundamental parts of personhood. This ethnography thus recognises the inevitable dependency caused by dementia and depicts the diverse ways that people, families and communities creatively manage this dependency through care. By revealing how relationality, belonging and collectivity shape dementia care in *Pueblo*, I suggest avoiding individualistic approaches, at times inadvertently propelled by a person-centred care focus that reifies exclusive definitions of personhood dependent on health, independence and an emphasis on who the person was pre-dementia. Instead, we should move towards a 'community-centred' approach to care that recognises people's interdependence, reliance on those around them, and the importance of local contexts in shaping care.

The importance of community-centred care was particularly highlighted in chapter five, where I explored how *Pueblo's* collective religious rituals were experienced as deeply therapeutic for people with dementia and thus were deliberately harvested through creative care practices that incorporated these community rituals. Furthermore, in chapter seven, I revealed how *Pueblo's* care institutions, rather than being isolated, formed integral parts of its wider community. These institutions also provided a micro-community for *abuelos* living within them. Sense of belonging generated through this community could be deeply meaningful for *abuelos* who had been experiencing feelings of isolation from having moved from their long-term homes into care institutions.

Dementia care therefore should not be reduced to an individualised focus, at times inadvertently implied by an emphasis on person-centred care, but must be explored through people's lived experiences within the social context where they exist. This turn towards community highlights the importance of place-specific cultural practices that influence experiences of dementia care. As Warren and Sakellariou stated, 'care is a relational, enacted practice' (2020, p. 1). Practices of care-giving reveal the fundamental sociality and interdependence of humankind. This ethnography has journeyed through everyday dementia care experiences in *Pueblo*, to uncover how care is an inherently relational practice that demonstrates the profoundly human desire to connect with others. Through exploring dementia, as a condition that brings human fragility and dependence into light, the way people care for those with this condition through sociability and solidarity is revealed. This recognition of a more relational interdependent form of personhood that diverges from traditional western understandings, implies the need to shift from individualistic care approaches that take the person as a self-functioning unit. Instead, this ethnography, through revealing the diverse ways that the people and community around a person with dementia inform their care, opens the way for approaches towards 'community-centred care'. As social

anthropologists who investigate culture, we are well-equipped to investigate the complicated and diverse ways that communities shape dementia care across the globe.

### **Applications of Research Findings**

This thesis shows care to be fundamental to human experience. Although it focuses on dementia care, through ethnographic exploration of people's everyday lived experiences within a certain context, this research has revealed how care seeps into all aspects of life. Care is not limited to private homes, care homes or healthcare sites but filters into everyday practices- community events, *fiestas* and celebrations can become important components of care. Care's omnipresence may have caused it, until recently, to be overlooked by anthropology. Rather than approached as academically stimulating, care has been conceived as a 'practical necessity' (Mol, Moser, Pols, 2010, p. 7). Care research, narrowly focused on practical application, has sought 'wholeness, conformity, and civility' (Duclos and Sánchez-Criado, 2019, p. 155). Such holism has resulted in the reductive dichotomies of care which I outlined in the introduction to this thesis. This ethnography has attempted to breakdown these binaries and breathe life into the spaces in-between, exploring the chaotic, contradictory and complex diversity of care experience.

Advocating 'community-centred care' this research deconstructs the dichotomy separating institutional from community/home-based care. A huge appeal of *Pueblo's* care home to *abuelos* was its location in the heart of the town. Visitors would pop in and out, whilst *abuelos* who were able could come and go as they pleased. For more dependent *abuelos*, staff arranged regular outings. The care home also organised seasonal events which the whole town were invited to. *Pueblo* was well-known for its vibrant *fiestas* which both care institutions participated in actively. The Virgin Mary statue processions made special stops at the day centre and care home, where the saints offered the care institutions their divine spiritual protection. By recognising dementia care as deeply social and relational, shaped through place-specific cultural practices, we move from reductive understandings of care institutions as all powerful 'total institutions' (Goffman, [1961] 2017), isolated from the outside world, to places which form integral parts of the communities they lie within.

Research outside of anthropology had begun deconstructing this institutional versus community/home-based care dichotomy. Bartlett and O'Connor (2010) advocated the term 'citizens' for referring to people with dementia, in order to accentuate community membership. Goffman's [1961] (2017) analysis of care institutions as 'total' was reformulated by Quirk, Lelliotta and Seale (2006), who found modern-day psychiatric institutions with assigned leave were much more 'permeable' with the outside world than prior institutions. I move this a step further by claiming that

*Pueblo's* care institutions formed a fundamental *part* of its community. Care institutions were spaces for key community events and formed part of a profoundly community-centred care. Taking an anthropological approach enables explorations of how care filters into diverse aspects of everyday community life. This thesis thus deconstructs reductive binaries that separate institutional from community/home-based care to show how care institutions are part of community-centred dementia care.

Through revealing the complexity of care relationships this ethnography also deconstructs misleading understandings of formal paid care as in opposition to informal family care. In chapter three, I presented family care-givers who lived with elderly relatives and looked after them due to their own economic instability; thus, despite care being 'informal', it was in exchange for material support. Meanwhile, many formal paid carers developed meaningful relationships with those they cared for, describing them using kinship terms and providing additional unpaid care. We thus need to accept more diversified understandings that recognise the multiple subjectivities of care, avoiding depending on restrictive terms like informal/formal to define care relationships to recognise the complex, shifting nature of subjective care relationships.

In revealing more complex, polysemic care relationships this ethnography also demonstrates the problematics of viewing such relationships as consisting of active care-givers and passive care-receivers. In chapter seven, migrant women working as live-in carers described developing relationships with the people they looked after as providing respite from isolation they had suffered from moving to a new cultural environment. Some described a cultural exchange occurring between themselves and the person they cared for, where the older person helped them learn the language and customs to manage their new life in Andalusia. Thus, as Warren and Sakellariou have critiqued, we must stop approaching care relationships as 'unidirectional' (2020, p. 3). This ethnography thus disrupts misconceived binaries between passive care-receivers and active care-givers to reveal complex, muddled relationships, where care-giving is co-constructed as a joint relational process.

Through detailing the everyday lived experiences of people with dementia this ethnography has helped deconstruct reductive medicalising assumptions that present people with dementia as cognitively malfunctioning and dependent on the cognitively functioning majority. The *abuelas* at the start of this chapter were vital to the success of the crosses celebrations; the prize-winning decorated crucifix would not have been produced without their prolonged efforts. José, an *abuelo* who had spent his life working on the *olivros* (olive groves) possessed an agricultural knowledge that, despite his short-term forgetfulness, was more advanced than anyone else's at the day centre and he would often advise staff in how to care for the day centre's garden. I observed *abuelos* at the care

home spend weeks dutifully rehearsing for a Christmas play which was later broadcast on *Pueblo's* TV station. This ethnography thus helps deconstruct reductive understandings of people with dementia as cognitively malfunctioning, by presenting the range of knowledge and practices that people with dementia actively participate in.

By deconstructing dehumanising images of people with dementia as cognitively malfunctioning this ethnography also widens narrow understandings of personhood, propelled by the successful ageing movement, which explain individuals as self-reliant and independent. In chapter three, I outlined the high presence of intergenerational households in *Pueblo* that enabled both dependent younger and elder kin to be looked after by wider kinship networks and participate in one another's daily lives. I described the complicated patterns of rotational care across kinship networks that enabled people with dementia to remain at home. Such ethnographic data shows how kinship interdependence and relational forms of personhood continue to be co-constructed in European settings. Human interdependence has been demonstrated as fundamental to everyday life across contexts (Ferguson, 2013). This ethnography, by describing people's lived experiences of dementia care in Andalusia reveals how human beings, even across western contexts, co-construct relational interdependent personhoods. This brings us closer to more nuanced understandings of personhood that avoid reducing people to self-functioning independent individuals, and destabilises reductionist dichotomies that separate 'the west from the rest'. It also demonstrates the importance, when investigating dementia care, of focusing not only on the individual, but on social and community networks.

The ethnography also questions the value of dementia care interventions propelled by the far-reaching Euro-American healthcare establishment based on medicalising framings of dementia. Considered pioneering, cognitive exercises used in *Pueblo's* care institutions subscribed to successful ageing paradigms claiming to improve cognition and resist dementia. In chapter six, I detailed the inconsistency of people with dementia's participation in such interventions and questioned their value as dementia interventions. This research thus also challenges binaries that divide modern and traditional care techniques and claim modern dementia interventions as most effective. I observed culturally-specific community activities, such as participation in *Pueblo's fiestas* and religious rituals, stimulating enthusiastic participation by *abuelos* with dementia. This active participation appeared far greater than the despondency I witnessed from many *abuelos* being made to engage in cognitive exercises. This ethnographic data thus deconstructs understandings of traditional versus modern care approaches, to reveal the diverse, global yet local, new yet old, reality of dementia care. It critiques medicalising assumptions around the superiority of modern dementia interventions, instead showing how long-standing culturally-embedded rituals within communities can have

greater impact on the engagement of people with dementia. This suggests a need to demedicalise and deglobalise dementia care to ensure it is culturally relevant and meaningful within the context in which it is experienced.

Yet beyond the breaking down of these binaries of care this thesis also makes a broader call to the discipline of anthropology to open up its theoretical explorations of power, to understand how these forces, although setting limits, obligations and restrictions, are also ways in which human beings express care, affection and ultimately love for one another. I hope that this work will help pave the path towards an anthropology that remains critical and questioning of the structures and power relations that infiltrate and determine human experience, but that is more nuanced and sensitive to how these forces are also formed through a profound sense of care shown through acts of kindness in everyday practice that embed us into the social relations we engage within and shape us into the people we are.

Highlighting lessons for the subjects which have guided me, I believe this ethnography has revealed how occupational therapy, deemed a 'caring' profession with a focus on practical solutions to everyday problems, can learn from the critical analytical position of anthropology, just as anthropology can learn from the practical solution-based focus of occupational therapy. Reflecting on this point an image comes into my mind of an imagined interaction between two figures which I associate strongly with each subject- the prominent occupational therapist Elizabeth Yerxa and the renowned social theorist, hugely influential to modern anthropology, Pierre Bourdieu. Pierre Bourdieu is brooding, forehead furrowed in concentration as he vexes over the inescapable structural determinism of practice theory. Elizabeth Yerxa enters the room, and in true occupational therapy style, on seeing his evident discomfort offers him a cup of tea. My hope is that rather than continue to brood, Bourdieu accepts Yerxa's kind offer, takes the cup of tea and drinks it, enjoying the real-life warmth and soothing care that this practical gesture offers him. On his acceptance of her tea, Yerxa sits with Bourdieu and has a conversation about the theoretical conundrums that he is embroiled with. I hope this thesis will enhance the conversation between occupational therapy and anthropology, and in doing so will help a bridging between theory and practice, abstraction and application, and power and care.

Considering more concrete, practical applications, this ethnography, undertaken by an anthropologist and occupational therapist, has illuminated the benefits of ethnographers taking a critical but applied and practical approach to conducting research. By taking active roles in participant-observation that go beyond that of pure ethnographer, by becoming carer to families in *Pueblo* struggling to support older relatives with dementia, and volunteer in *Pueblo's* care

institutions, assisting staff with the day-to-day running of life in these institutions, I gained deep insight into the ways that dementia care is made through everyday practice. For future ethnographers of dementia care I recommend taking this practical approach of a *caring* participant-observation whereby engaging oneself in genuine acts of care-giving one is able to reach critical theoretical insights about dementia care.

This thesis, through detailed everyday ethnographic exploration has shown how certain place-specific cultural practices, such as participation in *fiestas*, can have a profound effect on people with dementia. It has illustrated how long-established cultural practices were carefully incorporated into local dementia care forms in *Pueblo*. This resonates with international dementia care initiatives, such as *The Alzheimer's Society's* 'Dementia-Friendly Communities' programme, first implemented into UK health and social care policy through the 'Prime Minister's challenge' in 2012, that attempts to enhance social inclusion for people living with dementia by making communities more aware of dementia (*Alzheimer's Society*, 2022; Lin, 2017). It is interesting that this policy intervention may be speaking to something that appears to have emerged more or less naturally in communities like *Pueblo*. I believe by moving dementia care understandings into an approach to care that is community-centred and culturally-informed, communities will inevitably become more 'dementia-friendly'. As Brittain and Degnen advocate, we must 'critically question how dementia care is enacted outward and beyond the fixed points of the private domestic realm or institutional settings' (2022, p. 429). It is therefore critical that we do not limit studies or practices of dementia care to certain healthcare sites, professionals or settings, and instead take a more holistic approach to dementia care that recognises and explores how it is embedded into diverse aspects of community life.

By presenting rich qualitative data, this thesis has displayed the value of using ethnography to explore the lived experience of dementia care. By focusing on the diversity of people's lived experiences, the umbrella term of dementia and the range of experiences that shape its care can be thoroughly explored to help demedicalise our understandings of dementia and turn our focus instead to the social experience of the condition and its care. By using ethnography and a *caring* participant-observation as its investigative tool, this research has revealed how dementia care, rather than being confined to public healthcare sites, care homes, hospitals and private homes, filters into everyday life and local cultural practices. It thus shows the need to investigate dementia care ethnographically and practically in everyday life across differing cultural contexts. It has revealed how collective cultural practices can have a profound effect on people with dementia and should be incorporated into culturally-informed local dementia care forms. It has also recognised the influence of spirituality on dementia care and raised the need for further research exploring how this

spirituality affects people's experience of dementia care, a critical consideration for a condition which, as usually experienced in later life, inevitability brings up existential questions around life and the afterlife. Above all it has demonstrated a need to shift the focus of dementia care research from person-centred to community-centred care, moving investigations of dementia away from the individual as a self-existing, self-maintaining unit, to open up and explore people with dementia through their social networks and cultural and community contexts. As investigators of cultural context, anthropologists are well-positioned to explore this move towards community-centred dementia care. By approaching care, not as something medically or physically required by a sole individual, but as a relational need, co-created through social interactions and relationships within certain contexts, we can recognise the cultural diversity of care and the need to consider not just the person but the community and culture that shape dementia care.



## Afterword

The last time I attended *Pueblo's* care home before finishing fieldwork was for the Christmas play in mid-December 2019. The play attracted a large audience, with friends and family of *abuelos* and staff packing out the assembly hall. After the performance, the care home director pulled me on stage to thank me, presenting me with a collage staff had made filled with photos of me with the *abuelos* and I was given a round of applause. After further announcements, tables with food and drinks were laid out, Christmas carols played, and a party got started. People ate, drank and chatted about holiday plans. The atmosphere was jubilant and festive. Nobody could have known what was about to hit the care home, and the rest of the world, in the troubled months that were to follow.

Spain was the second European country after Italy to fall into a catastrophic outbreak of Covid-19, resulting in a national state of emergency being called. On 14<sup>th</sup> March 2020 Spain's president, Pedro Sánchez made a speech addressing the nation, calling for intergenerational solidarity:

'Today we must remember the 2008 economic crisis, when we were saved by our elders. *Abuelos* were the lifeline for many families and therefore, for our society as a whole. The money came out of their pensions to fill our pantries, to pay the bills...Their roof was, on many occasions the roof that sheltered the entire family...In this crisis, it is they who need our help the most. This crisis gives us the opportunity to demonstrate what we have learnt from their example'

(Sánchez, 2020)

Covid-19 has transformed the global landscape of dementia care. This afterword reflects on how the pandemic impacted *Pueblo's* community and eldercare more broadly. I write in March 2022, two years from the pandemic's initial outbreak. I begin by describing hearing from informants in *Pueblo* about how events there unfolded. I then discuss findings from online follow-up interviews I conducted with family and professional care-givers in *Pueblo* in spring and summer of 2021. Finally, I discuss how applications of the research findings have reached new relevance as dementia care is reshaped in a world that continues grappling the Covid-19 pandemic.

Back in the UK I heard how the pandemic was unfolding in *Pueblo*. I read horrifying news articles, and messages from friends in *Pueblo* to learn the devastating effects of the pandemic which took hold of *Pueblo* and especially its care home in that first wave. In late March 2020, several of *Pueblo's* care home staff unwittingly came into work carrying asymptomatic versions of the virus. The care home, like others across the world, was struggling to meet demands for personal protective

equipment (PPE), and with several staff unknowingly infected, the virus spread rapidly throughout the home. In the first week of the outbreak several *abuelos* and one staff member were admitted into hospital with the virus, and tragically the home lost its first victim to Covid-19.

The assembly hall that just a few months previously had hosted the Christmas play was made into a make-shift ward for sick *abuelos*. Once the outbreak had torn through the care home, out of 72 residents, 44 had caught the virus, with 13 tragically dying. One *abuelo* caught Covid-19 and recovered, but his wife, who lived in the community, died of the virus. He was so grief-stricken that he committed suicide by jumping out of the assembly hall's window. Isa and Santiago, the only married couple living in the care home, caught the virus within days of each other and both died. Pablo, the brother of Tano who I used to visit regularly, was hospitalised and went from being active to bedbound. It is hard to imagine the horror that passed within the walls of *Pueblo's* care home, but this tragedy was echoed in care institutions across the world. I remained in touch with staff and felt deeply saddened learning from a distance of the trauma that the care home, its staff, *abuelos*, and their families faced.

During online interviews with relatives and care workers in *Pueblo* a year after the pandemic's beginning, an issue repeatedly raised was how Covid-19 restrictions negatively impacted people with dementia by disrupting routines. *Abuelos* at *Pueblo's* care home used to daily visitors were suddenly left without contact. Staff used videocalls to maintain communication, and although this worked for some, for *abuelos* with dementia videocalls could increase confusion. Staff recounted how *abuelos* with dementia who before the pandemic had remained stable through structured routines and family contact, drastically regressed with the sudden abortion of activities and visits. This resonates with Russell's recent piece reflecting on the care of her mother, who had dementia and was living in a UK care home during the pandemic. She critiques how the impact of Covid-19 restrictions in drastically reducing meaningful contact between her mother and her family 'saved my mother's body, through destroying her mental capacity' (Russell, 2022, p. 261). An insight I emphasised throughout the thesis was how the care home was part of *Pueblo's* wider community. The pandemic, however, meant the care home was cordoned off. It thus became closer to the 'total institution' described by Goffman [1961] (2017). One carer explained:

'There's the *abuelos* who died from the virus and then there's those who died from the restrictions. Normally we have loads going on...But with everyone stuck in their rooms, the care home became a prison...I saw so many *abuelos* decline dramatically, *abuelos* who had been really independent stopped getting out of bed.'

People spoke about missing *Pueblo's* community events. One relative showed me a videoclip of a *cofradía* (religious brotherhood) member taking out their rubbish during lockdown dressed in their *semana santa* outfit just so they could wear it as all processions were cancelled. Another explained how for many religious *abuelos* the cancellation of these rituals left them feeling spiritually unprotected at a time when they needed it most.

In July 2020, once lockdown restrictions were loosened, the council organised for the Virgen del Pilar to be given a special visitation to the care home. The socially-distanced ceremony consisted of a small group of *cofradía* members wearing face-masks, carrying the Virgin statue. Standing in front of the care home they recited prayers for those who had lost their lives during the outbreak and to enable the Virgin to send her spiritual protection over the home during the ongoing crisis. The organisation of this special, socially-distanced ceremony demonstrates how local cultural rituals are a crucial part of elder and dementia care in this community. These rituals can be turned to in times of crisis to seek solace, spiritual protection and solidarity for *Pueblo's* elderly population, and are a striking example of the 'community-centred care' I advocate throughout this thesis.



Figure 1. A socially-distanced ceremony with the Virgen del Pilar statue in front of *Pueblo's* care home, July 2020.

Care-givers complained of difficulties wearing PPE around people with dementia. One relative explained how her mother would become frightened when she wore a face-mask, so she had to keep lowering it, which made it less effective. A home carer explained she was obligated to

wear a gown, shoe protectors, face-mask and safety glasses and that some *abuelos* with dementia, alarmed by her outfit, refused to let her into their homes, whilst others found it amusing.

Care-givers also discussed problems maintaining physical distance with care-receivers. Spanish cultural communication norms rely on physical touch, such as the standard greeting of kissing someone on each cheek. Therefore, people complained of no longer being able to give greetings or comforting touches. One home carer described:

‘How do you greet somebody without kissing them?...It feels cold. Especially when you know you’re the only person they’ll see all day.’

Many care-givers however commented that despite restrictions they continued physically comforting *abuelos* who they felt needed it. A care home carer said:

‘It was a horrendous time, without family, frightened of the virus and with people getting sick all around them [*abuelos*]...For us [staff] it was bad but we could go home. They were stuck in the building with the infection rising...I did not stop being *cariñosa* [caring]. I would still give hugs. It was more important during that time than ever...We toilet them and we touch them then, so why not when they’re crying?’

Another carer explained how it was impossible to maintain physical distance with people with dementia for whom their communication form was touch:

‘Rosita barely speaks. If you want her to do anything you take her by the hand. It’s impossible to follow the distancing rules with somebody like that.’

Cristina Douglas, who conducted research with people with dementia in a Scottish care facility, critiqued the pandemic’s social distancing rules as caring for people with dementia ‘is intimately entangled with touching and being touched’ (Douglas, 2021, p. 13). Social distancing drastically impacted people with dementia who relied on touch to communicate.

One home carer commented however, that she thought dementia was protective during the pandemic as people’s lack of awareness meant they did not suffer with fear as did other elderly people:

‘It was fine for *abuelos* with dementia. Nothing really changed for them. They’re in their own world anyway so they didn’t realise the craziness going on. It was harder for those *abuelos* who knew what the virus was and how dangerous it was for them.’

Relatives also recounted difficulties in reducing *abuelos'* exposure to different people when they had shared care patterns across family networks, and criticised that government restrictions did not account for care over multiple households. One woman looking after her elderly mother through rotational care with her siblings, complained that lockdown meant this shared care became impossible. Although the government allowed people to leave their households to provide care, many felt intimidated by police patrols, and families were afraid of increasing elderly relatives' exposure to different people due to the virus, so many abandoned their rotational care systems. This resulted in *abuelos* becoming disorientated through sudden routine change, and all responsibility falling on one relative which could cause this person overload and stress.

Several families I spoke to cancelled the home-care service, despite it being publicly provided, as they were fearful of carers going from home-to-home spreading the virus. One relative explained how she moved from her house with her husband and adult children to live with her elderly parents during lockdown, cancelling the home-care service, and taking responsibility for all their care. She described missing her husband and children who only lived a ten-minute walk away but whom she barely saw for the first two-months of lockdown. This suggests the pandemic caused a shift towards people once again turning to family over formal care.

The pandemic drastically impacted care home reputations. Many outbreaks in care homes across the world were broadcast on national media, and combined with the local outbreak in *Pueblo's* own care home, people lost trust in care institutions as safe care forms. Staff from *Pueblo's* care home explained that three families removed their relative from the care home due to concerns about future outbreaks. Other families who had relatives living in *Pueblo's* care home spoke about intense guilt and worry. Patricia, whose uncle Pablo was in the care home and became infected and severely impaired by the virus, explained how her cousin blamed herself for having admitted him into the care home. In general, the pandemic increased stigma around institutional care and may have shifted reliance back towards kinship care, seen as safer and more dependable.

Some healthcare practitioners commented positively that the pandemic had raised public awareness of their role and that this helped them feel valued. The day centre closed during the pandemic's initial months, losing income from *abuelos* who paid privately. However, speaking to the day centre's director, she felt the pandemic had raised the public profile of care and revealed current gaps in provision. She explained this gave her hope that care would be higher on the political agenda and that there might be future increases in publicly-funded care. One home carer I spoke to emphasised how the pandemic had raised her job's status:

‘I think it’s made people appreciate what we do...I was scared of getting the virus...But I also felt proud that I was doing this job and that I was helping all those people who really needed me. I think now there will be more funding for services like ours.’

## **Relevance of Research Findings Post-Covid-19**

The Covid-19 pandemic has been the biggest global health crisis for generations. However, despite the devastation, it has also resulted in elevating awareness around eldercare. The pandemic shone a public light on many issues discussed within this thesis, causing global outrage over formal eldercare standards. In March 2020, a Madrid care home hit international news when it emerged that the army, who had been despatched to disinfect the home, found abandoned elderly residents in their beds, some of whom had died (Jones, 2020). By revealing deprived conditions within institutional care, the pandemic triggered public calls to improve institutional and formal eldercare standards.

As several carers I spoke to commented, despite the pandemic reducing trust in formal care, it also raised awareness of the need for well-trained health and social care professionals. Carers described feeling proud to stand at the pandemic’s frontline, fighting to protect vulnerable people. Public applauding for carers began in Italy, quickly spreading to Spain, the rest of Europe and beyond, to demonstrate gratitude for the effort of healthcare workers. It will however, be telling to observe whether such public gestures translate into genuine transformations in working conditions.

The pandemic has displayed a human need for sociality and community. The mandatory lockdowns and social restrictions, causing people to be separated from loved ones for months or years, have shown how sociality is a crucial part of making life meaningful. A key emphasis of this ethnography is the demonstration of the fundamental sociality and interdependence of humankind. People’s attempts to maintain social connections and spread community solidarity throughout the lockdowns, such as neighbourhood help schemes, volunteer food deliveries, companionship phone calls and other acts of kindness, highlight this human interdependence, sociality and need to care for one another. This ethnography has revealed the diverse ways that the people and community around a person with dementia shape care-giving, and led me to advocate care that is not just person-centred but *community-centred*. The pandemic further accelerates recognition of meaningful care as profoundly integrated within communities. As we continue to move through the Covid-19 pandemic and attempt to navigate a socially-distanced world, it is even more vital that we recognise human interdependency, and work towards cultures and communities that recognise the need and value of care.

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## **Images:**

### Chapter two:

*Figure 1: El Valle de los Caídos*. Available at: <https://www.pinterest.com/pin/135530270007689291/> (Accessed: 20 July 2018).

*Figure 2: Map of Spain's autonomous communities*. Available at: <https://alcala-gijon.wikispaces.com/andalucia> (Accessed: 20 July 2018).

*Figure 3: Image from El Obrero de la Tierra, 1936*. Taken from Collier, G. 1987. *Socialists of Rural Andalusia*, p. 150.

*Figures 4-5: Photographs taken by author.*

#### Chapter four:

All photographs displayed were taken by the author.

#### Chapter five:

All photographs displayed were taken by the author.

#### Chapter six:

*Figures 1,2, 5, 6, 7, 11 and 12:* Photographs taken by author.

*Figures 3-4:* Available at: <https://www.gameiros.pt/imobilizacao/65732-salvaclip-confort-scc4316-cinto-imobilizador-pelvico-l-5601000000382.html> (Accessed: 30 October 2021).

*Figures 10 and 13:* Images formulated by author.

#### Chapter seven:

*Figures 1-3:* Photograph taken by author.

*Figure 4:* Screenshot taken from *Arrugas* (2011). Directed by Ferreras, I. [Feature film] San Sebastián: Perro Verde Films.

#### Chapter eight:

All photographs displayed were taken by the author.

#### Afterword:

*Figure 1:* Photograph from a newspaper local to *Pueblo* [publication name/date/online location withheld to protect anonymity].